

Evaluation of the Participation Trials for the My Health Record

Final Report

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Executive Summary

The participation and use trials of the My Health Record system were designed to achieve the following outcomes:

1. Understand public reaction to an opt-out participation arrangement for the My Health Record
2. Understand the extent to which healthcare provider contribution and use of the My Health Record system improves when the majority of their patients have a My Health Record
3. Understand any implementation issues that would need to be addressed before any decision is made about future participation arrangements.

These outcomes are measured through the extent to which the following is achieved:

- increased awareness and understanding of the My Health Record system
- increased confidence to use the My Health Record system
- increased participation in, and use of, the My Health Record system
- increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system.

The evaluation of the My Health Record system participation and use trials was commissioned in late 2015 and commenced in January 2016. Data collection concluded on 31st October 2016. Progressive data analysis (of all sources) occurred between 12th September and 18th November 2016.

The terms of reference for the evaluation were:

to assess all aspects of the participation and use trials and to make recommendations to Government to inform the future decisions on national participation arrangements to deliver the potential benefits in the shortest possible timeframe.

A program logic of the overall efforts in the My Health Record system participation and use trials was developed (refer to page 5). This links the trial activities to intermediate outcomes and the end benefits of the My Health Record system. The program logic is built on the premise that the intermediate outcomes are short-term or lead indicators of progress towards the end benefits (long-term outcomes) of the My Health Record system. Due to the timeframe of the trials, progress to achieving intermediate outcomes was evaluated.

Based on a range of selection criteria the Minister identified sites based generally on Primary Health Network (PHN) boundaries. Two opt-out trial sites were identified, the Northern Queensland (NQ) PHN

and the Nepean Blue Mountains (NBM) PHN. Two opt-in trial sites were also identified to trial methods of innovative opt-in participation in two different healthcare settings. One opt-in site was in the Ballarat Hospital, Victoria and one covered a number of private general practices in Perth, Western Australia (WA) that used a software product designed to facilitate multi-disciplinary team care of people with an identified chronic illness.

The key elements of trial activities in the opt-out sites were:

- mapping of digital health readiness of healthcare providers
- healthcare provider education and engagement
- individual and community-focused communication and engagement
- work with the hospital (private and public) sector to support use of the My Health Record system
- face to face education and training in general practices and other work places encompassing the full range of healthcare and aged care providers
- consultation with vulnerable and hard to reach population groups

The key elements of trial activities in the opt-in sites were:

- education and training of healthcare providers to prepare them to provide assisted registration and to use the My Health Record system
- dissemination of individual-focused communication resources
- dissemination of healthcare provider-focused resources
- work with software developers to link the My Health Record system to existing clinical information systems
- provision of assisted registration

The extent of consultation

3,579 individuals participated in the baseline survey, and 3,295 (92%) of them agreed to take part in the follow up survey. 1,918 (54%) took part in the follow up survey during the period allocated to collect data.

Aboriginal and Torres Strait Islander people in remote North Queensland responded to a pen and paper survey – 197 at baseline and 171 at follow-up.

8,251 healthcare providers participated in the baseline survey. A total of 2,036 (24.7%) responded at baseline and follow up, of which only 2,012 were able to be used in the analysis after data cleaning.

Focus groups ranged in size from six to 15 participants. The total number of participants was 391. This consisted of 140 individuals attending focus groups in Northern Queensland, and 117 in the Nepean Blue Mountains trial site. There were 101 participants in the Ballarat focus groups, and 33 in the Western Australia focus groups.

Interviews (n=90) were conducted with a range of healthcare providers, including GPs, nurses, pharmacists, practice managers, clinical practice managers, practice and hospital administration staff

Reflection workshops were conducted with PHN My Health Record team members in each of the trial sites. Interviews were conducted with National Trial Team members and Federal and State Departmental officers involved in the opt-out trials.

The outcomes of the trial

The evaluation suggests that:

- the opt-out approach to increase both individual and healthcare provider participation and use is the preferred option
- continuation of current or accelerated opt-in approaches is considered to be unsustainable
- the opt-out trial sites achieved better outcomes, in terms of participation, understanding and some aspects of use of the My Health Record system
- key lessons were learned to inform Government's understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system

Key Findings

Did opt-out result in greater use and participation in the My Health Record system? – Yes

On most measures, the opt-out participation arrangement yielded stronger statistically significant increases (compared to the opt-in trial sites and the rest of Australia) in My Health Record system uptake and participation. These included increases in:

- individual exposure to information about the My Health Record system
- individual and healthcare provider recall of communication about the My Health Record system
- individual registration and use of the My Health Record system
- healthcare provider organisations registered to use the My Health Record system
- healthcare provider document uploads to and viewings of My Health Records
- My Health Record system activity per healthcare provider

Support for automatic creation of My Health Records? - almost universal, with different reasons given by healthcare providers and individuals

For both individuals and healthcare providers interviewed there is a high level of support for the automatic creation of My Health Records. For healthcare providers, the burden of assisted registration is seen as a major impost that is not practical without additional funding. There is also a belief that, even if these additional resources were available, they would be unsustainable in the health system or could be better used for direct health service delivery.

For most individuals, after automatic creation was explained and the benefits of the My Health Record system were understood, the sentiment was positive. They said the fact that they did not have to do anything to create their My Health Record was a major plus. They expressed the view that they would not have registered for a My Health Record themselves and would have expected that their healthcare providers already would be sharing information with other healthcare providers in this way.

Based on data from all sources available to the evaluation, a national opt-out approach is not only acceptable to individuals, healthcare providers, participating health service and health department managers, it is seen by these participants as the only sustainable and scalable approach.

Concerns about confidentiality and security of the My Health Record system by individuals? – few once the My Health Record system and its benefits were explained

Once the My Health Record was explained to individuals (briefly during focus groups) all but a very small number of focus group participants in both opt-in and opt-out sites were very positive about the My Health Record and its benefits for them, their families, dependants and the health system.

Once the benefits of the My Health Record system were clear, nearly all focus group participants said that their concerns about security and privacy, or about the fact that a My Health Record had been created, disappeared. They most often said that, while they thought that no computer-based systems were totally safe, on balance they thought that the benefits to them, their families and the health system far outweighed those risks. This attitude held firm across general population, people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islander participants, gender, age groups, varying levels of computer literacy and access to computers or reliable internet. This reinforces the need for national awareness activities which make clear the benefits of the My Health Record system as well as the privacy and security protections.

Awareness and understanding of the public? - moving in the right direction

Overall the level of awareness and understanding remains low based on focus groups in all trial sites.

There has been improvement in individual exposure to messages about the My Health Record that will raise awareness in the opt-out sites, but less so in opt-in sites and the rest of Australia.

The findings of the focus groups strongly suggest the need for any future national change and adoption strategy to include a much bigger emphasis on awareness and education. This would include:

- putting the My Health Record system on peoples' radar in a positive way
- alerting people to the existence of the My Health Record system and what they need to do under any participation arrangements (be that opt-in or opt-out)
- informing people that they should not assume that the health system already shares information from one part of it to another
- making clear the benefits of the My Health Record system and the privacy and security protections built into the system

A general population communication strategy, appropriately targeted for each audience segment and using multiple channels of communication (including social media), will also reach healthcare providers, alerting them to expect more of their patients to approach them or their practice staff about the My Health Record.

Data suggests that the mail out of a letter and brochure at the beginning of the opt-out trial period has not worked well. In addition, feedback also suggests that the efforts to produce targeted information resources for some groups, such as Aboriginal and Torres Strait Islanders, have not achieved the desired acceptability, outcome, penetration and reach.

Individuals are still reporting difficulties with the myGov website and in getting assistance from call centre helplines (e.g. long wait times) and staff who cannot answer their questions when they do get through.

Healthcare providers are also still citing instances where call centre helplines were not able to answer all their questions and were sometimes difficult to access in a timely way.

What did trials teach us about communication support for the My Health Record system? – a number of lessons

Any national rollout of changed participation arrangements in the My Health Record system must be supported by a comprehensive, nationally driven but locally supported communication strategy. The strategy needs to focus first on the benefits of the My Health Record system and then promote where people can go to get more detailed information. This would include information on:

- how to make an informed decision about whether to opt out, if they choose to,
- how to use the My Health Record to best effect
- the details of their privacy rights and additional information on the privacy and security provisions

Without this investment, based on the experience of these trials, it is likely that the opt-out rate will remain low; but the use of the My Health Record system by individuals will also remain low and they will not ask their healthcare providers to use it.

A key tool noted by stakeholders to motivate continued engagement with the My Health Record system is a road map that is updated as progress is made towards improving the clinical relevance of information in the My Health Record system. This will encourage engagement with the My Health Record system by individuals and healthcare providers while the maturity of the system builds.

There are champions of the My Health Record system that have been identified during the trial in primary care and in the hospital sector and in State Health Departments who have had a direct line of sight of the trials. These people can play a strong role in persuasive communication efforts.

Taking all the evaluation information together and aligning it with the evidence base for a hierarchy of the determinants of behaviour change in the direction desired (in this case, for use of the My Health Record system), suggests that the next iteration of the change and adoption strategy could include the following range of activities under its communication efforts:

Agenda setting: getting the public/target audience segments thinking about the issue

Information: education that makes the issue interesting, understandable, personally meaningful

Incentive: elaboration of the positive personal and social benefits

Skills: providing step by step instruction and resources

Action: education to trigger the trial adoption of the new behaviour/s

Maintenance: developing social and other support for continuation of the changed behaviour

Should healthcare providers be allowed to ‘opt out’? – a resounding ‘no’ from individuals

There is a consistent view among individuals that the Government should make use of the My Health Record system by healthcare providers compulsory. The logic behind the view is that: ‘if the benefits are so good, then why wouldn’t doctors use the My Health Record system for the good of their patients?’; ‘if the cost to taxpayers [of the system] is as high as it would seem to be, then why wouldn’t the Government make it compulsory for practitioners to use it?’. This sentiment, expressed in focus groups, is also noted in the reflection logs of some PHN staff after their public engagement activities.

What was learned about Aboriginal Community Controlled service providers and the people in remote communities? – overwhelming support but practical barriers

The providers of healthcare in the Aboriginal Community Controlled Health Services (ACCHS) sector have also had significant investment in electronic records internally over a long period of time and are keen to maximise the benefits of the My Health Record system for their clients. Their clients are very keen to have My Health Records that will assist with the management of chronic disease and move with them. The main barrier to healthcare provider and individual participation and use is the impact of remoteness and rurality on access to reliable internet, access to computers and computer literacy. Interestingly the ownership and use of smart phones in remote communities is reported to be high and the introduction of third party applications suitable for smart phones may mean a significant increase in the use of the My Health Record system in these settings if it is matched with reliable connectivity. These findings for Far North Queensland are likely to be generalisable to other remote and very remote parts of Australia.

What was learned about vulnerable groups?

People from CALD backgrounds, especially recently arrived immigrants, greatly appreciate the My Health Record system. Experience in the NQ PHN suggests that the best approach is to work with key community leaders through interpreters in a train-the-trainer model so that they can convey messages and support use of the My Health Record system in their communities. In more established CALD communities, materials and resources translated into the key languages will also be necessary.

PHN staff and others directly involved in the implementation of the trials consistently noted difficulty in answering questions about how My Health Record would work for people in certain situations such as

those under child protection orders or those in domestic violence situations, as well as where there may be sensitivities such as for staff of health services who are treated in the facilities where they work. In addition to the privacy provisions in the My Health Record Act, which protect these at-risk individuals, there are processes in place to handle these risk and sensitivity areas, and personal controls which enable people to limit or restrict who can see their health information.

Costs to healthcare providers more or less? – it depends who you ask

Across all healthcare providers interviewed, the average time per patient for using My Health Record was reported to be approximately 3 minutes. Whilst pharmacists reported on average a saving per patient from using the My Health Record system, all other healthcare providers reported an increase in time spent. From surveys, there were no significant differences over time or between trials in the time spent by healthcare providers in using the My Health Record system per patient. Healthcare providers interviewed mainly feel the My Health Record adds time (and therefore cost) to their work, but cannot quantify it. On the other hand, practice managers and practice nurses who do most of the administrative work involved in chasing up information about patients from other healthcare providers (including hospitals) feel that having the My Health Record system has or will decrease that time significantly with overall gains in the efficiency of the practice.

Does the Practice Incentive Program eHealth (ePIP) work? - it depends who you ask

General practitioners interviewed do not see the ePIP as being a major determinant of their use of the My Health Record system. Conversely, their practice managers say it is and believe that without ePIP healthcare provider use of the My Health Record system would decrease. The data from the national infrastructure operator (NIO), when mapped against the key deadlines for meeting targets for payments, suggest that the ePIP has played a significant role in use of the My Health Record system by general practitioners. Further tracking of the data is required to confirm the trends observed during the evaluation period.

Did the extent and nature of media coverage and sentiment change since baseline? - No

Noting the impact of the caretaker period from May to July 2016, where no significant new communication work could be conducted by the Department, it appears that, with the exception of media coverage generated by the launch of the My Health Record in March 2016, there was no significant difference in the amount of coverage or sentiment expressed in media coverage at a national

or local level. The capacity to generate positive unpaid editorial about the My Health Record system could be leveraged through cooperative consultation with the media.

Did the trials achieve their objective of informing next steps to promote participation and use? – Yes

The design of the trials and the change and adoption strategy they were built upon were evidence based. They reflected best practice for implementing innovation and change.

In retrospect, the strategy and design assumed a level of awareness of the existence of the My Health Record system in individuals. In the field, based on focus groups, it quickly became evident that individual awareness was very low.

The evaluation design was robust. It was a quasi-experimental field research design.¹ The rest of Australia was used as the business as usual comparison group for both the opt-in and opt-out trial sites. There was no indication in the available data that there were any parts of the comparison area where there was a level of activity in public or healthcare provider education and support that would make the comparison unreliable.

The timeframe for the evaluation means that the impact of a number of activities across all four trial sites (NQ PHN, NBM PHN, WA and Ballarat Hospital) could not be included in the measurement period for the evaluation. Commissioned work has been implemented or continued since the close of the data collection/measurement period for the evaluation. This includes:

- work by the Australian College of Rural and Remote Medicine (ACRRM)
- a Facebook public education campaign
- the evaluation results of kiosks in general practices
- work with medical specialists, residential aged care facilities and allied healthcare providers
- work in the ACCHS sector and in Aboriginal communities (in the case of NQ)

The results of the evaluation will need to be interpreted taking the exclusion of this substantial effort into account.

Within these parameters, we find that the trials:

¹ A quasi-experiment is a type of experimental research which uses two or more groups that are chosen on the basis of a pre-existing characteristic rather than through random assignment.

- were successfully implemented by the hard work of the PHNs involved in the trials the commitment and skill of Departmental officers and the support of key staff from the Australian Digital Health Agency, and a wide range of stakeholders at State Government level in New South Wales and Queensland and health service providers in Ballarat and Perth.
- have met their objective of providing Government with an increased awareness of the effectiveness of different methods to promote participation and use of the My Health Record system.

**Did healthcare provider awareness of the My Health Record change? – in the two opt-out trial areas
yes, outside no**

During the evaluation period, exposure to information about the My Health Record was relatively low, ranging from 20-39%. Exposure to My Health Record information was higher in the opt-out trial sites compared to the rest of Australia. However, there was no difference between the opt-in trial sites and the rest of Australia comparison site. Of healthcare providers, general practitioners were more likely to have seen or heard about the My Health Record system than any other healthcare provider type across the whole of Australia. This difference could be explained by the education and support provided by all PHNs nationally to general practice about the ePIP.

What did we learn about online training for healthcare providers?

There is a very low awareness about the availability of online training across Australia, in all settings and in all types of healthcare providers. The uptake of the online training available has therefore been very low. Advice from those who have completed some of the available modules suggests there is a need to promote them effectively alongside awareness raising about the existence of the My Health Record system and its benefits.

What did we learn about face to face training for healthcare providers?

In relation to face to face training, the participating PHNs, the National e-Health Transition Authority (NEHTA) and the Australian Digital Health Agency (the Agency) achieved as much coverage of general practice in the opt-out trial sites as was possible in the timeframe available. The training was well received and thought to be effective. A key lesson is that it might be best in the future to focus training efforts on practice managers or practice nurses in a train-the-trainer model to ensure even more penetration, reach, sustainability and affordability of the effort.

What is left to understand better?

Work with other medical specialists, allied healthcare providers, with the Aboriginal Community Controlled sector, the hospital and residential aged care sectors began late in the trial period and mostly after the measurement period of the evaluation. Some information provided to the evaluation team in the last weeks of the evaluation suggests progress with these parts of the health workforce and with the other parts of the health system outside the primary care sector. The information available to this evaluation suggests that the work on the digital health readiness of these other parts of the health workforce and the My Health Record system readiness of the hospital and aged care sectors will need to be a major part of the preparation for any future work to improve participation and use by healthcare providers.

Recommendations

Overarching recommendation

1. We recommend that Government proceed to a national opt-out approach.

Implementation at the national level

2. Taking all the data into consideration we can see no reason not to proceed with an opt-out approach in one national step rather than any progressive staged approach.
3. Priority enhancements and improvements to the My Health Record system identified by the evaluation or implied by it should be addressed prior any significant increase in participation and use. These enhancements include:
 - inclusion of Pathology and Diagnostic Imaging Reports (public and private)
 - stimulation of the creation and launch of accredited third party My Health Record applications to facilitate access and use by individuals
 - improved healthcare provider registration and online authentication processes
 - improved individual registration and evidence of identity processes
 - improved user-friendliness for both individuals and healthcare providers (e.g. navigation, search functions, improved titles and labelling of individual documents, highlighting of critical data, enhanced display)
 - a summary view of medications and MBS data
 - improved access to My Health Record for all pharmacies through connected pharmacy software
 - streamlining and improving myGov or removing My Health Record from myGov (a major barrier consistently cited by individuals)
4. Work should be undertaken with States and Territories, hospital and health services and software vendors to address and implement these enhancements. In particular, this work should include an assessment as to whether their IT systems can cope with increased volumes of information being uploaded and viewed.
5. Develop and disseminate a clear road map that describes what has been done to improve the My Health Record system to date as well as planned technical enhancements and changes to increase its clinical usefulness.
6. Investigate the extent and nature of software that has been developed (e.g. cdmNet, health pathways, electronic medical records viewer in NQ) to see if they have the potential to add to the value proposition for broader healthcare provider use of the My Health Record system.

7. Ensure that there is adequate capacity to meet demand in call centres and service centres. This includes providing enough staff and training them to adequately answer questions from users or potential users of the My Health Record system. Such support should be available for both individuals and healthcare providers.
8. Ensure dedicated content rich expertise in healthcare and the role of the My Health Record is available to support the next stages of system wide change management and social marketing.
9. Commission a national support, monitoring and evaluation service to support the implementation and change management efforts at the local level. This will ensure those at the local level have access to timely information to guide continuous improvement and refinement of efforts.
10. Monitor key variables in the National Infrastructure Operator (NIO) data. Analysis to date highlighted some interesting usage and participation differences from baseline and between trial sites. The period of time from implementation to analysis makes long term predictions impossible. It is recommended that the following key variables continue to be monitored going forward:
 - Shared Health Summaries are a key indicator of use and have an important role in encouraging general practice contributions as part of the ePIP. Given that there was only one ePIP quarter within the evaluation period, continued monitoring of uploads and views is recommended to establish whether increased uploads are maintained in the trial sites and whether this translates to increased views in the long term.
 - Proportion of MBS items with an associated activity (upload or view) in the My Health Record system by a healthcare provider. The proportion of MBS attendance items followed by healthcare provider activity in the My Health Record system is a good measure of use at the time of care.
 - Individual views of documents. Individuals are likely to view their My Health Record around the time of visiting a healthcare provider. Some key documents of interest for individuals (e.g. Diagnostic Imaging Reports) are not currently being uploaded anywhere except in NT. It would be important to monitor individual views into the future when more individuals are registered and more healthcare providers are uploading.

Education and training

11. Consider sustainable solutions whereby pharmacies are a key place to invest in public education and support for individuals at the local level for a period necessary to achieve optimum My Health Record system uptake.
12. Broaden training for healthcare providers to include education about using the My Health Record system clinically and about its benefits for their patients and the health system, including appropriate scenarios relevant to the full range of healthcare providers across disciplines and clinical settings.
13. Work with academic institutions to embed digital health competencies and awareness and understanding into undergraduate, postgraduate and continuing professional development (CPD) programs of all health professionals, allowing for CPD points to accrue for completion of online modules.
14. In the general practice setting consider reorienting the training and education effort from targeting GPs only to targeting their practice managers or practice nurses as “bridgers” in a train-the-trainer model and provide them with resources and ongoing advice and support to provide the sustained effort that will be needed.
15. Consider face to face train-the-trainer programs for community leaders in local CALD and refugee communities, who also act as “bridgers”.
16. Work with the State and Territory Health Departments to implement solutions and communication to cater for complex privacy and safety issues, e.g. in domestic violence victims, children in the care of the state and people in custody prior to any national rollout; as well as healthcare professionals who are treated in the facilities where they work. Noting that there are privacy provisions in the My Health Record Act, which protect at-risk individuals and processes in place to handles these risk and sensitivity areas and personal controls which enable people to limit or restrict who can see their health information.

Strategy

17. Consider how to use current incentives that promote best practice such as the Indigenous Health Incentive and other chronic disease incentives. This would be consistent with the current PIP consultation and redesign process to achieve quality improvement in the detection and management of chronic conditions.
18. Develop engagement strategies and business cases for different segments of healthcare providers, engaging senior professionals and representative bodies to enhance credibility of the My Health Record within professional groups.



19. Work with accreditation agencies in primary, secondary and tertiary healthcare sectors to develop standards in relation to digital health and My Health Record.
20. Use all mechanisms available in commissioning and funding health services as vehicles to require the use of the My Health Record to obtain funds where practical.
21. Consider ways to require the use of the My Health Record system by all healthcare providers and how to best use the Government's purchasing power directly (e.g. in the aged care sector), via new initiatives as they arise (such the Health Care Home initiative) or via PHNs commissioning clinical services (e.g. require use of the My Health Record system in all clinical and aged care services that receive Commonwealth funds). Such requirements should have a timeframe within which healthcare providers need to become compliant.
22. Explore with health insurers how they could encourage preferred suppliers and clients to use the My Health Record system as part of their push for preventive care and cost containment.
23. Use the good working relationships established with the New South Wales and Queensland health departments and their participating health services to promote other jurisdictional buy-in and the use of tools and processes that have been developed. For example, NSW Health, Mackay Health Service and Cairns Health Service have developed tools that can showcase how the My Health Record system can be used as the "free highway" between healthcare providers across sectors involved in an individual's care to bring together key information along the patient pathway.

Communications

24. Engage a suitably qualified social marketing agency, supported by dedicated content rich expertise in healthcare, to develop a multifaceted marketing strategy for each relevant market segment of healthcare providers and individuals. This strategy should include a staged approach that:
 - puts the My Health Record firmly on the healthcare provider and public agenda in a positive way through focusing on improving people's understanding of the benefits at the individual, family, healthcare provider and health system levels
 - alerts healthcare providers and individuals to where they can find more detailed information, including about their individual privacy rights and the existing privacy and security frameworks that apply to the My Health Record system

- makes clear the privacy and security protections built into the My Health Record system, the privacy provisions of the My Health Record Act and the personal controls in the system
 - promotes interpersonal communication about the My Health Record so that members of each audience segment become promoters within their sphere of influence
 - links healthcare providers into online and face to face training
 - outlines the road map for key system enhancements and additions, especially in relation to ease of access (mobile applications, streamlined registrations and evidence of identity, improvements to myGov) and new clinical content
 - promotes messages about how the My Health Record system will evolve over time
 - notifies individuals and healthcare providers when improvements and milestones have been achieved
 - addresses issues specific to key target segments such as children 14 years and over and their parents, victims of domestic violence, children in the care of the state and people in custody. Noting that there are privacy provisions in the My Health Record Act, which protect at-risk individuals and processes in place to handles these risk and sensitivity areas and personal controls which enable people to limit or restrict who can see their health information
 - develops communication mechanisms matched to each segment including tools and templates and approved messages for use by PHNs, jurisdictions and private and not for profit health services locally
25. Ensure that whatever awareness raising comes next builds on the results of individual and healthcare provider engagement from this evaluation. The results of individual and healthcare provider surveys, interviews and focus groups contain useful information for the development of key messages and appropriate channels of communication.
26. Include the independent monitoring and evaluation of the marketing strategy in the suggested work of the overall national support monitoring and evaluation service to support continuous refinement of the campaign over time.

Implementation by PHNs

27. Any future national rollout needs to:

- Have appropriate PHN level governance structures that allow for collaborative planning across healthcare disciplines; across public, private and not for profit healthcare providers; across service settings; and includes representation of individuals, Aboriginal and Torres Strait Islander people and where appropriate rural and remote healthcare providers
- Allow adequate time for local mapping of digital capacity, local professional groups and their ways of working
- Allow adequate time for the development of plans based on all available evidence (including evidence from national healthcare provider and individual surveys conducted for this evaluation and location-based NIO data)
- Allow adequate time for recruitment and induction of implementation staff
- Allow flexibility in timing/sequencing of steps to accommodate local issues and contexts (e.g. remoteness, internet access, special populations, local labour force issues that impact on capacity to recruit the right people in a timely way)
- Be supported nationally by people with both health system experience and knowledge of the detail of the My Health Record system, its benefits for all stakeholder groups and change management. This could be achieved by either appropriate recruitment into the Australian Digital Health Agency or through the commissioning of a national support, monitoring and evaluation service.

Implementation by States and Territories

28. Resources made available to assist with the integration of the My Health Record system in hospital and health services should be within a model where the health services employ their own staff. The job design and recruitment of these support and implementation officers should be in line with the plans and strategies for digital health in each jurisdiction and supported, where possible, at the state-wide level by the health system wide digital health functions of each State and Territory.

29. In cooperation with the local health services and health departments, promote materials and processes that were developed to support the integration of the My Health Record system in the public health system.

Implementation in the private and not for profit hospital sectors

30. Use the private and not for profit hospital and residential aged care sectors as key partners in both the integration of the My Health Record system within these settings and as a way to reach visiting medical specialist staff with messages about use of the My Health Record system in their private practices.
31. Work collaboratively with the professional associations, education providers and CPD providers to:
 - promote the use of the online training modules developed for the trials
 - include My Health Record knowledge and skills in training and education programs
 - make CPD points available for completion of relevant online training modules

Introduction

My Health Record, formerly known as the Personally Controlled Electronic Health Record (PCEHR), is a way of securely sharing an individual's health information between registered healthcare providers who are involved in the individual's care. In its current form, the My Health Record system is an "opt-in" system in which both individuals and healthcare providers must register to participate. Owing to a lack of uptake and low participation in and use of the PCEHR, and in response to the findings of a review in December 2013, the Australian Government announced a system overhaul which included redevelopment and restructure of the current system.² Part of this process included renaming the PCEHR to My Health Record, and trialling new individual participation arrangements that include an opt-out system, to inform strategies for increasing uptake and use.

The Government has acknowledged that any potential transition to opt-out participation arrangements could potentially present a number of risks for individuals and healthcare providers. They include risks to reputation and the practical possibility that adoption and use of the reformed system by healthcare providers could be lower than expected. To understand the risks, benefits and lessons of implementing a national opt-out system, and to identify effective mitigation strategies, two opt-out trials (in NQ and the NBM PHNs) were planned and implemented. Two opt-in trial sites were also identified to trial methods of innovative opt-in participation in two different healthcare settings. One opt-in site was in the Ballart Hospital, Victoria and one covered a number of general practices in Perth, Western Australia (WA) that used a software product designed to facilitate multi-disciplinary team care of people with an identified chronic illness.

The purpose of the evaluation is to:

- obtain evidence-based evaluation results of the participation and use trials to allow informed decision making by Government on the most effective way to increase participation in and use of the My Health Record system.
- obtain defensible evaluation results using a well socialised and robust evaluation framework and methodology.

² Australian Department of Health (2016). Tender brief for Request for Quotation for the provision of evaluation of participation trials.

- ascertain public and healthcare provider reactions to the different participation arrangements being trialled (e.g. opt-out and opt-in), including evidence measures and justifications on decisions made by all key stakeholder groups (e.g. why an individual chose to opt out, why a healthcare provider has increased interest, why individual or healthcare provider interest did not change).
- assess the effectiveness of different strategies for healthcare provider engagement and involvement in the trials.
- determine the effectiveness of the communication and support activities for individuals in the trial sites.
- determine the effectiveness of the communication, education and training activities for healthcare providers in the trial sites.
- assess all relevant stakeholders experience with the My Health Record system (including healthcare providers, individuals, Government bodies, and system providers).
- provide recommendations to Government to inform the future national participation arrangements to deliver the potential benefits of the My Health Record system (in the shortest possible timeframe).

Brief Methodology

Overarching design of the trial evaluation

The My Health Record system participation and use trials were designed as a quasi-experiment. This is a type of experimental research which uses two or more groups that are chosen on the basis of a pre-existing characteristic, rather than through a random assignment. This evaluation was a non-equivalent group design in which a comparison is made between comparison and trial groups that have been established on some basis other than through random assignment of subjects to groups.

In a pre-test/post-test, non-equivalent groups design data is collected before and after the trial activities and because assignment of subjects to trial and control groups is not random, evaluators cannot assume equivalence between the different groups. Instead, evaluators must assess the differences at baseline and account for any demographic or behavioural differences in the analysis. If, however, the two groups are similar in their pre-test scores prior to trial activities but differ in their post-test scores following trial activities, researchers can more confidently make a claim about the effect of treatment.

The design of the current evaluation is represented diagrammatically below. In this instance, the Comparison Group is not a classic control group.

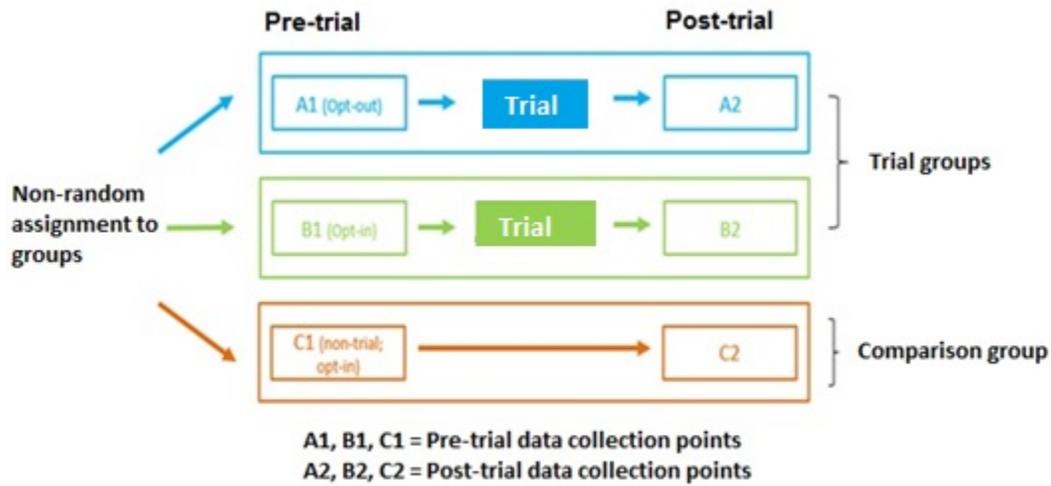


Figure 1. Pre-test/post-test non-equivalent groups design.

Figure 2 below presents the national program logic of the overall efforts in the My Health Record system participation and use trials. It describes a ‘road map’ that shows the logic or theory behind and the expected outcomes of the participation and use trials of the My Health Record system. The intermediate outcomes chosen were those that progress towards could reasonably be expected based on the extent and nature of the trial activities and given the timeframe of the evaluation period.

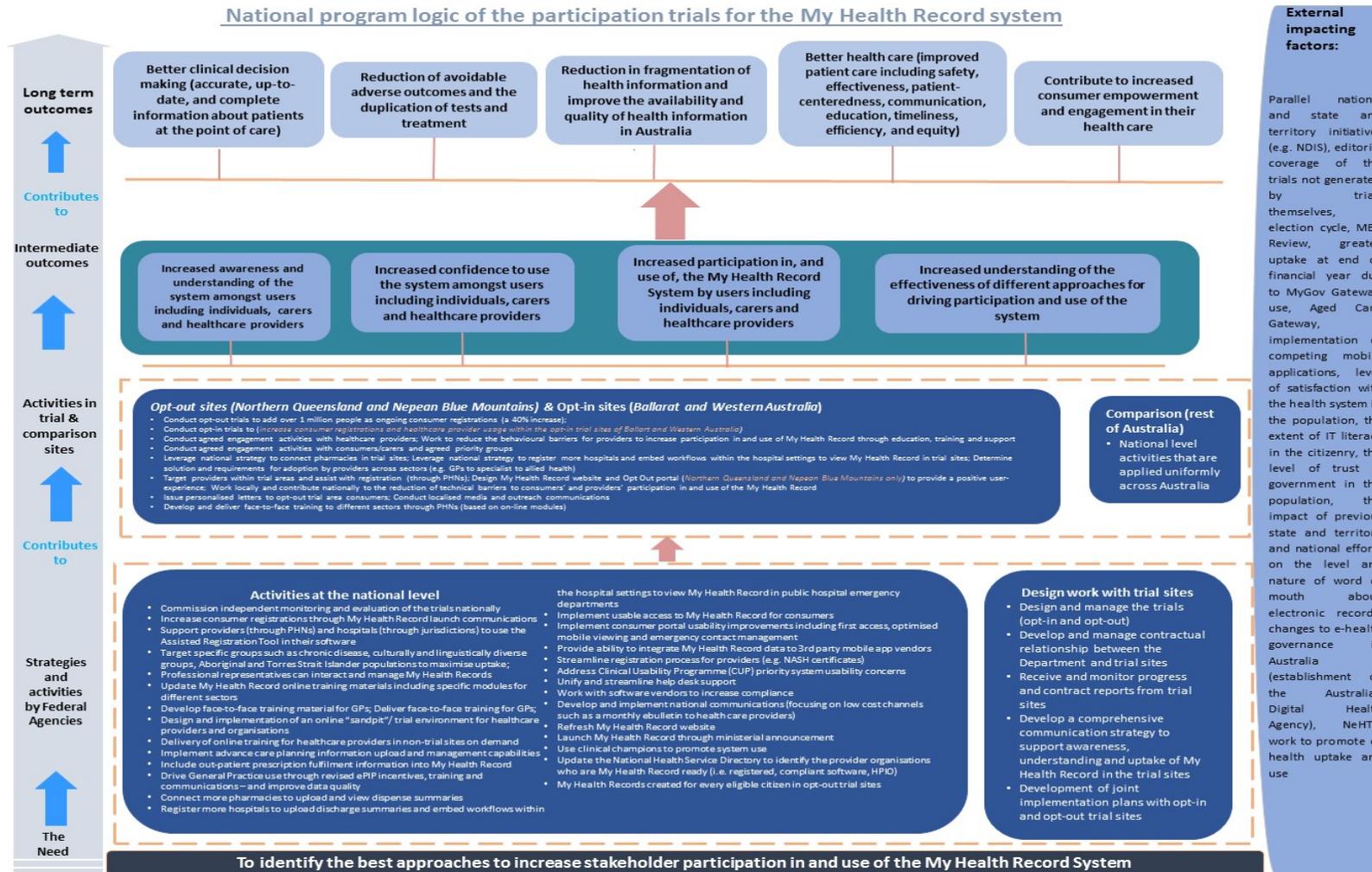


Figure 2 National program logic of the participation and use trials³

³ A printable version of figure 2 is available at appendix 15.

A detailed list of evaluation questions for each agreed outcome is at Appendix 1. A costing study was originally included in the evaluation framework, however, this was excluded from the final report on the basis that only a subset of the required costing data was available. This would have resulted in a cost comparison that was not sufficiently reliable and did not produce a meaningful comparator at a macro or unit cost level.

Results

High level summary of results by outcome

The detailed findings of the evaluation are presented in appendices 1 – 15:

1. A detailed list of evaluation questions for each agreed outcome
2. Summary of results by outcome by evaluation question and relevant data source
3. Analysis of My Health Record system operator data
4. Findings from focus groups with individuals
5. Findings from interviews with healthcare providers
6. Findings from survey of individuals
7. Findings from survey of healthcare providers
8. Summary of interviews with National, State and Health Service officers with direct line of sight of the trials
9. Northern Queensland Primary Health Network opt-out Trial (Case study)
10. Nepean Blue Mountains Primary Health Network opt-out Trial (Case study)
11. Western Australia Primary Health Alliance opt-in Trial (Case study)
12. Western Victoria Primary Health Network opt-in Trial (Ballarat Hospital) (Case study)
13. Analysis of media monitoring and sentiment from baseline to final report
14. Aboriginal and Torres Strait Islander pen and paper survey findings
15. National program logic of the participation and use trials of the My Health Record system

The detail for each element of the methodology is included in its relevant appendix.

Presented below are the major findings of the evaluation related to each outcome area.

Increased awareness and understanding of the My Health Record system amongst users including individuals, carers and healthcare providers

Individuals

Overall, levels of exposure to information and materials that were designed to increase awareness in all trial areas improved in comparison with the rest of Australia. At the time of the follow up surveys, more people in both opt-in (19%) and opt-out (41%) trial areas had heard about the My Health Record than those in the rest of Australia (10.7%). Exposure to awareness-raising materials improved most in the opt-out areas. From the surveys and focus groups, and reflections with trial teams, it appears that the influence of trusted healthcare providers and key staff within practices or organisations is important. In focus groups, participants repeatedly mentioned pharmacists as an accessible, trusted location where they could get information about or assistance with their My Health Record. The individual survey found that the most common sources of exposure to the My Health Record system was via healthcare provider and the myGov website (21.6%, 22%).

In the opt-out areas, survey respondents were more likely to recall receiving a letter about My Health Record, than focus group participants. At follow up, just under half of respondents in the opt-out trial site (42%) recalled receiving a letter about the My Health Record. Survey respondents' awareness of the My Health Record, and their recollection of receiving a letter about it, could have been heightened by completing the baseline survey between 17 February and 7 March, just prior to the issuing of letters to individuals on 8 March 2016. In this context, the survey itself could have contributed to awareness raising. This in turn could point to the effectiveness of broad awareness raising prior to any specific contact about the My Health Record system.

Regardless of people recalling whether they received a letter (in opt-out areas) and or whether people had recently received assisted registration (in opt-in areas)⁴, the level of understanding of the My Health Record was still low across both trial sites. This suggests that a single intervention - receiving a letter or being offered assistance to register - is insufficient to increase individuals' understanding of the purpose, functionality and benefits of the My Health Record system.

Healthcare Providers

The baseline awareness of healthcare providers who were surveyed was relatively high (82% in opt-out and rest of Australia; 63% in opt-in). GPs were the healthcare provider group most likely to be aware of the My Health Record system (>70%).

⁴ Note: in opt-in focus groups, all the participants had accepted the offer of assisted registration. People who declined the offer had also been invited to focus groups but did not accept.

The key reason given by healthcare providers who said that they had not accessed the My Health Record system was their lack of awareness/information. Not having access to the My Health Record system at their workplace or not seeing the need for the My Health Record system were the second most frequent reasons reported.

Healthcare provider awareness of whether their workplace/organisation was registered with the My Health Record system increased in a more pronounced way in both opt-out trial sites (11%) and opt-in trial areas (9%) than in the rest of Australia, although this was not statistically significant.

These results support the findings of the case studies and reflections with trial teams: that different healthcare provider groups were harder to reach and did not always immediately see the relevance of the My Health Record system to their own practice; and that, as observed in the focus groups with individuals, once people (including healthcare providers) are informed about the My Health Record system, the majority understand and see the benefits of it.

Increased confidence to use the My Health Record system amongst users including individuals, carers and healthcare providers

Issues of 'confidence' were explored from two aspects: an individual's confidence (as a healthcare provider or consumer) to use and view a My Health Record; and confidence in the confidentiality and security of the My Health Record system.

Individuals

In focus groups, low confidence or doubts about the practical use of the My Health Record system related to: concerns about computer literacy; poor internet access for some population groups; or the difficulty in accessing My Health Record via myGov.

A minority of people (n≈1 per focus group) initially expressed concerns about confidentiality and security issues. This changed once participants had access to information about how the My Health Record system works and the opportunity to ask questions about its functionality and regulation. The common conclusion in all groups was that the potential benefits of the My Health Record system outweighed any potential risks and therefore they were confident to use it or for their carer or healthcare provider to use it on their behalf.

Overall, individual survey respondents were 'unsure' or 'not confident' in the ability of the My Health Record system to keep their information confidential and secure, with just over a third of the respondents indicating that they were 'confident' or 'really confident'. Respondents (40%-48%) in all

sites trusted the Government and others ‘somewhat’⁵ to always treat their medical information appropriately. Those who were registered with the My Health Record system were more confident that their information was secure with 56% stating they were confident or very confident compared to 35% of those who were not registered.

The number of My Health Records where individuals had restricted access to either documents (n= 4,442, 0.1%) or healthcare providers (n=9,632, 0.2%) was low and did not vary across trial site and the rest of Australia. This supports the qualitative data that, once informed about the features of My Health Record, individuals’ concerns about privacy, confidentiality and security are low.

Healthcare Providers

Those healthcare providers interviewed who had been exposed to the My Health Record system and had received training as part of the trial activities expressed confidence in using it. In the survey, there were no significant differences in healthcare provider confidence levels between trial sites, but significantly higher levels of confidence (6.2%) between those in opt-out trial sites who received training and the rest of Australia were seen. Over all sites, there was an increase in the perceived effectiveness of training during the trial period.

From the case studies and reflections by trial team members, there was concern that training, especially in the early stages of the trial, could have been better developed. The negative healthcare provider attitude towards online training, which trial teams reported, was supported by the survey data that showed very low numbers of healthcare providers using online training (in single digits in all sites) and a strong preference for face to face training (70+%). From healthcare provider interviews, it was evident that key staff (e.g. practice managers) often completed the training and then trained the healthcare providers internally. This was confirmed in trial team reflections.

Taken together, the findings support survey data that suggest that healthcare provider confidence in and consequent non-use of the My Health Record system is due to a combination of:

- low awareness (29% of non-users)
- lack of access to the My Health Record system in the workplace (28%)
- shortage of training (14%)
- low perceived need to use the system (15%).

⁵ Where ‘somewhat’ was the mid-point on a Likert scale, ranging from trusting ‘to a great extent’ to ‘not trusting at all’.

Nevertheless, there was a significantly increased volume of documents viewed and uploaded by healthcare providers during the trial, especially in the opt-out trial sites compared to the rest of Australia (see the next outcome area).

In terms of healthcare provider confidence in the confidentiality and security of the My Health Record system, the healthcare providers interviewed at all trial sites were almost equally divided. A similar proportion of healthcare provider survey responses were in the 'uncertain' or 'not confident' categories when asked about confidence in Government's capacity to protect the confidentiality and security of the My Health Record system. In general, across all trial sites, the confidence in the Government to ensure confidentiality fell over time.

Considering the increase in healthcare provider use of the My Health Record system, it appears that healthcare provider confidence in the Government's ability to ensure security and confidentiality of the My Health Record system may not affect their use of it.

Increased participation in, and use of, the My Health Record system by users including individuals, carers and healthcare providers

Individuals

There were approximately 2.6 million individuals registered for a My Health Record at baseline. 971,245 My Health Records were automatically created as part of the opt-out trials. An additional 80,444 records were created in the opt-in trial sites over the trial period. 1,726 of these My Health Records were created as a direct result of the opt-in trial activities. This is in comparison to the 596,345 My Health Records that were created through opt-in registration in the rest of Australia between March and September 2016.

There was a small but statistically significant increase in individuals' use of their My Health Records. The increase in both uploading documents and viewing personal information was proportionally greater in trial sites than in the rest of Australia, especially in opt-out trial sites.

Individuals also rarely restricted access to their My Health Record and allowed MBS data to be added to their My Health Record.

Individuals uploaded a number of different documents to the My Health Record system, including: Consumer Entered Health Summary, Consumer Entered Notes, Advance Care Directive Custodian Report, Advance Care Documents, Personal Health Observation, Personal Health Achievement, and Child Parent Questionnaire. There was a 10% proportional increase in uploads by individuals in the

follow up period in the opt-out trial sites, and a 50% proportional increase in uploads by individuals in the opt-in sites compared to the rest of Australia.

The proportion of Aboriginal and Torres Strait Islander people registered with My Health Record was low and did not significantly change during the trial period. This also confirms the results of focus groups and trial team reflections that there are particular barriers to the participation of Indigenous people in rural and remote areas (computer literacy, internet access, health literacy and lack of linkages with other Indigenous specific healthcare programs like the Closing the Gap PBS Co-payment Measure).

At the time of the follow up survey, very few individuals said they intended to cancel their My Health Record.

Healthcare providers

There was consistent growth in healthcare provider registrations across all three sites, especially for GPs. The increase was greatest in the opt-out sites. There was an increase in the uploading of documents in all three sites, but quite significantly in the opt-out sites. There is evidence that the increase in uploading of Shared Health Summaries is linked to ePIP deadlines, but it would be helpful to track the data over a longer period of time.

The number of documents uploaded by healthcare providers in the trial sites increased significantly during the trial period. *[Numbers in brackets indicate (proportional change in opt-out sites/opt-in sites versus the rest of Australia)].* These included: Shared Health Summary (36.8/15), Discharge Summary (7.8/3.7), Event Summary (8.2/9.5), Dispense Record (6471⁶/4.6) and Prescription Records (15.4/1.5).

The number of uploads associated with MBS attendance items examined in the evaluation increased from baseline to follow up. The proportional increases were greater in the opt-out trial site compared to the rest of Australia.

There were increases in the number of Shared Health Summary uploads occurring within 24 hours of a certain MBS attendance item upload. These increases were significantly greater in the opt-out trial sites than the rest of Australia. The MBS items associated with increased Shared Health Summary uploads included GP attendances (22.9 proportional increase on rest of Australia), and Managed Care Plan and Health Assessment by GPs (35.1) in opt-out sites (all statistically significant). Also, in the opt-in trial sites there was an increase in the number of Shared Health Summary uploads occurring within 24 hours of GP

⁶ Dispense records uploads in opt-out trial sites increased from a baseline of 5 to follow up of 32,365.

attendances (10.1) but a reduction for Managed Care Plan and Health Assessment by GPs (-1.2), compared to the rest of Australia.

There were a number of document types that had statistically significantly increased views between baseline and follow up. Views increased significantly more in the opt-out trial sites compared to the rest of Australia. These included (*proportional change*): Discharge Summary (36.3), Medicare overview and documents created by other providers (30.0). In opt-in trial sites, the significant increases in viewed documents were; Medicare overview (879.4) and Medicare Department of Veteran Affairs (DVA) benefits (2.4). These findings confirm the data from healthcare provider interviews and from jurisdictional officers that MBS data have been immediately useful to hospital-based healthcare providers in trial sites.

Healthcare providers indicated that they did not plan to decrease their use of the My Health Record system in the near future. They also indicated that they would use the My Health Record system if their patients wanted them to.

Healthcare Provider Organisations

Registration of healthcare provider organisations increased consistently over the trial period. The opt-in trial sites had a proportional gain greater than the rest of Australia. There were 131 additional healthcare provider organisations registered in the opt-out trial sites and 161 additional healthcare provider organisations registered in the opt-in trial sites, which equates to 28% and 17% proportional increase respectively over the rest of Australia when taking baseline registration into consideration.

The main healthcare provider organisation types registered in the trial period were general practices, followed by pharmacies, and public hospitals and health services.

Lack of access to the My Health Record system in a workplace was reported in healthcare provider surveys as a reason for not using the system (14%). This was also identified in reflections with trial teams, where they reported expending considerable effort in facilitating the registration or re-registration of practices. In all trial sites, embedding the My Health Record system into existing IT systems and into practice or hospital workflows also required considerable effort by trial teams.

Increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system

To what extent have the trials achieved their intended outcomes for individuals, healthcare providers and other groups? How has this varied across trial sites?

On most measures, the opt-out participation arrangement yielded more significant increases (compared to opt-in trial sites and the rest of Australia) in My Health Record system uptake and participation. These included increases in: individual awareness of the My Health Record system, individual and healthcare provider recall of communication about the My Health Record system; individual registration and use of the My Health Record system; healthcare provider organisations registered to use My Health Record; healthcare provider document uploads to and viewings of My Health Records. The opt-out trial sites also had greater activity than the rest of Australia per healthcare provider.

These quantitative results confirm the qualitative findings from consultations with stakeholders closely involved in the trial process: that the opt-out participation arrangement would be more efficient if rolled out nationally.

Across all healthcare providers, the average time per patient for using the My Health Record was reported to be approximately 3 minutes. Whilst pharmacists reported on average a time saving per patient from using the My Health Record system, all other healthcare provider types reported an increase. There were no significant differences over time or between trials identified in the reported time associated with using the My Health Record system per patient.

Individual awareness of the My Health Record was low at the beginning of the trials and remained low at the end of the trial period, although it had increased slightly in the opt-in trial sites. The initial communication strategy for the opt-out sites (a letter and brochure to all individuals) was poorly recalled. For those who did read it, few understood the content and no more than 1 or 2 people per focus group acted upon it. Despite one-to-one communication with individuals in the opt-in sites, those who accepted assisted registration did not demonstrate a high level of awareness of the purpose and features of the My Health Record.

There are particular challenges to engaging some populations. In particular, Aboriginal and Torres Strait Islander people in rural and remote communities continued to have low levels of awareness the My Health Record.

The engagement of healthcare providers proved more challenging than expected in all trial sites. For PHNs, the trials required a broadening of the scope of their usual activities and networks. Building knowledge and understanding of healthcare providers beyond primary health care (medical specialists, aged care facilities, a range of allied care providers and public and private hospitals) proved a challenging task for opt-out sites. For the Ballarat opt-in site, there were the same challenges:

differences between professions (hospital departments/ units), ways of working and levels of healthcare provider awareness of the My Health Record and achieving provider engagement in the time available. As a result, engagement levels for medical specialists, allied health and aged care facilities remain low; and the engagement of different parts of the hospital varied.

Understanding the effectiveness of the different participation arrangements in the My Health Record system for increasing use has been limited by the short time period allowed for the trial. This has been compounded by non-program factors that further limited the time available for the trial teams to implement their engagement strategies. This meant that planning and preparation was rushed, trial teams were learning as they implemented and some strategies were unsuccessful and had to be revised.

There were also some complex policy issues about the My Health Record system raised by healthcare providers, individuals and Departmental officers that could not be resolved prior to or during the trial period. These related to children in the care of the state, people in detention, domestic violence scenarios etc. which need to be resolved cross-jurisdictionally. In addition to the privacy provisions in the My Health Record Act, which protect at-risk individuals, there are processes in place to handle these risks and sensitivity areas, and personal controls which enable people to limit or restrict who can see their health information.

The time limitation also affected the ability to measure all outcomes of the trial activities. Some activities were only just commencing at the end of the trial period (e.g. engagement with allied healthcare providers) and will take longer to show results. It is not possible to make projections of activity at this point. Other impacting factors, e.g. the influence of ePIP, need a longer period to measure in a meaningful way.

Discussion and Conclusions by outcome

Context

The My Health Record system is essential national health system infrastructure. It should be recognised as the foundation of the country's capacity to address the current fragmentation in the health system and services, and achieve patient-focused and sustainable healthcare through the better availability and use of health information.

Acknowledgements

All parties involved in the trials should be commended, including those:

- that hosted the trials
- that participated in the localisation of the design
- that implemented the trials
- Departmental officers responsible for the design and implementation of these complex trials at the national level
- Departmental officers who facilitated access to key data sources for the evaluation
- participating public sector health services and health departments in trial sites

The design elements of the change and adoption strategy and the trials themselves were sound. Implementation by the trial sites was thorough and in line with the contracts between them and the Department.

Non-program factors

All stakeholders involved in designing and running the trials reported that the period of time was too short to complete all the activities that are known success factors and to realise all the potential results of their efforts. The seven-week caretaker period compounded this and resulted in a period of restricted activity in the trials, delayed their progress and potentially their effectiveness as measured at the end of the trial period. Therefore, data available to this evaluation may not reflect the full impact of all activities and clearly does not reflect the impact of those activities that fell outside the measurement period for the evaluation. For example, the results of a Facebook based awareness raising campaign in NQ launched in October, the results of PHN efforts to engage hospitals in NQ, Aboriginal and Torres Strait Islander healthcare providers and communities, private hospitals, other medical specialists and allied healthcare providers.

In both the opt-out trial sites there were significant hospital and health service system upgrades underway that meant that the education and training efforts targeting healthcare providers in these

settings had to be delayed in the case of the NQ PHN. In the case of the NBM PHN were felt by the officers involved in the My Health Record system promotion and support to have reduced their impact.

The key role of digital health functions in the central offices of both Queensland Health and New South Wales Health was an important enabler. These central functions helped to bridge skill gaps and act as conduits of communication and advocates.

The 'unfriendliness' of myGov, in particular the log-in process and navigation of the website emerged as a major obstacle to individuals' access to their My Health Records.

Existing sources of information and support for consumers (helpline and Medicare Service Centre staff) did not always meet the needs of consumers.

Changes to incentive arrangements (ePIP) were controversial within general practices and the peak bodies who represent them. The professional peak bodies' views about the ePIP changes may have influenced the rates of uploading Shared Health Summaries. The ePIP arrangements for the My Health Record system received publicity, and even though it was predominantly negative, it may still have created raised awareness among GPs and caused increased engagement.

Overarching conclusions

The objective of the trials was to test different participation arrangements, including opt-out, to understand the public's reaction and test the extent to which healthcare providers participate when most of their patients have a My Health Record. The purpose of this evaluation was to measure and report the findings of the trials and provide advice on different methods of driving participation and this has been achieved.

There is evidence to support the stakeholder consensus that opt-out should be the participation model into the future. Stakeholder views are supported by the statistically significant findings that suggest increases in opt-out sites (in comparison with opt-in sites and the rest of Australia) in: individual awareness of the My Health Record, individual and healthcare provider recall of communication about the My Health Record; individual registration and use of the My Health Record system; healthcare provider organisations registered to use My Health Record; healthcare provider document uploads to and viewings of My Health Records. The opt-out trial sites also had greater activity than the rest of Australia per healthcare provider.

Continuation of current or accelerated opt-in approaches were considered by all stakeholder groups to be unsustainable and unscalable to a national level.

There was a very low level of community concern about the Government's initiative of automatic record creation. The very low level of concern was population-wide and included those most at risk and disadvantaged, such as those in very remote settings, Aboriginal and Torres Strait Islander peoples and people from CALD backgrounds. The very low level of concern present can be accommodated by the opt-out approach in that individuals who are concerned can opt out.

There was a very strong level of community support for making healthcare providers obliged to use the My Health Record system.

To maintain the momentum that has been established in the opt-out trial sites, activities to support healthcare providers need to continue. This would mean continuing to learn implementation lessons about the primary care sector; and in sectors where the work was only beginning at the end of the evaluation period (hospitals, residential aged care facilities and ACCHS).

Outcomes

Increased awareness and understanding of effectiveness of different approaches for driving participation and use of the My Health Record system.

The design of the trials and the design of the evaluation have produced findings that provide an improved understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system.

Most stakeholders believed that, on balance, the opt-out model is the only sustainable and scalable approach to get whole-of-population uptake and benefits from the My Health Record system within the shortest time possible.

This view is supported by the participation and use data. The opt-out trial sites exceeded the performance of opt-in and the rest of Australia on most indicators of success (participation, use and contribution).

The opt-out approach achieved greater relative registrations, but it did so at an increased cost over the rest of Australia. However, this increased cost is likely to be offset by:

- bringing forward the benefits of the My Health Record system

- achieving registrations with potentially vulnerable and hard to reach groups that may not otherwise have been engaged

Neither the opt-out nor the opt-in trials have provided lessons on how to best deal with the impact of no or unreliable internet access on the use of the My Health Record system by healthcare providers or individuals.

While both the healthcare provider and individual surveys demonstrated that people in the opt-out trial sites were more likely to be exposed to communication, due to time and resource constraints, none of the trial sites could implement a communication strategy of the scale and nature required to affect significant changes in community awareness and engagement, given that the My Health Record was not even on the radar of the population at the beginning of the trial period.

Based on advice from individuals, healthcare providers, the PHNs involved in the trials, State and Territory health departments involved in the trials, there is a need to develop a comprehensive, well targeted national marketing campaign. The campaign focus would need to be on the benefits of the My Health Record to individuals, families and the health system. It would need to align with the evidence of what works in such campaigns:

- audience segmentation
- matching of channels of communication to each audience segment's known sources of credible information
- messages and resources are tested and trialled with each audience segment to ensure they are understood as intended and match the literacy and conceptual levels of each audience segment
- messages are delivered by sources that are credible to each audience segment
- messages include encouragement to seek out more detailed information from reliable sources and promote interpersonal communication
- messages in specially designed resources are supported by paid and unpaid editorial through cooperative consultation and education and awareness raising in writers from main stream and social media
- mass media buying strategies take into account the media habits of each audience segment and the overall communication strategy is designed to ensure that the My Health Record and its benefits are firmly on the agenda of each audience segment before attempts are made to

provide information about how to use the My Health Record or opt out, prompt action and so on

Due to the existing Commonwealth and State funding arrangements (i.e. the Commonwealth funds primary care), the timing of the changes to the ePIP and the resources available, the primary focus of healthcare provider adoption was in general practice. Many stakeholders advised that it could have been more productive to have the resource capacity to address all levels of the health system and different types of healthcare providers at the same time.

The significant impact of the time available for the trials when combined with the impact of the unrelated activities such as concurrent upgrades to clinical information systems in public hospitals placed some limits on the amount, impact and timing of activities in the opt-out trial sites in those settings. However, hospital and health department stakeholders in both opt-out trial settings agree that the resources to support participation and use in the public hospital system should be allocated to the My Health Record system to ensure high levels of executive and public health system-wide support. The role of State and Territory health departments' system-wide digital health functions will be key to: supporting the engagement of public hospital-based healthcare providers to upload Discharge Summaries, and view My Health Records; and to the delivery of hospital-based pathology and radiology records to the My Health Record system. These activities will in turn provide the impetus for GPs and other healthcare and aged care providers to access the My Health Record system as it will contain clinically useful information for them.

Most of the training received by healthcare providers in the trial sites was face to face. Data from the online training provider indicates that across Australia only 0.3% of registered health professionals used the online training. Noting that the promotion of these online modules was primarily directed towards general practice, the data from the evaluation suggests either people were unaware of the available training or did not see it as an appropriate method for increasing their understanding and confidence in their use of the My Health Record system. Some stakeholders suggested this would not change unless there was significant advertisement about the availability of the training via credible sources, such as professional associations, and unless the completion of training would attract CPD points.

Education and training is an important driver of confidence to use the My Health Record system as it can both promote the benefits at a clinical level and enhance healthcare providers' confidence to use it. It needs sustainable and scalable methods for delivery. There was a statistically significant increase in the uptake of training in the opt-out trial sites relative to the rest of Australia however it was a low

proportion of healthcare providers overall. There was no significant difference in the uptake of training in the opt-in sites relative to the rest of Australia.

Taking all sources of data and information together there is evidence and a consensus in both opt-out and opt-in trial sites (individuals, those running the trials at national and local levels, state health department officers with direct line of sight of the trials and healthcare providers interviewed), that the opt-out model achieved greater participation and use of the My Health Record.

Taking the information from all sources, there was no statistically significant impact of assisted registration in the opt-in trial sites on participation measured at the population level.

There were no statistically significant differences between trial sites and the rest of Australia in what drove use of the My Health Record system by healthcare providers. However, motivators to use the My Health Record were most often described as: access to information and the influence of patients' use of the system or their own beliefs that the My Health Record system will improve access and save them time.

There was a consistent view across stakeholder groups that making the upload of documents to the My Health Record system automatic in both hospitals and in primary care and ultimately in all other settings, as software is developed and refined, would enhance participation and use.

Several system issues are barriers to participation and use by both individuals and healthcare providers. These include: difficulties in accessing the My Health Record through myGov; the lack of availability of My Health Record third-party applications; the need to improve the healthcare provider registration and online authentication process; the need to improve the individual identity processes for registration; and the need to improve access to the My Health Record system for all pharmacies through connected pharmacy software.

The inclusion of pathology and diagnostic imaging reports in both private and public sectors should be a priority to ensure that when healthcare providers or individuals view a My Health Record they see clinically relevant material.

Stakeholders noted that future efforts need to be supported by clear and accessible statements about the journey that the My Health Record system is following. This includes providing information to healthcare providers and individuals about what is planned and the likely timeframes for the realisation of those plans. This is seen to be a key factor in motivating continued viewing and use of the My Health

Record system. It is also consistent with findings from evaluations of earlier attempts to implement system-wide digital health records in Australia (Northern Territory and New South Wales) and internationally.

Some stakeholders (public health service based stakeholders) suggested that ePIP being attached to what is often perceived to be an administrative act, rather than a clinical act, was also driving the wrong behaviour and not rewarding good practice. Suggestions were made as to how the incentive could be integrated within other PIP incentives and other programs of Government such as Health Care Homes, Closing the Gap, chronic care planning and mental health planning.

Awareness and understanding started and remained at a low level, in spite of centrally-generated and local communication efforts. However, participants in the individual survey in the opt-out sites were most likely to hear about the My Health Record through their healthcare provider or myGov. This may be in part due to the PHNs effort in engaging with general practices and the information (letters and brochures) provided to general practices in the trial areas.

In the relevant survey, healthcare providers suggested they would use the My Health Record if patients want it, suggesting public demand is a potential key driver. This finding reinforces other findings about the need for a significant evidence-based communication strategy targeting the public and prompting them to ask their healthcare providers to use My Health Record.

The trials have prompted participating PHNs to consider strategies for promoting the uptake and use of the My Health Record system by healthcare providers, for example, making use of the My Health Record system a requirement of the service commissioning process.

Increased participation in and use of the My Health Record system by users including individuals and healthcare providers

Individuals

971, 245 records were created as part of the opt-out trials. An additional 80,444 records were created in the opt-in trial sites over the trial period. 1,726 of these records were created as a direct result of the opt-in trial activities. This is in comparison to the 596,345 records that were created in the rest of Australia between March and September 2016.

Overall, there was very little evidence of individuals adding information to their records. However, there were more uploads conducted by individuals in the opt-out and opt-in trial sites when compared to the rest of Australia.

The opt-out rates of individuals in opt-out trial sites was low (1.9%), which is in line with international experience with opt-out systems for electronic health records.

Focus groups and individual surveys also found low levels of intention amongst the public to cancel their My Health Record.

Healthcare providers

The ability of the opt-out trials to test the hypothesis of greater healthcare provider use because more of their patients had a My Health Record was challenged by the duration of the trial and the capacity to mount a comprehensive communication strategy.

All trial sites reported an increase in the number of healthcare provider organisations registered. There was a statistically significant difference between trial sites and the rest of Australia, with the opt-out trial site performing better; however, the difference was small and of minimal impact.

Healthcare providers contributed to the My Health Record system in a number of ways including Shared Health Summaries and Discharge Summaries. For opt-out trial sites, healthcare provider uploads for Shared Health Summaries, Discharge Summaries, Event Summaries, Prescription Records and Dispense Records were greater than the rest of Australia. Similarly, for these outcomes, opt-in trial sites were greater than the rest of Australia, but not at as higher level as the opt-out trial sites. Viewing activity by healthcare providers was low across the trial sites and the rest of Australia. However, there were a number of document types that significantly increased in viewing activity between baseline and follow up and increased significantly more in the opt-out trial sites compared to the rest of Australia. These included: Discharge Summary (2.5-fold increase over rest of Australia), Medicare Overview (36.3)⁷ and documents created by other healthcare providers (30). Documents that were more likely to be viewed in the opt-in trial sites were the Medicare Overview (879.4) and Medicare DVA Benefits Overview (2.4). However, these differences were mainly due to the low level of baseline activity.

Increased confidence to use the My Health Record system amongst users including individuals and healthcare providers

Healthcare providers' and individuals' confidence to use the My Health Record system did not change significantly between baseline and follow up. There were also no significant differences between confidence in the trial sites and the rest of Australia.

⁷ Proportional increases

One determinant of healthcare provider confidence to use the My Health Record system was access to and participation in the training that was offered during the trial period (either online or face to face).⁸ The evaluation suggests that while there was a statistically significant increase in the uptake of training in the opt-out trial sites relative to the rest of Australia, only a modest proportion of healthcare providers were reached. There was no statistically significant difference in the uptake of training in the opt-in trial sites relative to the rest of Australia. In general, most people who received the training considered it effective on some level.

There were a number of healthcare providers who reported that the My Health Record system:

- provided them with information otherwise unknown to them
- gave them confidence in making a clinical decision
- led to a change in their clinical treatment –

Whilst the number is low it is nevertheless notable from a clinical practice point of view given the maturity of content in the My Health Record system.

Once individuals and healthcare providers are aware of the My Health Record system and understand its benefits, they have a high level of acceptance and a strong view that the benefits of the My Health Record to individuals, healthcare providers and the health system outweigh any risks.

Individuals consistently identified pharmacies as a trusted source of information and advice that could assist them in activating and using their My Health Record.

Unprompted in the individual surveys, and in the context of the low level of awareness about the My Health Record at both baseline and follow up period, concerns about privacy and confidentiality of the My Health Record and its security against external threats was relatively high. However, when provided with information about the purpose and benefits of the My Health Record system, during focus groups, the almost universal view of participants was that the benefits far outweigh the possibility of risks to privacy, confidentiality and security. The personal privacy settings and other control functionality of the My Health Record system are positively regarded by individuals and influential in their confidence about privacy and security.

The majority of healthcare providers had some level of trust in the Government and others to keep patients' information safe and used for appropriate purposes.

⁸ Most training was face to face. The low uptake of the online training developed to support the trial (0.3%) is reported in the previous outcome area and reasons for the low uptake are presented.

The personal privacy settings and other control functionality of the My Health Record system are positively regarded by individuals and influential in their confidence about privacy and security.

Some confidentiality issues raised during the consultations are complex and of concern to healthcare providers and individuals. These are largely in the area of child protection, domestic violence, mental health and alcohol and other drugs issues (e.g. parental access to the records of children, access by perpetrators of domestic violence to spousal and dependents' records) and sensitivities for people who receive treatment in the same facility where they work. In addition to the privacy provisions in the My Health Record Act, which protect at-risk individuals, there are processes in place to handle these risk and sensitivity areas, and personal controls which enable people to limit or restrict who can see their health information.

Increased awareness and understanding of the My Health Record system amongst users including individuals and healthcare providers

Individuals awareness and understanding

In the opt-out trial sites, 58% of people who were not registered at baseline for the My Health Record stated in the follow up survey that they either did not receive a letter or did not know whether they received a letter. This finding is supported by the findings of focus groups in the opt-out trial sites, where very few people reported they received a letter. If they remembered receiving it they report discarding it without reading it like all other Government "junk mail", filing it away for later as the letter implied there was time to do that, read it and did not fully understand it, or were expecting another letter as the one they remembered implied they would.

Participants in the trial areas were more likely to be exposed to information about My Health Record than the rest of Australia. Over 40% of respondents in the opt-out trial had heard about the My Health Record system and 19% of respondents in the opt-in trial compared to 11% in the rest of Australia. Overall 26% of people reported seeing information about the My Health Record. The most common source of My Health Record information was the myGov website (22.0%), followed by healthcare providers (21.6%) and national media (17.1%). People in the opt-out trial locations were more likely to see information about the My Health Record through their healthcare provider than the rest of Australia.

Awareness and understanding of the My Health Record system in a representative sample of individuals (in focus groups) began low and stayed low in the opt-in trial sites, despite the efforts of host organisations and use of personal forms of engagement. In opt-out trial sites there was an increase in

public awareness in the follow up survey, although it is difficult to attribute this to a particular form of engagement. The focus groups and individual surveys suggest that the letter was not an effective communication. Other data (e.g. greater likelihood in opt-out trials of getting information from a healthcare provider) could suggest that healthcare provider engagement in opt-out sites has had a flow-on effect of enhancing individual awareness, although causal links cannot be established from the data.

There are three additional factors suggested by the data that may also explain the observed low level of change:

- Despite the My Health Record being around since 2012, the baseline level of awareness was so low that national and local efforts to promote awareness and understanding did not and perhaps could not reach the dose effect required off such a low base.
- By design the PHNs were contracted to primarily focus on the healthcare provider side of the equation.
- The trials officially started in March (in both opt-out trial sites) and July (in both opt-in sites). After recruitment, planning and contracting were finished the trial ran until the end of October with some sites only having some staff recruited in July and August (in the case of NQ).

Focus groups with members of the general public demonstrated the consequences of the very low public awareness of the My Health Record system and the ineffectiveness of low profile communications methods such as mail outs, brochures and posters without a significant advanced positioning of My Health Record in the community as a public good.

Once people have the My Health Record system and its purpose and benefit explained to them, they are very supportive of it and express an intention to use it /discuss it with their doctors.

Aboriginal and Torres Strait Islander communities and the healthcare providers who work with them, once informed about the purpose of the My Health Record system, are very supportive of it in regional, remote, very remote and more urban settings.

People from a CALD background also express a high level of support for the My Health Record system but need written materials in language or interpreters to work with community leaders who in turn educate their communities.

Focus group participants also believed it should be a requirement that all healthcare providers use the My Health Record system.

Internet connectivity and reliability, access to computers, computer and health literacy and general literacy remain a challenge in some remote and very remote Aboriginal and Torres Strait Islander communities and will require further and more detailed attention.

Healthcare provider awareness and understanding

Baseline awareness of the My Health Record system was higher in the opt-out areas and the rest of Australia than in the opt-in trial sites (approximately 80% as opposed to 63%).

All healthcare providers interviewed from both opt-in and opt-out trial sites reported some level of understanding and awareness of the My Health Record system – partly due (35%) to awareness of the ‘PCEHR’. Most healthcare providers interviewed reported they had received some form of information and/or training, in varying capacities across the trial period. Those interviewed from opt-out trial sites were more likely to report that they had received education and training that was effective in raising their awareness of all aspects of the My Health Record system and their understanding of its benefits.

Understanding of the My Health Record system was also relatively high in a group of people who volunteered to be interviewed. The clear majority of (trial site) healthcare providers interviewed had a positive view of the My Health Record system and could describe the potential benefits of having a record for both individuals and healthcare providers.

There was a statistically significant difference in the proportion of healthcare providers in the opt-out trial sites compared to the rest of Australia (39% vs 23%) who had seen or heard information about the My Health Record system during the trial period and it was lower in the opt-in trial sites (20%). However, this proportion is less than 40%. Local media was identified as a key mode of communication in the opt-out trial sites relative to the rest of Australia. There was no statistically significant difference in the proportion of healthcare providers in the opt-in trial sites compared to the rest of Australia who had seen or heard communications about the My Health Record system during the trial period.

Appendix 1 Evaluation Questions

In consultation with the Department, the overarching statement of purpose of the evaluation has been broken down into questions implied by it. These questions mapped to the relevant agreed intermediate outcomes and the data sources, which will be used to answer them, appear in the table below. The questions are categorised as questions that will be asked at pre (baseline) and post-implementation points, and whether they are questions about process, implementation, or about outcomes achieved, lessons learned, generalisability and costs.

Outcomes	Evaluation questions (for opt-out, opt-in and non-trial sites)	Data sources/methodologies to identify what happened and why
<p>Increased awareness and understanding of the My Health Record system amongst users including individuals, carers and healthcare providers</p>	<p>Pre</p> <p>What is the level of awareness and understanding of the My Health Record system in the trial sites <i>prior</i> to the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the level of awareness and understanding of the My Health Record system in the general population (non-trial site) relative to the level of awareness in the trial sites?</p> <p>Are you aware that you can have an electronic health record that you can control if you register for it?</p> <p>Post</p> <p>What is the level of awareness and understanding of the My Health Record system in the trial sites <i>after</i> the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the level of awareness and understanding of the My Health Record system in the general population (non-trial site) relative to the level of awareness in the trial sites?</p>	<p>Triangulation of data sources (for pre and post):</p> <p>Online surveys, interviews, focus groups, document review, media monitoring</p>
<p>Increased confidence to use the My Health Record system amongst users including individuals, carers and healthcare providers</p>	<p>Pre</p> <p>What is the level of confidence to use the My Health Record system in the trial sites <i>prior</i> to the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? 	<p>Triangulation of data sources: Online surveys, document review, National Infrastructure Operator (NIO) data, progress reports</p>

Outcomes	Evaluation questions (for opt-out, opt-in and non-trial sites)	Data sources/methodologies to identify what happened and why
	<p>- Other groups?</p> <p>What is the level of confidence to use the My Health Record system in the general population (non-trial site) relative to the level of confidence to use the My Health Record system in the trial sites?</p> <p>How confident are you that the Government can ensure the security and confidentiality of the electronic health record which you can control?</p> <p>Do individuals and healthcare providers have the skills and knowledge to use the My Health Record system?:</p> <ul style="list-style-type: none"> • For individuals: for registration, to set privacy settings, and to use it with the doctor? • For healthcare providers: for registration, to upload event summaries, discharge summaries, advanced care planning documents and shared health summaries, access record to upload documents, to view documents and to use the record clinically? • At the organisational level: registered as an organisation, embed software and processes in workflows, and obtained digital certificates? <p>Post</p> <p>What is the level of confidence to use the My Health Record system in the trial sites <i>after</i> the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the level of confidence to use the My Health Record system in the general population (non-trial site) relative to the level of confidence to use the My Health Record system in the trial sites?</p> <p>Do individuals and healthcare providers have the skills and knowledge to use the My Health Record system?:</p> <ul style="list-style-type: none"> • For individuals: at registration, to set privacy settings, and to use it with the doctor? • For healthcare providers: for registration, to upload event summary, discharge summaries, advanced care planning documents and shared health summary, access record to upload documents, to view documents and to use the record clinically? • At the organisational level: registered as an organisation, embed software and processes in workflows, and obtained digital certificates? <p>How confident are you that the Government can ensure the security and confidentiality of your</p>	<p>by departmental offices running the national design and trial activities, progress reports from the trial sites, national helplines for providers and individuals, retrospective and prospective data from clinical safety and quality audits, data sourced from national helplines (e.g., National E-Health Transition Authority (NEHTA) and Department of Human Services (DHS) for activity, missed calls and complaints), media monitoring</p> <p>Triangulation of data sources: Online surveys, focus groups, interviews, document review, NIO data, progress reports from departmental offices running the national design and trial activities, progress reports from the trial sites, national helplines for providers and individuals, retrospective and prospective data from clinical safety and quality audits, data sourced from</p>

Outcomes	Evaluation questions (for opt-out, opt-in and non-trial sites)	Data sources/methodologies to identify what happened and why
	electronic health record which you can control?	national helplines (e.g., NEHTA and DHS for activity, missed calls and complaints), post education training and education survey, media monitoring.
<p>Increased participation in, and use of, the My Health Record system by users including individuals, carers and healthcare providers</p>	<p>Pre</p> <p>What is the level of participation in the My Health Record system in the trial sites and the rest of Australia <i>prior to</i> the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the level of contribution to the My Health Record system in the trial sites and the rest of Australia <i>prior to</i> the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the level of use to the My Health Record system in the trial sites and the rest of Australia <i>prior to</i> the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the extent of intentions to participate in, the My Health Record system in the trial sites and the rest of Australia <i>prior to</i> the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>Post</p> <p>What is the change in level of participation in the My Health Record system in the trial sites and how does it compare to the change in level of participation in the rest of Australia prior to the trial activities for the</p>	<p>Triangulation of data sources: Online surveys, document review, NIO data, national helplines for providers and individuals, media monitoring, My Health Record website statistics, data sourced from the opt-out portal (reasons of why people chose to opt-out)</p> <p>Triangulation of data sources: Online surveys, focus groups, interviews, document review, NIO data, post education training and education survey, data sourced from the opt-out portal (reasons of why people chose to opt out)</p>

Outcomes	Evaluation questions (for opt-out, opt-in and non-trial sites)	Data sources/methodologies to identify what happened and why
	<p>following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the change in the level of contribution to the My Health Record system in the trial sites and how does it compare to the change in level of contribution in the rest of Australia prior to the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the level of use to the My Health Record system in the trial sites and how does it compare to the change in the level of use in the rest of Australia <i>prior to</i> the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>What is the extent of the change in intentions to participate in, the My Health Record system in the trial sites and how does it compare to the change in intentions to participate in the rest of Australia prior to the trial activities for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? 	
<p>Increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system</p>	<p>Questions related to implementation of the different approaches</p> <p>What are the stakeholders' views on the different participation arrangements being trialled (e.g. opt-out and opt-in)? Why did stakeholders choose to opt out? Why did stakeholders choose to opt in?</p> <p>Have the trial activities been implemented as designed across opt-out and opt-in trial sites? (including the integrity of the rollout of trial activities and whether this changed in light of individual and/or healthcare provider feedback or unforeseen barriers encountered)</p> <p>What is the extent and nature of the dissemination of electronic and written material/communication to individuals and healthcare providers related to trial activities within opt-out and opt-in trial sites? (i.e. considering reach, penetration, the extent to which the population in the trial sites have seen these</p>	<p>Triangulation of data sources: Focus groups, interviews, online surveys, NIO data, media monitoring, document review, case studies of each trial site, reflection journals, engagement and dissemination logs, post-education and training</p>

Outcomes	Evaluation questions (for opt-out, opt-in and non-trial sites)	Data sources/methodologies to identify what happened and why
	<p>messages and the frequency in which they are seen)</p> <p>Which communication methods have been undertaken and which appear to be the most appropriate for targeting and delivering critical information about the My Health Record to populations within trial sites?</p> <p>What is the extent and nature of the support made available to individuals and healthcare providers to participate in and use the My Health Record system?</p> <p>What was the community reaction to communication and messages about the My Health Record system, including their reaction to the opt-out participation arrangements? What do they think about ease of access and use by individuals and healthcare providers, privacy and/or security issues (in particular in relation to opt-out participation arrangements)?</p> <p>What were the key challenges (barriers) during the implementation of the trial? How were these challenges overcome?</p> <p>What are the factors (enablers) that contributed to the successful implementation of the trial? How can these enablers/strengths be sustained into the future?</p> <p>Are/were there any incentives (Practice Incentives Program)/disincentives for participation and/or use of the My Health Record system for the following groups:</p> <ul style="list-style-type: none"> - Individuals? - Healthcare providers? - Other groups? <p>Outcome-based questions</p> <p>How effective were the trial activities (i.e. communication and support activities) for individuals in the trial sites?</p> <p>How effective were the trial activities (i.e. communication, education and training activities) for healthcare providers in the trial sites?</p> <p>What are the participation rates of both individuals and healthcare providers for opt-out trials compared to opt-in trials over the evaluation period? Are there any emerging trends in sub-populations within trial sites?</p> <p>What are individual and healthcare provider views on their experience with the My Health Record system?</p> <p>To what extent have the trials achieved their intended outcomes for individuals, healthcare providers and other groups? How has this varied across trial sites?</p>	<p>evaluation surveys, progress reports by departmental offices running the national design and trial activities, progress reports by the trial sites, retrospective and prospective data from clinical safety and quality audits, My Health Record website statistics, data sourced from national helplines (e.g., NEHTA and DHS for activity, missed calls and complaints), market research done by the Department prior to implementation and during implementation, data from the opt-out portal (reasons given by individuals who opt out), costs associated with each trial approach for the Department, local PHNs and the State and Territory Health Departments, Data about activities conducted by PHNs in the non-trial sites and relevant State and Territory agencies in all sites to promote participation in and use of the My Health Record</p>

Outcomes	Evaluation questions (for opt-out, opt-in and non-trial sites)	Data sources/methodologies to identify what happened and why
	<p>How have the characteristics of the populations within the trial sites affected the likelihood of outcomes being achieved?</p> <p>How have outcomes for individuals, healthcare providers and other groups changed over time?</p> <p>How do the outcomes for the different trial sites compare to each other?</p> <p>What are the factors that helped (enablers) or got in the way (barriers) of the trial achieving its hoped for outcomes?</p> <p>Lessons learned</p> <p>What lessons can be learned from the trials to inform the future choices about models for participation and use of the My Health Record system at a national level?</p> <p>Generalisability</p> <p>To what extent can the outcomes of the trials be generalised to the broader health system?</p>	

The evaluation involved both primary (i.e. data collected specifically for the purpose of this evaluation) and secondary data (i.e. data such as administration by-product or internal program monitoring data).

Appendix 2 Summary of results by outcome by evaluation question and relevant data source

The detailed findings of the evaluation are presented in appendices 3 – 14:

16. My Health Record system operator analysis
17. Findings from the focus groups with individuals
18. Findings from interviews with healthcare providers
19. Findings from survey of individuals
20. Findings from survey of healthcare providers
21. Summary of reflections from National, State and Health Service stakeholders
22. Northern Queensland Primary Health Network Opt-out Trial (Case study)
23. Nepean Blue Mountains Primary Health Network Opt-out Trial (Case study)
24. Western Australia Primary Health Alliance Opt- in Trial (Case study)
25. Western Victoria Primary Health Network - Ballarat Health Services Opt-in Trial (Case study)
26. Analysis of media monitoring and sentiment from baseline
27. Aboriginal and Torres Strait Islander pen and paper survey findings

The detail for each element of the methodology is included in its relevant appendix.

Presented below are the major findings of the evaluation related to each outcome area and its relevant evaluation questions presented by data source.

Increased awareness and understanding of the My Health Record system amongst users including individuals, carers and healthcare providers

What is the level of awareness and understanding of the My Health Record system in the trial sites after the trial activities?

Results that address this question from focus groups with individuals

The level of individuals' awareness and understanding of the My Health Record system in both opt-in and opt-out trial areas remained low after the trial activities were conducted. Most people did not recall receiving any information about the My Health Record system or participation trials during the period of the trial (March to September). Participants from opt-in areas who were approached for assisted registration in each setting (general practice/hospital) had low awareness and understanding of the My Health Record system, its usability and functionality. Most people in the opt-out areas (whether they recalled receiving a letter or not) had a low awareness of the My Health Record system.

Results that address this question from individual surveys

Approximately a quarter of respondents had heard about the My Health Record system since the initial survey in March 2016, with the myGov website the most common source of knowledge. At follow up, most respondents in the opt-out trial sites (58%) did not recall receiving a letter about the My Health Record system. At the time of the follow up surveys, more people in both opt-in (18.5%) and opt-out (41%) trial areas had heard about the My Health Record than those in the rest of Australia (10.7%). The key sources of exposure to the My Health Record were reported as: the myGov website (22%), a healthcare provider (21.6%) and national media (17.1%).



Results that address this question from healthcare provider interviews

The healthcare providers interviewed had volunteered to participate in the research, through some form of contact with/awareness of the trials. All interviewees from both opt-out and opt-in trial sites reported some level of understanding and awareness of the My Health Record system. Awareness levels were relatively high in these sites with interviewees stating they had received some form of information and/or training, in varying capacities, across the trial period. Understanding of the My Health Record system was also relatively high among the majority of these healthcare providers and most could identify the potential benefits for both individuals and healthcare providers.

Results that address this question from healthcare provider surveys

Baseline awareness of the My Health Record system (or the PCEHR) was higher in the opt-out trial areas (82%) and in the rest of Australia (82%) than in opt-in trial areas (63%). Respondents in the opt-out trial areas (39%) were significantly more likely to have heard about the My Health Record system during the trial period than the rest of Australia (23%). Respondents in the opt-in trial areas (20%) were not statistically significantly more likely to have heard about the My Health Record system during the trial period than the rest of Australia. Awareness of whether their workplace/organisation was registered with the My Health Record system increased in both opt-out trial areas (11%) and opt-in trial areas (9%) than in the rest of Australia, although this was not statistically significant. GPs were more likely (>70%) to be aware of the My Health Record system than other healthcare providers. The most common reason cited for not accessing the My Health Record system by all types of healthcare providers was 'lack of awareness'.

What is the level of awareness and understanding of the My Health Record system in the general population (non-trial site) relative to the level of awareness in the trial sites?

Results that address this question from individual surveys

Participants in both the opt-out trial areas and the opt-in trial areas were more likely to have heard about the My Health Record system during the trial period than the rest of Australia.

Results that address this question from healthcare provider surveys

Awareness among healthcare providers in the rest of Australia (non-trial site) was high (82%); however, only 56% of respondents knew if their workplace was registered with the My Health Record system at the end of the trial period. Respondents in the rest of Australia were most likely to have heard about or seen information regarding the My Health Record system from professional networks (i.e. other colleagues, PHN, professional bodies).

Increased confidence to use the My Health Record system amongst users including individuals, carers and healthcare providers

What is the level of confidence to use the My Health Record system in the trial sites after the trial activities for the following groups?

Results that address this question from focus groups with individuals

Due to low awareness and understanding in both trial sites only a small percentage of individuals had used or viewed their My Health Record (n≈1 per focus group) but fewer in some groups, such as Indigenous people in remote areas and older or chronically ill people). Whilst some issues were raised



around the arduous log-in process required to access their My Health Record via myGov, individuals who had accessed their My Health Record predominantly reported that it was easy to use and navigate. Some participants expressed concern that vulnerable groups such as the elderly, Aboriginal and Torres Strait Islanders in remote locations and people with a disability may not be confident in accessing their My Health Record due to low levels of computer literacy or poor internet access. This was frequently raised by elderly participants in the opt-in trial areas. Individuals commonly suggested that alternative platforms that could be accessed directly, e.g. via an application, would be more accessible and easier to use.

Results that address this question from individual surveys

Overall there was a reduction in the confidence to use the My Health Record system across all trial sites, with people stating that they had lower confidence in uploading documents or updating health information and in cancelling their My Health Record. However, there was no change in confidence to change privacy settings, view documents, update details regarding their health, or use their My Health Record with a healthcare provider.

My Health Record System Operator data - Individuals

Individuals contributed to the My Health Record system in a number of ways, but particularly by not restricting access to healthcare providers (n=4.2 million). The number of My Health Records with restricted access to either documents (n= 4,442, 0.1%) or healthcare providers (n=9,632, 0.2%) was low and did not vary across participation trials and the rest of Australia.

Results that address this question from healthcare provider interviews

The healthcare providers interviewed reported that the training and education activities provided to them as part of the trials were useful and had increased their confidence in using the My Health Record system. Interviewees from all healthcare provider types either 'somewhat confident' or 'extremely confident' after training. Those who had participated in the trial activities reported greater confidence to use the My Health Record system and to explain it to their patients.

Results that address this question from healthcare provider surveys

Across all three groups (opt-in; opt-out and rest of Australia), there was an increase in the proportion of respondents who had received training in the My Health Record system. The difference in the increased proportion between the opt-out and rest of Australia groups who had received training (6.2%) was statistically significant, but not between opt-in and the rest of Australia. However, the proportion of participants who had received training remained relatively low (<15%) with most training provided face to face (72%-76%). Responses showed an increase in the perceived effectiveness of training between baseline and follow up with no statistically significant differences between the groups.

What is the level of confidence to use the My Health Record system in the general population (non-trial site) relative to the level of confidence to use the My Health Record system in the trial sites?

Results that address this question from individual surveys

There were no differences in any indicators of confidence between the opt-out trial sites and the rest of Australia. Also, there were no differences in any indicators of confidence between the opt-in trial sites and the rest of Australia.



Results that address this question from healthcare provider surveys

There were no significant differences in any indicators of confidence between healthcare providers in the trial sites and those in the rest of Australia.

My Health Record System Operator data – Individuals (rest of Australia)

Levels of restricting access to documents and healthcare providers were as low in the trial sites as the rest of Australia.

Individual uploads of documents in the rest of Australia increased (2.5 proportional change), but to a lesser extent than in both the opt-out sites (3.6) and the opt-in trials (4.0).

Individual views were lower in the rest of Australia than in opt-out trial sites, but the same as in the opt-in trial sites.

Do individuals and healthcare providers have the skills and knowledge to use the My Health Record system? For individuals: at registration, to set privacy settings, and to use it with the doctor?

Results that address this question from focus groups with individuals

The majority of opt-in trial site participants said that little or no information about the personally controlled aspects of the My Health Record was provided to them at the point of assisted registration. Participants in the opt-out areas also reported low levels of awareness and understanding about the consumer controlled aspects of the My Health Record system, in particular, when it came to setting privacy settings. Participants were positive about these aspects/functions of the My Health Record. However some stated they were apprehensive about providing the function to hide or not share aspects of your My Health Record with certain healthcare providers.

Results that address this question from individual surveys

Overall there was a reduction in the confidence to use the My Health Record system across all trial sites. People stated they had lower confidence in uploading documents or updating health information and in cancelling their My Health Record. However, there was no change in confidence to change privacy settings, view documents, update details regarding health, or using their My Health Record with their healthcare provider.

My Health Record System Operator data - Individuals

Individuals restricted access to their My Health Records at low rates (0.5%<), and increased use of their My Health Record from baseline. There were significant proportional changes in opt-out sites for viewing; and in both opt-in and opt-out sites for uploading documents.

For healthcare providers: for registration, to upload Event Summaries, Discharge Summaries, Advanced Care Planning Documents and Shared Health Summaries, access My Health Records to upload documents, to view documents and to use the My Health Record system clinically?

Results that address this question from healthcare provider interviews

Of those healthcare providers interviewed who had roles which entailed using the My Health Record system to perform the tasks outlined above, none reported not having the skills or knowledge to do so. All healthcare providers commonly noted that more education and training should be offered in both



online and face to face formats. It should be noted that face to face training delivery was the preference for most healthcare providers interviewed. Most expressed the view that, after receiving training, they were confident to use the My Health Record system.

Results that address this question from healthcare provider surveys

The most frequent type of additional qualitative response (n=16) about clinical confidence from healthcare providers who have used the My Health Record system, was that use reassured the healthcare provider that they were not missing any important information (n=10).

My Health Record System Operator data – Healthcare providers

The upload of a number of document types significantly increased in volume between baseline and follow up and increased significantly more in the opt-out trial sites compared to the rest of Australia. These are described in more detail under the next outcome. Prescription Records and Dispense Records were the most regularly uploaded documents by healthcare provider organisations over both the baseline period and follow up period.

At the organisational level: registered as an organisation, embed software and processes in workflows, and obtained digital certificates?

Data source that address this question - reflections by the trial teams

The opt-out trial teams received feedback from healthcare providers that the registration process and the online authentication process to gain access to the My Health Record system were arduous and complex. A few of the practices that had registered with the My Health Record system prior to the trial commencement had expired digital certificates and/or misplaced their digital certificates. Support provided by the opt-out trial teams was vital in assisting healthcare providers/provider organisation to be registered with the My Health Record system.

In the opt-in trials the design integrated the My Health Record system into existing workflows and processes prior to the implementation of the trial activities. The health service and participating practices in the opt-in trial sites were already registered and had obtained digital certificates prior to the implementation of the trial activities. Owing to the nature and design of the opt-in trial in Western Australia, the evaluation team was unable to determine whether healthcare providers had the knowledge and skills to use the My Health Record system at the organisational level. In Ballarat, the trial team was able to embed use of the My Health Record system into the hospital's software. They iteratively modified other processes (e.g. admissions) to embed the option of assisted registration into their normal workflow.

Results that address this question from healthcare provider interviews

Results from the healthcare provider interviews in the opt-out trial sites suggest that, once practice managers and/or practice nurses understood the My Health Record system, its benefits and how to use it, they acted as a trainer in the practice to train others to use the My Health Record system. They also could assist in embedding the My Health Record system into existing clinical process/workflow.

My Health Record System Operator data - Healthcare provider organisations

There was consistent growth in the number of healthcare provider organisations registering for the My Health Record system across the trial period. The opt-out trials demonstrated consistently higher



proportional growth compared with opt-in sites and the rest of Australia. The opt-in trial sites also had a proportional increase greater than the rest of Australia.

How confident are you that the Government can ensure the security and confidentiality of your electronic health record which you can control?

Results that address this question from individual focus groups

The common majority conclusion in each focus group was that, while there are risks of security breaches in any online system, the potential benefits of the My Health Record system outweighed any such risks, and would not alter their confidence to use the My Health Record system.

Results that address this question from individual surveys

Overall, participants were 'unsure' or 'not confident' in the ability of the My Health Record system to keep their information confidential and secure. Just over a third of the respondents indicated that they were either 'confident' or 'really confident'. Respondents (40%-48%) in all sites trusted the Government and others 'somewhat'⁹ to always treat their medical information appropriately.

Those who were registered with the My Health Record system were more confident that their information was secure. 56% stated they were confident or very confident compared to 35% of those who were not registered. A smaller proportion of people who were registered reported being not confident or really not confident (14% vs. 34%) than those who were not registered.

Results that address this question from healthcare provider interviews

Healthcare providers' levels of confidence about the confidentiality and security of the My Health Record system varied within the opt-out and opt-in trial sites. Interviewees in both groups were almost equally divided in their views. In hospital settings, the privacy of staff members was also raised as a concern for staff who were receiving medical treatment.

Results that address this question from healthcare provider surveys

There were no differences in any indicators of confidence between the opt-out trial sites or the opt-in trial sites and the rest of Australia. In general, across all trial sites, the confidence in the Government to ensure confidentiality fell over time. There were no statistically significant differences in any of the trial sites about changes in confidence in the Government to ensure confidentiality of the My Health Record system during the trial period. In the rest of Australia confidence in the Government's capacity to ensure confidentiality of the patients' My Health Records decreased over the trial period.

⁹ Where 'somewhat' was the mid-point on a Likert scale, ranging from trusting 'to a great extent' to 'not trusting at all'.



Increased participation in, and use of, the My Health Record system by users including individuals, carers and healthcare providers

What is the change in level of participation in the My Health Record system in the trial sites and how does it compare to the change in level of participation in the rest of Australia prior to the trial activities for the following groups?

Results that address this question from individual surveys

Between baseline and follow up surveys

- there were no significant differences in the number of respondents who reported having registered for myGov in the trial sites compared to the rest of Australia
- there were no significant differences between respondents in opt-in trial sites who reported registering for a My Health Record and respondents in the rest of Australia

My Health Record System Operator data - Individuals

Overall there was an increase in registration across the opt-out and opt-in trial sites and rest of Australia. By design, the opt-out trial sites had significant increases over the rest of Australia, whereas the opt-in trial sites had only a small proportional increase over the rest of Australia. The proportional coverage of Aboriginal and Torres Strait Islander people did not seem to change regardless of the method of participation.

Individuals uploaded a number of different documents to the My Health Record system, including:

- Consumer Entered Health Summary
- Consumer Entered Notes
- Advance Care Directive Custodian Report
- Advance Care Documents
- Personal Health Observation
- Personal Health Achievement
- Child Parent Questionnaire

These were combined to examine the total change in the number of uploads by individuals. There was a 1.1 proportional increase in uploads by individuals in the follow up period in the opt-out trial sites compared to the rest of Australia. There was a 1.5 proportional increase in uploads by individuals in opt-in sites in the follow up period compared to the rest of Australia.

While MBS attendance information is uploaded directly from the Department of Human Services (DHS), individuals allow these to be added to their My Health Records. There was a significant increase in the number of MBS attendance items added to the My Health Record system in both the opt-out trial site and the rest of Australia. In the case of the opt-in trial areas this change was a 2.1 proportional increase over the rest of Australia.

There was an increase from baseline in individuals viewing documents in their My Health Record. The key documents being viewed included:

- Consumer Entered Health Summary
- Audit View



- Diagnostic Imaging Report
- Health Record Overview
- Medicare Overview
- Prescription Record View
- Prescription Dispensed View

Overall the level of viewing of documents between baseline and follow up increased more in the opt-out trial site than in the rest of Australia, though these differences were low. Similarly, viewing in the opt-in trial sites increased more than in the rest of Australia, but were lower than for the opt-out trial sites.

Results that address this question from healthcare provider surveys

Across all three groups, there was an increase in the number of respondents who reported their workplace as being registered with the My Health Record system. The increase during the trial was greater in the opt-out trial site (9.8%) relative to the rest of Australia (4.6%) although the difference (4.3% adjusted) was not statistically significantly different.

My Health Record System Operator data - Healthcare provider organisations

The main types of healthcare provider organisation registered in the trial period were General Practices, followed by Pharmacies, and public hospitals and health services. General Practices were the healthcare provider organisation that had the most additional registrations during the trial period. This was consistent across the three trial sites. The opt-in trial sites had a proportional gain greater than the rest of Australia. There were 131 additional healthcare provider organisations registered in the opt-out trial sites and 161 additional healthcare provider organisations registered in the opt-in trial sites, which equates to 28% and 17% proportional increase respectively over the rest of Australia when taking baseline registration into consideration.

There were additional healthcare provider organisations registered in all areas. These increases in registrations were consistent throughout the trial period, with a few sudden increases due to bulk registrations of HPIOs.

What is the change in the level of contribution to the My Health Record system in the trial sites and how does it compare to the change in level of contribution in the rest of Australia prior to the trial activities for the following groups?

Results that address this question from individual surveys

Overall there was an increase in the number of individuals who accessed their My Health Record from baseline to follow up. There was a significant increase in the number of participants who reported using their My Health Record in the opt-out trial sites compared to the rest of Australia, but not in the opt-in trial sites compared to the rest of Australia.

My Health Record System Operator data - Individuals

Individuals in general were unlikely to restrict access to their My Health Record either by restricting documents or healthcare providers (<1%). Very few actively changed their MBS or PBS item uploading restrictions which led to a large volume of MBS attendance items being recorded. These increases were proportionally higher in opt-out trial sites compared to the rest of Australia and in opt-in trial sites compared to the rest of Australia.



Individuals are also able to upload their own personal health related documents to their My Health Record; however, very few individuals availed themselves of this capability.

Results that address this question from healthcare provider surveys

Although there was an increase over the trial period in the proportion of healthcare providers uploading documents to the My Health Record system, this increase was across all three groups. The increase was more pronounced in the opt-out trial site relative to the rest of Australia, although the difference was not statistically significant.

My Health Record System Operator data -Healthcare provider organisations

There were a number of documents that significantly increased in volume between baseline and follow up and increased significantly more in the opt-out trial sites compared to the rest of Australia. These included:

- Shared Health Summary
- Discharge Summary
- Event Summary
- Dispense Record
- Prescription Records

Similarly, Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Record uploads increased significantly more in the opt-in trial sites compared to the rest of Australia.

Prescription records and Dispense Records were the most regularly uploaded documents by healthcare provider organisations over both the baseline period and follow up period. These uploads occur with limited input from the healthcare provider as they occur automatically once the My Health Record system is linked to the localised software.

The increase in Shared Health Summary uploads is closely linked with the deadline of the practice incentive program ePIP target deadline. Increases were greater in the opt-out trial site than the rest of Australia and maintained a higher proportion following on from this period. The availability of My Health Records may have led to this prolonged increase and this may continue into the future. It would be helpful to track the data over a longer period of time.

What is the level of use to the My Health Record system in the trial sites and how does it compare to the change in the level of use in the rest of Australia prior to the trial activities for the following groups:

Results that address this question from focus groups with individuals

Due to continued low levels of awareness and understanding of the My Health Record post trial activities in all trial locations, qualitative responses gained from the focus groups reflect that the use of the My Health Record system is minimal at the individual level. Only a small group of participants in focus groups held in both opt-out and opt-in trial sites stated they had accessed their My Health Record. Additionally, even less reported to be active users of their My Health Record. Many of those who responded as having accessed their My Health Record reported that they had been prompted to log in by the initial letter but had not entered in any personal information or gone on to ask their healthcare provider to use their My Health Record.



Results that address this question from healthcare provider interviews

All healthcare providers interviewed across both opt-in and opt-out trial sites reported using the My Health Record system in some capacity.

My Health Record System Operator data - Individuals

Individuals viewed documents in their My Health Record, with the key ones been viewed in increasing amounts from baseline including:

- Consumer Entered Health Summary
- Audit View
- Diagnostic Imaging Report
- Health Record Overview
- Medicare Overview
- Prescription Record View
- Prescription Dispensed View

Overall the level of viewing of these documents between baseline and follow up increased more in the opt-out trial sites than the rest of Australia though these differences were low. Similarly these differences were seen in the opt-in trial sites compared to the rest of Australia, but these were lower than for the opt-out trial sites.

Results that address this question from healthcare provider surveys

There was no statistically significant difference between baseline and follow up in the proportion of healthcare providers uploading documents to the My Health Record system in any of the trial sites or rest of Australia. The change over time in self-reported document uploads was also not statistically significantly different across the three groups.

My Health Record System Operator data - healthcare provider organisations

(numbers in brackets indicate proportional change in opt-out sites/opt-in sites versus the rest of Australia)

The number of My Health Record system uploads associated with MBS attendance items examined in the evaluation increased from baseline to follow up. The proportional increases were greater in the opt-out trial sites compared to the rest of Australia. Of note, there were only minimal differences between opt-out and the rest of Australia in the percentage of MBS attendance items with a Shared Health Summary upload, suggesting that the trial may have had a small affect in this area.

Uploading of documents increased dramatically during the trial evaluation period with opt- out site accesses increasing significantly more than the rest of Australia. These included: Shared Health Summary (36.8/15), Discharge Summary (7.8/3.7), Event Summary (8.2/9.5), Dispense Record (6471¹⁰/4.6) and Prescription Records (15.4/1.5).

There were increases in the number of Shared Health Summary uploads occurring within 24 hours of a number of MBS items and these increases were significantly greater in the opt-out trial site than the rest of Australia. This increase included after-hours services (2.8), GPs (14.2) and specialists/non-GPs (3.2) in opt-out sites. In particular, Shared Health Summary uploads were markedly increased for GP

¹⁰ Dispense records uploads in opt-out trial sites increased from a baseline of 5 to follow up of 32,365.



attendances (22.9/10.1) and managed care plans overall (35.1/-1.2). Increases were greater in the opt-out trial sites compared to the rest of Australia.

Also of note there was an increase in the number of My Health Records accessed that had no clinical documents in them, with healthcare providers in opt-out and opt-in trial sites more likely to access and upload the first clinical document than the rest of Australia. The level of accesses of documents also increased dramatically during the trial evaluation period for the opt-in trial sites significantly more than the rest of Australia.

Viewing activity significantly increased for a number of document types between baseline and follow up and increased significantly more in the opt-out trial sites compared to the rest of Australia. These included: Discharge Summary, Medicare Overview and documents created by other healthcare providers. However, healthcare providers in the opt-out trial site were less likely to view Event Summaries than the rest of Australia. Similar trends were seen in the opt-in trial sites though the documents were slightly different. The types of documents that were more likely to be viewed in the opt-in trial sites included; Event Summary and Medicare Overview; however, these differences were mainly due to the low level of baseline activity. Healthcare providers in the opt-in trial sites were less likely to view Shared Health Summaries than the rest of Australia

What is the extent of the change in intentions to participate in, the My Health Record system in the trial sites and how does it compare to the change in intentions to participate in the rest of Australia prior to the trial activities for the following groups?

Results that address this question from focus groups with individuals

Many focus group participants who had not previously been engaged with the My Health Record system indicated that they would consider using the My Health Record system. Their disengagement was typically associated with lack of awareness or understanding. There were a handful of exceptions among the participants who would not consider using it (e.g. due to firmly held views on privacy or the role of Government). Some participants indicated certain conditions that would change their intention to use the My Health Record system. Indigenous participants said they would need it linked to the Closing the Gap PBS Co-payment Measure.¹¹ A common response was that individuals would want all healthcare providers (or a critical mass) using it, otherwise it would not be worth their effort to participate. A small number of participants who had expressed opposition to the My Health Record system changed their intentions after listening to the views of others and obtaining more information about the My Health Record system's features and purpose.

Results that address this question from individual surveys

There was no difference in participants' intention to use their My Health Record into the near future between the trial sites or between baseline and follow up. Approximately half of all respondents planned to continue to use their My Health Record at the same level. Very few respondents intended to cancel or decrease use of their My Health Record and again there were no differences across trial sites.

¹¹ Which, for healthcare provider organisations other than Indigenous Health Services, requires the healthcare provider to be participating in the Indigenous Health Incentive under the Practice Incentives Programme. <https://www.humanservices.gov.au/health-professionals/services/medicare/closing-gap-pbs-co-payment-measure>



Results that address this question from healthcare provider surveys

There was no statistical difference in respondents' intention to use the My Health Record system over the next four months between the trial sites. Less than 6% of all respondents planned to decrease their use of the My Health Record system.

Increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system

Questions related to implementation of the different approaches

What are the stakeholders' views on the different participation arrangements being trialled (e.g. opt-out and opt-in)? Why did stakeholders choose to opt out? Why did stakeholders choose to opt in?

Note: Data provided to the evaluators by the Department indicate that 1.9% of the total population in opt-out trial sites chose to opt-out of having a My Health Record automatically created for them.

Results that address this question from focus groups with individuals and healthcare provider interviews

The majority of individuals and healthcare providers expressed the view that the opt-out participation arrangement would be the most efficient and effective way to achieve the desired program outcomes. The most common responses from individuals about their reason for opting-out were: concern about the security of their medical information being stored online; concern about others having access to their private medical information and that they saw no use for a digital health record. Individuals in the opt-in trial areas who took up assisted registration reported that they saw benefit in the My Health Record system in contributing to their own personal health outcomes and making it easier to see multiple healthcare providers or travel. It should be noted that some people within the opt-in areas were still unsure about what they had signed up for during the assisted registration process.

Results that address this question from representatives from State Health Departments who had direct line of sight to the opt-out trials, Departmental officers, and local hospitals and health districts officers. Most stakeholders, both nationally and locally, were highly supportive of a national opt-out participation arrangement model. In particular, lessons learned from the opt-in trial sites demonstrate that the assisted registration process was resource intensive and time consuming, particularly when patients had little to no awareness about the My Health Record system. State Health Departments that had been involved in the opt-out trials were supportive of a national rollout. Commonwealth officers, who had observed both the opt-out and opt-in trial sites were also of the view that the opt-out approach had achieved better outcomes.

Have the trial activities been implemented as designed across opt-out and opt-in trial sites? (including the integrity of the rollout of trial activities and whether this changed in light of individual and/or healthcare provider feedback or unforeseen barriers encountered)

Results that address this question from case study of each trial site

Based on the key elements of the National Change and Adoption Strategy, the design and implementation of the opt-out trial sites included providing support on the ground for: widespread population registration through the automatic creation of the My Health Records; generating more clinically useful content in the My Health Records; extensive adoption by healthcare providers across sectors; education and training and communication. Overall, the trial activities in the opt-out trial sites



were implemented as designed. The approaches taken to implement the activities, however, were changed in light of lessons learned about the trial sites and workflows/business operations of different healthcare providers across the PHN footprint; and as a result of non-program factors that affected the timing of the trials.

The opt-in trials in Western Australia and Ballarat Health Services were conducted to test two innovative approaches to achieve increased participation in and use of the My Health Record system under the current opt-in participation arrangements. The activities in the opt-in trial sites were designed specifically to suit the local setting - in a health service (in Ballarat Health Services) and participating practices that used cdmNet (in the case of the WA opt-in trial). Overall, the activities in both opt-in trial sites were implemented as designed. Approaches to activities were also modified in light of lessons learned as the trials progressed, such as hospital workflows/business operations and the appropriateness of approaching patients in different departments within the hospital (in the case of Ballarat); or as a result of lower than expected response from healthcare providers (in the case of WA). Non-program factors also affected the implementation, largely related to the timing and sequencing of activities.

What is the extent and nature of the dissemination of electronic and written material/communication to individuals and healthcare providers related to trial activities within opt-out and opt-in trial sites? (i.e. considering reach, penetration, the extent to which the population in the trial sites have seen these messages and the frequency in which they are seen)

Media monitoring report

A total of 138 media articles were collected between 8 March 2016 and 30 September 2016. Overall, the My Health Record was most prominent in the media in the months of March and April, following the announcement of the opt-out trials. This reduced slightly in May and June, which could potentially be attributed to the large amount of election media coverage taking precedence during this period. After a decrease in July, media coverage increased again in August, much of coverage across this period was about the appointment of the new CEO for the Australian Digital Health Agency as well as the My Health Record system reaching an important milestone in which registrations exceeded 4 million. A number of articles across the month of September reported issues surrounding ePIP and calls from general practitioners stating that up to 1,500 practices would lose out on ePIP payments due to system issues. The Government responded to these calls by granting a six-month extension to the deadline for ePIP registered General Practices to upload Shared Health Summaries to the My Health Record system.

Results that address this question from case studies of each trial site

Across the two opt-out trial sites, the principal, initial communication channel was a mail out of letters and brochures from the Government advising individuals that a My Health Record was going to be automatically created for them unless they chose to opt-out.

In addition, PHNs communicated with members of the public and healthcare providers about the trial and the My Health Record system through various communication channels, such as social media, print, website, emails, and face to face interactions. Both PHNs increased the frequency of their communications (or local media campaign) during key points of the trial such as when individuals and healthcare providers could access newly created My Health Records (on 15 June for individuals and 15



July for healthcare providers). Trial teams reported that a total of 124 communication messages were delivered in NQ PHN across February to July 2016 and 330 in NBM PHN from February to October 2016.

Individuals and healthcare providers in both opt-out trial sites also received resources/communication materials about the My Health Record system at the point of engagement. Healthcare providers received materials such as generic and targeted factsheets and brochures, software guides, flyers, Frequently Asked Questions sheets, registration information packs, and ePIP guides. In addition to distributing resources/communication materials when engaging individuals, the opt-out PHNs also disseminated information/communication materials to healthcare providers and services to distribute to their clients during their visit.

In the opt-in trials, individuals and healthcare providers also received information about the trial and the My Health Record at the point of engagement, such as brochures, flyers, information sheets, culturally and linguistically diverse resources and posters. Those managing the trial in Ballarat Health Services also published a few local media releases. They also communicated about the trial to their clinicians and hospital staff through the health service's intranet. Patient resources about the My Health Record system were provided to participating practices in the WA trial to be distributed to patients when they visited.

An estimated total of 51 engagement activities were conducted in Ballarat Health Services and 34 activities in WA with healthcare providers only from July to September/October 2016. A total 23 communication messages were disseminated in the trial period at WA from June to September 2016.

Results that address this question from focus groups with individuals

Few focus group participants recalled seeing or hearing communications about the My Health Record. The low recall of the letter in the opt-out sites has been noted above. When individuals did recall a communication, it was often related to the PCEHR and had occurred before 2016. However, where a recent communication had been noticed it was most commonly a poster in a health service waiting room.

Results that address this question from individual surveys

Approximately a quarter of respondents had heard about the My Health Record system since the initial survey in March 2016. The penetration (i.e. recall) of information to participants in the opt-out trial site was greater than in the rest of Australia. There was no difference between the opt-in trial sites and the rest of Australia.

Results that address this question from healthcare provider surveys

During the trial period, 39% of respondents in the opt-out trial site recalled having seen or heard about the My Health Record system which was statistically significantly higher than the 23% in the rest of Australia .



Which communication methods have been undertaken and which appear to be the most appropriate for targeting and delivering critical information about the My Health Record to populations within trial sites?

Results that address this question from focus groups with individuals

Individuals were forthright and animated in suggesting their preferred communication channels. The key points made were that communication needs to:

- be 'everywhere' and available in multiple formats/channels to reach all segments;
- tell people the benefits of the My Health Record system;
- show people how to use it (e.g. on youtube or facebook);
- provide the information in digestible chunks (not too many words or too much detail all at once); and
- use trusted people to promote it in advertising.

They suggested that, if letters are used again, people should be warned that a letter will arrive and then followed up later to remind them of the next steps; and that, if hotlines or service centres are part of the promotion, the staff need to be well trained.

Results that address this question from case studies of each trial site

Trial teams across all sites utilised various communication methods such as those described above.

Lessons learned across all trial sites strongly suggest the need for mass mediated communication at the national level, which is then followed up at the local level. Social media marketing was thought to be an appropriate communication channel, where national level expertise would be most useful with approaches that can then be adapted and localised to specific regions in the PHN and/or to target a specific community segments. The trials in the opt-out sites also demonstrate that approaching service providers or support groups for some population groups (e.g. veterans, carers and homeless people) were more effective. For Indigenous populations, communicating through Aboriginal healthcare providers and through trusted people in communities was recommended by Indigenous participants.

The lessons learned across all trial sites also demonstrate the importance of ensuring individual members of the public are aware of the My Health Record system as a first step. Additionally, ensuring people were aware of the letter prior to receiving them was also noted as lessons learned by stakeholders managing the opt-out trial sites. The opt-out trials also suggest the need to follow up with individuals after the letter is disseminated, informing them about how they are able to opt out from having a My Health Record and access the My Health Record.

The opt-out trial sites also demonstrate that face to face engagement, training and education activities have been important in increasing awareness and understanding of the My Health Record system in healthcare providers.

Results that address this question from individual surveys

The myGov website was the most common source of exposure about the My Health Record system, followed by healthcare providers and national media. The survey did not seek advice on communications from survey respondents.



Results that address this question from healthcare provider surveys

Respondents in the opt-out trial areas were more likely to have heard about the My Health Record system during the trial period than the rest of Australia. Participants in the opt-in trial areas were not statistically significantly more likely to have heard about the My Health Record system during the trial period than the rest of Australia. Hearing about or seeing information on the My Health Record system from professional networks (i.e. other colleagues, PHNs, peak professional bodies) was the most common source cited by respondents.

What is the extent and nature of the support made available to individuals and healthcare providers to participate in and use the My Health Record system?

Results that address this question from individual focus groups and healthcare provider interviews

Because individual awareness, understanding and use of the My Health Record across all trial sites was low, very few individuals made reference to support which was provided to them to participate and use the My Health Record system during the trial period. Those in the opt-out areas who had used the My Health Record and who required support often stated that they enquired with their healthcare provider (with mixed results). Of those who said they had tried to access the telephone helpline it was often reported that wait times were long and the advice provided to them was either insufficient or incorrect. In the opt-in trial sites, similar anecdotes were told by those who had attempted to use the telephone hotline. Many who were provided assisted registration were not provided with any further additional take-home information or follow-up communications. This often led the individual to not log-in to view or use their My Health Record as they were unaware of the next steps. Individuals had mixed reports about the available information about the My Health Record system.

Healthcare providers commonly cited the education and training activities which occurred as part of the trials as being the primary support available to them. They stated that the face to face training activities were the most efficient and effective and requested that more be provided in the future to keep them engaged in the use of the My Health Record system and up to date with any functionality/system changes. The online training modules were rarely reported by healthcare providers as being used and many healthcare providers (across all sites) said they were unaware they existed. Healthcare providers also frequently noted that the communication materials provided to them to assist in discussion with individuals were useful and supported them in answering questions individuals had regarding their My Health Records.

Results that address this question from case studies of each trial site

Across the two opt-out trial sites, mapping the digital health capacity of healthcare providers in each trial site was conducted and has been continually updated or extended throughout the trial period. Various types of issues arose in different healthcare provider groups, such as:

- the types of clinical information software used
- validated My Health Record system registration
- the currency of their digital certificate (NASH PKI)
- their use of the My Health Record system
- different types of benefits from use of the My Health Record system for various provider groups
- how the My Health Record can be integrated as part of the workflow in their business operation



The results of the mapping were used to inform the strategy and approach for engagement activities with healthcare providers, to provide assistance with healthcare provider or practice registration, training and education activities and/or other additional support where required (e.g. providing technical support).

Providing face to face education and training to healthcare providers (predominantly GPs) has been the major focus of effort in both opt-out trial sites. This has included using training materials provided from the national level, the development of resources locally to fill gaps in that material as they became apparent and the implementation of resource guides from some software vendors. There are different software issues for the various products used across healthcare provider segments. There are differences between the willingness/capacity of software vendors to collaborate with PHN staff in supporting training. Both sites have had to adapt their activities accordingly. The provision of online training has been more of a challenge, partly due to delay in availability of the modules and a lack of promotion of their availability at the national level and partly due to less interest in online training from healthcare providers.

As part of their engagement activities with healthcare providers, officers in both PHNs distributed resources/materials to healthcare providers that were targeted to both healthcare providers and their patients. Engagement with most private and public hospitals and health services within the opt-out PHNs' footprint included relevant State Health Department central office personnel and local health district personnel. In the private hospital sector the intensity of engagement has varied between the two sites (partly depending on the number and corporate structure of the private hospitals). There appeared to be greater complexity in engaging the private hospitals if the hospital was part of a larger organisation or corporation. In NQ, the PHN continues to deliver engagement activities with the private hospital sector through direct support prior to and when the My Health Record system becomes live in their internal clinical information systems.

Efforts to increase awareness and support individuals to use the My Health Record system by engaging consumer groups and other non-health service providers in their region were conducted in both opt-out sites. The PHNs in both trial sites actively sought to engage the key priority groups, with varying degrees of success, such as:

- Aboriginal and Torres Strait Islander peoples
- elderly people
- people with a mental health condition
- people with a chronic disease/condition
- homeless people
- parents with newborns

Some lessons learned were related to the appropriateness of venues and occasions to attempt to engage target groups about health-related matters. Individuals in some engagement sessions were educated to set privacy settings and access control to their My Health Record system in the opt-out trial sites.

Both opt-out trial sites report challenges in engaging (beyond information dissemination) with allied health and other medical specialist providers and with Residential Aged Care Facilities. The evaluation team notes that the PHNs were therefore revising their approaches to engage these healthcare provider groups in the August/September 2016.



The opt-in trials focused on providing assisted registration to patients in the hospital (in the case of the trial in Ballarat) and patients with a chronic disease who attended a participating practice in the trial (in Western Australia). Patients were informed about the My Health Record system prior to being offered assisted registration. Healthcare providers were supported by education and training provided by Ballarat Health Services and WAPHA in the opt-in trial sites.

Across all trial sites, all stakeholders involved were responsive to requests made by practices/providers in the region. They had assisted healthcare providers in resolving technical issues experienced such as the requirements needed to register a practice for a My Health Record system and the configuration of the My Health Record system to their clinical information system as well as delivering training when requested.

What was the community reaction to communication and messages about the My Health Record, including their reaction to the opt-out participation arrangements? What do they think about ease of access and use by individuals and healthcare providers, privacy and/or security issues (in particular in relation to opt-out participation arrangements)?

Results that address this question from focus groups with individuals and healthcare provider interviews

The level of community awareness and understanding of the My Health Record system in both opt-in and opt-out areas remained low after the trial activities were conducted. Therefore, the evaluation finds that the communication activities and messaging about the My Health Record system were largely ineffective during the trial period.

Community responses provided in focus groups with individuals highlighted that many participants in the opt-out trial sites did not recall receiving any information about the My Health Record participation trials or My Health Record system during the period of the trial. This includes reading, hearing or viewing editorial news coverage or advertisements which ran locally and nationally during the trial period. Participants from opt-in areas said that, although they were approached for assisted registration in each respective setting (general practice/hospital), awareness and understating of the My Health Record, its usability and functionality remained low.

Individuals who were already aware and understood the concept of the My Health Record stated that it was beneficial to their own personal health management and believed it would be extremely beneficial to healthcare providers seeking to access and share their health information. Those who had low awareness of the My Health Record system recognised the same potential benefits once the My Health Record, its use and functionality had been explained to them. There was a small group of participants across all trial sites who did not agree with the concept of the My Health Record system, primarily due to privacy concerns. However, these groups were minimal across each site.

Results that address this question from individual surveys

Participants were unsure or not confident in the ability of the My Health Record system to maintain their information as private, confidential and secure, in the Government's capacity to protect their My Health Record data from security threats and in the Government's capacity to keep their personal information held in the My Health Record confidential. Just over a third of the population indicated that they were confident or really confident. There was no difference in change in attitudes over the trial period between participants in all trial sites and the rest of Australia.



What were the key challenges (barriers) during the implementation of the trial? How were these challenges overcome?

Results that address this question from reflections by PHNs (and Ballarat Health Services)

Timing and duration

All stakeholders involved in the opt-out trials in NQ PHN and NBM PHN felt that, while the opt-out nature of the trials (the automatic creation of My Health Records) clearly demonstrated the effectiveness of this method on widespread population registration the length of the trial was too short to observe and document the full impact of efforts to change individuals' and healthcare providers' use of the My Health Record. There were also lessons learned about the timing and sequencing of activities which showed the need for a significantly longer lead time at both the national and a local level. In particular, time available to alert and prepare healthcare providers about communication efforts targeting individuals caused some concern at the PHN and healthcare provider levels. This is particularly important for areas such as NQ PHN where there are very large geographic distances that are remote and very remote and the highly variable internet connectivity across the PHN footprint.

Similarly, all stakeholders involved in the opt-in trials believed the time period for the trial and the evaluation were too short to observe and document the full impact of efforts to change individuals' and healthcare providers' use of the My Health Record system. Healthcare provider access commenced at the same time in all trial sites. However, opt-in trials commenced later than opt-out trials and consequently had a shorter trial period. Stakeholders managing the trial in Ballarat Health Services believed that more preparatory time would have assisted in determining where and how assisted registration could be provided for patients in the hospital context. They felt that more training could be provided to equip hospital administrative staff with information about the My Health Record system and how to provide assisted registration to patients. With more lead time, different approaches to training all staff in the hospital could be planned in advance to fit into the schedules of clinical meetings, clinical education sessions, and/or administrative meetings within the hospital. It was also noted that in a hospital context, where many staff are shift workers, visiting medical officers, trainees on rotation, finding suitable times for training was challenging. Those managing the trial in WA indicated that with more lead time, practices that are not digital health ready could be engaged to participate in the trial.

PHN scope and capacity

The scope of the opt-out trial activities necessitated the PHNs working outside their normal scope, for example, working with the secondary care sector (medical specialists) and the tertiary care sector (private and public hospitals and residential aged care facilities). While most PHNs have experience of working collaboratively with these other sectors to ensure a more joined-up health system, other interactions and interventions in those sectors have not previously been part of the PHN brief. The PHN therefore had to build this capacity and the type of relationships, contacts, networks and content knowledge to support it in a very short time.

A longer trial period would have allowed for adequate preparatory work to enable them to understand these groups. They suggest that with this lead time, the PHNs would be able to develop a more targeted effort for these healthcare provider groups and the public.

Trial management and internal communication

There were key lessons learned from the opt-out trials about the importance of a balance between top-down input from the national level and bottom-up input from the trial site level in the direction, design



and implementation of trial activities. PHNs perceived the relationships between the local trial teams and the Department as not always working collegially, especially in the initial design and contracting phase and in the early steps of implementation. In addition, the adherence to a generic project management approach, coupled with some lack of health sector and My Health Record system content expertise in the Department, meant that the local knowledge of the PHN was in many instances not fully utilised to enhance the trial.

Additionally, a strong working relationship between all local stakeholders, including support from the top level of stakeholder organisations, would also facilitate the implementation of activities to increase participation in and use of the My Health Record system in various healthcare settings across the PHN footprint. It would be a challenge to rollout activities to achieve the intended outcomes in the hospital settings (private and public) within the short timeframe without the right level of sponsorship from senior management. Having the support and engagement from senior executives in large settings such as the hospital would drive the use of the My Health Record system by healthcare providers within the hospital.

The opt-in trials demonstrate how a balance of top-down from the national level and bottom up from the trial site level in the direction, design and implementation of trial activities is important to achieving intended outcomes within a short timeframe. This was thought particularly crucial when communicating changes to the scope of the trial from what was initially proposed. Stakeholders in the opt-in trial sites felt that strong collaboration with the Department was a strength of the trial. Stakeholders in Ballarat Health Services suggested that a feedback mechanism could also be established for hospital staff/local healthcare partners to provide suggestions to improve the content or usability of the My Health Record system.

Barriers for healthcare providers to participate and use the My Health Record system

The trials in NQ, NBM and WA suggest that having an understanding of the workflow of different types of healthcare providers and the key benefit to each group is critical to overcoming resistance to My Health Record system use.

The trial in NQ and NBM suggest that future efforts should focus on improving the registration process and the online authentication process for healthcare providers/organisations to access the My Health Record system. Support from the PHN in assisting practices/organisations in registering, connecting and using the My Health Record system has been crucial in motivating healthcare providers to use it, and should continue.

The lessons learned from the trials in public hospitals and health services in NQ and NBM also suggest that contribution by healthcare providers outside of the hospital facilities is likely to persuade clinicians within hospitals to use the My Health Record system.

Barriers and issues for practices not yet using the My Health Record system were identified in NQ. For example, GPs' reliance on practice staff to upload Shared Health Summaries, and these practice staff are not able to upload documents to the My Health Record system; some have not had time to discuss the My Health Record with their patients and the practices opted out of ePIP payment.

There were also key lessons learned in the delivery of engagement activities or training from the trial in NQ. Group information sessions with healthcare providers were viewed to be effective in determining



how the My Health Record system could be integrated into the clinical workflow. Additionally, delivering training in a small group can be done in 30 minutes, should time be the limiting factor in delivering training. Resources/ materials drop off is also a good way to start a conversation with healthcare providers/ practices about the My Health Record.

The trials (both opt-in and opt-out) suggest the importance of ensuring the My Health Record system is continuously improved to attract more healthcare providers to use it. In particular, having more software vendors on-board to ensure their software is compatible with the My Health Record system and developing alternative methods for different types of healthcare providers, such as allied health providers and medical specialists, to access the My Health Record system to access and contribute to information, apart from the Provider Portal.

Barriers for individuals to adapt and use the My Health Record

The experience across all trial sites reinforces the need to make the registration process for a myGov account easier for people. The required information to set up a myGov account and link the My Health Record to it was observed to greatly lessen the likelihood that individuals would subsequently be able to use their My Health Record.

After assisted registration, lack of computer access was observed to be a barrier for patients to view or upload to their My Health Record.

There were lessons learned about the communication materials provided from the national level across all trial sites. Sufficient communication materials/resources need to be provided to local delivery partners. In particular, sufficient communication materials that target culturally and linguistically diverse populations need to be provided. Messages about the My Health Record system should also be disseminated continuously to get traction and buy-in from individuals and healthcare providers to participate in and use the My Health Record system.

The experience in the opt-in trial sites emphasises the importance of ensuring people are aware and informed about the My Health Record system, its purpose and benefits to them, their families and the health system. The opt-in trial demonstrates that providing assisted registration to individuals is difficult and time consuming particularly when people are not aware of the My Health Record.

What are the factors (enablers) that contributed to the successful implementation of the trial? How can these enablers/strengths be sustained into the future?

Results that address this question from reflections by PHNs and Ballarat Health Services

Commitment of the parties involved in the opt-in and opt-out trials

The commitment of all parties involved in both the opt-in and opt-out trials to ensure the success of the trials has facilitated their progress and success. In particular, good and collaborative relationships between all parties in the trials were viewed to be a key enabler of the successful implementation of the trials.

Additionally, a strong working relationship between all local stakeholders, including support from the top level of stakeholder organisations, also facilitated the implementation of activities to increase participation in and use of the My Health Record during the trial period. In particular, it would be a challenge to rollout activities to achieve the intended outcomes in the hospital settings (private and



public) within the short timeframe without the right level of sponsorship from senior management. Having the support and engagement from senior executives in large settings, such as hospitals, helped drive the use of the My Health Record system by healthcare providers within those settings.

The delivery of engagement, training and education activities to healthcare providers

The opt-out trials demonstrated that face to face engagement, training and education activities have been important to increasing awareness and understanding of the My Health Record among healthcare providers. Those healthcare providers who were trained and educated about the My Health Record system were more confident to use it and explain it to others. The experience in the opt-out trial sites also emphasises the need to equip healthcare providers to answer questions or clarifying any misunderstandings expressed by their patients. More engagement, training and education activities for other types of healthcare providers, apart from those in general practices/general practitioners were also noted as important by the PHNs of both opt-out trial sites.

Lessons learned from the opt-out trial activities about how the training to healthcare providers should be delivered suggest that training is best delivered when practices are registered with the My Health Record system and have conformant software. This means that the digital health mapping exercise of healthcare providers/practices across the PHN footprint should be completed prior to any engagement with healthcare providers in order to tailor the engagement activity to address the practice's needs.

The experience of the opt-out and opt-in trial suggests that having corporates buy-in from practices with parent organisations, GP and healthcare provider champions could increase engagement from practices to participate in and use the My Health Record system.

The automatic upload of documents to the My Health Record system that was set in place in some hospitals in NQ PHN, NBM PHN and Ballarat was viewed to be an effective mechanism to increase participation and use of the My Health Record system by healthcare providers. Having embedded the process of uploading documents as part of healthcare providers' workflow also appeared to also facilitate buy-in to participate and use the My Health Record system.

Are/were there any incentives (Practice Incentives Program)/disincentives for participation and/or use of the My Health Record system for the following groups?

Results that address this question from focus groups with individuals

Individuals from all trial sites did not report any incentives being provided to them for participation and use of the My Health Record system, nor did individuals see any disincentives to using the My Health Record system.

Results that address this question from healthcare provider interviews

The ePIP was reported by healthcare providers as the only incentive payment to general practices for participation and use of the My Health Record system.

Results that address this question from reflections by representatives from State Health Departments who had direct line of sight to the opt-out trial, Departmental officers, and local hospitals and health districts officers

It was observed during the trial that the ePIP incentive temporarily drove participation and use of the My Health Record system. Participation and use of the My Health Record system by GPs was not



sustained after the first quarter of the ePIP incentive. Some stakeholders suggested that the incentives for using the My Health Record system should be linked to good clinical practice. For example, embedding the use of the My Health Record system with the incentive for the planned Healthcare Homes initiative. GPs using the My Health Record system could also to be rewarded through existing incentive plans (e.g. care plans and mental health plans). Suggestions to include a requirement in any commissioning/tender/funding process by the PHNs to require commissioned services to demonstrate that they are My Health Record enabled were also mentioned.

Outcome-based questions

How effective were the trial activities (i.e. communication and support activities) for individuals in the trial sites?

Results that address this question from focus groups with individuals

Individuals from all trial sites reported the communication and support activities to be largely ineffective. This is reflected by the low levels of awareness and understanding of the My Health Record system and subsequent low levels of use. In the opt-out trial sites very few individuals recall receiving a letter regarding the My Health Record system or the trial activities; and supporting communication activities such as media reports, social media posts, brochures and posters within healthcare provider settings were sparsely recalled. Opt-in trial site participants who received assisted registration also reported the same low levels of awareness and understanding and use of the My Health Record system. Even though many had been engaged at a face to face level with someone offering assisted registration, respondents stated that they were still unsure about the purpose of the My Health Record and how to use it.

A small number of participants who had accessed the myGov website to submit their annual tax return reported that pop-ups on that website to invite them to set up a My Health Record had been effective and they had done so.

Results that address this question from individual surveys

The individual survey found that the most common sources of exposure to the My Health Record system was via healthcare providers and the myGov website (21.6%, 22%). It is not possible to establish from the survey whether the trial activities promoting the My Health Record to healthcare providers contributed to this exposure. Local media, in which some trial sites invested, was reported as a source of information by less than 10% of the respondents.

How effective were the trial activities (i.e. communication, education and training activities) for healthcare providers in the trial sites?

Results that address this question from healthcare provider interviews

Healthcare providers reported that the education and training activities in the trial sites were effective. All healthcare providers interviewed stated that they would like more education and training delivered in both online and face to face formats. However, face to face training was requested more often and was said to be far more effective. Some healthcare providers in the opt-in trial sites did mention that the education and training activities they had been involved in were ad-hoc and delivered quickly. Of those



who provided these responses most acknowledged the time pressure and workload of their work setting as contributing factors along with noting the fast pace of the trial rollout.

All healthcare providers recalled receiving or seeing some form of communication material regarding the trials and the My Health Record system. While responses regarding the communication were mainly positive, healthcare providers also requested additional information and support resources which could be provided to both individuals and staff within their setting. It was recommended that this material be developed and targeted at the local level to ensure the key messages are relevant to the intended audience.

Results that address this question from healthcare provider surveys

There was no statistically significant difference measured in the reported effectiveness of the training received on the My Health Record. Overall, over 80% of respondents who had received training considered the training to be at least slightly effective or better.

Evaluation of the online training program developed for the trials

Between April and September 2016, a total of 1,790 healthcare providers were registered with the national online training developed by the Department. This represents 0.3% of the total registered healthcare providers in Australia¹². The data suggests that there was little penetration and reach of education and training via the online channel. Nevertheless, 76% of those enrolled completed the online training. The online training data provided to the evaluation team also suggested that most participants were from general practices (81%), followed by training providers (12%). Non-clinicians were slightly more likely to register compared to clinicians (884 participants compared with 753 participants).

A total of 1,556 participants who completed the online training responded to the post-training evaluation form. Across all professionals, the majority of respondents felt the online training had 'somewhat improved' their understanding of the My Health Record system.

Most participants were neutral when asked whether the online training had improved their understanding about the following aspects of the My Health Record system:

- the potential benefits as a healthcare provider
- the potential benefits for patients
- the information that is available them
- the policies and procedures which underpin its use, including the legislation
- the medico-legal issues, including responsibilities and liability for security and confidentiality or information
- where to access further information and support, or escalate problem

What are the participation rates of both individuals and healthcare providers for opt-out trials compared to opt-in trials over the evaluation period? Are there any emerging trends in sub-populations within trial sites?

Results that address this question from focus groups with individuals

Focus group participants in the opt-out trial sites reported a low rate of use of the My Health Record system. Of those who stated they had used it, only a small group said they actively use the My Health

¹² Of the 610,148 registered health practitioners in 2014.



Record with most reporting they had logged into the My Health Record system once or twice to “*have a look*” and “*see what it is all about*” but did not progress any further in their use of the My Health Record, including prompting their healthcare provider to upload information to it.

My Health Record System Operator data - Individuals

971, 245 My Health Records were created as part of the opt-out trials. An additional 80,444 My Health Records were created in the opt-in trial sites over the trial period. 1,726 of these My Health Records were created as a direct result of the opt-in trial activities. This is in comparison to the 596,345 My Health Records that were created in the rest of Australia between March and September 2016 under the usual opt-in registration arrangements.

My Health Record System Operator data - Healthcare provider organisations

There were 131 additional healthcare provider organisations registered in the opt-out trial sites and 161 additional healthcare provider organisations registered in the opt-in trial sites. This equates to 28% and 17% proportional increase respectively over the rest of Australia when taking baseline registration into consideration.

What are individual and healthcare provider views on their experience with the My Health Record system?

Results that address this question from focus groups with individuals

Individuals who were already aware and understood the concept of the My Health Record system stated that the My Health Record was beneficial to their own personal health management and believed that it would be extremely beneficial to healthcare providers treating them. Those with low awareness did express an understanding of the same potential benefits of the My Health Record system once the My Health Record, its use and functionality had been explained to them. There was a small group of participants across all trial sites who did not agree with the concept of the My Health Record system, primarily due to privacy concerns.

Experience in using the My Health Record system was low among focus group attendees. However, those who had accessed and used their My Health Record were generally positive about the My Health Record system. The most common negative response regarding the user experience of the My Health Record system across all sites was the difficulty in initially accessing My Health Record via the myGov portal. Those who had accessed and used My Health Record almost uniformly stated that myGov is difficult to use and navigate and does not provide the most user-friendly experience. Individuals highlighted this as a barrier to uptake and use of the My Health Record.

Results that address this question from individual surveys

At follow up, 73% of respondents in opt-out trial sites who had a My Health Record found it useful. In opt-in sites, 50% of respondents with a My Health Record found it useful.

Overall, of the respondents who were registered for a My Health Record, 23% felt they were more informed about the healthcare they received, 20% felt they were more involved in decision making and 25% felt they were more aware about their health.

A total of 76 respondents felt that the members of their treating team worked better as a team owing to the My Health Record. Of these 76 respondents, 52% felt that their My Health Record had allowed their treating team members access to the same information (n=39). People also indicated that their My



Health Record assisted their healthcare providers in their clinical decision making because they had all the information they needed without having to rely on the patient's memory or having the patient repeat their medical history. Six respondents provided 'other' responses such as: they intended to find more information about the My Health Record or did not see the use of the My Health Record at the time of being surveyed.

[Survey questions did not explore the technical utility of the My Health Record system]

Results that address this question from healthcare provider surveys

A total of 32 healthcare provider respondents indicated that the My Health Record system provided them with a patient's information previously unknown to them. Of these respondents, 38% said that the My Health Record system provided them with information about patients' admissions/visits to the hospital, including Discharge Summaries (n=12). 34% said that the My Health Record system showed them previous medical history, diagnosis and test results of patients to inform their clinical care (n=11), and another 16% said that it provided them information about the changes to their medication or whether they got their prescription filled (n=5).

A total of 11 respondents indicated that the My Health Record modified their approach to diagnosis or treatment of their patient and described how it did so. Most said the My Health Record provided information about past medical history or additional information that was not disclosed by the patient. Others also indicated that the My Health Record provided them with information regarding their patient's hospital admissions, prescriptions, that led them to do further assessments, and the system allowed them to update a My Health Record to reduce confusion about a patient's condition.

Seventeen respondents described how the My Health Record system provided them with more confidence in their clinical decision making, as follows:

- 10 said that the My Health Record system reassured them that they were not missing any important information by showing them their patient's previous medical history, diagnosis, medication and previous treatments from GPs/medical specialists.
- three reported that the My Health Record system enabled them to make informed decisions about their patient's medication or future management.
- two said that it provided information that was not previously known/understood by patients themselves.
- two said it gave patients additional control over their health.¹³

How have the characteristics of the populations within the trial sites affected the likelihood of outcomes being achieved?

Results that address this question from focus groups with individuals

Awareness in the remote settings of Mapoon and Thursday Island was nil. While there were a number of participants in these groups who (prompted and unprompted) said they had received a letter or had seen some information about the My Health Record within their community (poster/brochure), all reported they did not understand the content and therefore took no notice of it.

¹³ Two other healthcare providers identified 'other' ways that the My Health Record improved their confidence in clinical decision making (full details in Table 32, Appendix 8).



In the NBM Indigenous specific focus group, none of the participants recalled receiving a letter. One of them said he was illiterate. Most were aware of My Health Record, and had been made aware by health or welfare professionals (either Indigenous support staff of the PHN, or staff from a local Aboriginal community centre) in face to face settings. Participants from both opt-out trial sites advised that face to face communication from a community elder or healthcare professional would be the best way to communicate the purpose and use of the My Health Record within their community.

Concerns about confidentiality and security were expressed more often in the focus group in Mapoon. Many of the participants in this remote NQ community said they were wary of the My Health Record system as another Government initiative to keep a watchful eye on their community.

Participants in the remote community settings of Thursday Island and Mapoon explained that connectivity to the internet by both computer and smart phones in the Cape York region was very poor. While many had smart phones, the connectivity by mobile networks in the region was extremely unreliable. Very few of these participants reported having access to computers or knowing how to operate them.

The focus group held in NQ with participants from culturally and linguistically diverse backgrounds (Myanmar, Uganda, Democratic Republic of Congo and Somalia) found that all 13 participants were aware of the My Health Record system and understood its functionality and purpose. The reason for the high level of awareness in this group, as reported by participants, was the significant local and face to face efforts by the NQ PHN in organising intense briefings to members of these communities, and co-facilitating briefing with a local settlement service.

The low functional literacy and computer literacy levels of many people in small remote communities was highlighted as a key barrier to promotion of the My Health Record. Focus group participants from these communities suggested that, to promote widespread engagement and use amongst their community, efforts to engage them should be focussed on individualised healthcare provider-supported processes. It was evident that written communication was highly ineffective. Similarly, in the CALD group, face to face information sessions translated into their first language were highly valued and resulted in a high level of awareness, understanding and use amongst this population group. In addition, those within the remote settings of Mapoon and Thursday Island highlighted poor internet connectivity and access to reliable technology (computers and/or smart phones) as a barrier for use of the My Health Record system.

Results that address this question from Aboriginal and Torres Strait Islander pen and paper survey

Most respondents at both baseline and follow up said they had not previously heard or received any written information about the My Health Record. Respondents were more likely to receive information about the My Health Record from their healthcare providers than from other sources such as the mass media, the myGov website, or other Government websites.

Very few respondents recalled having received a letter about the My Health Record. Those who knew they had a My Health Record were more likely to recall receiving such letter.

Respondents at baseline and follow up identified several benefits of the My Health Record, including:

- having a My Health Record would contribute to receiving high quality care
- allow healthcare providers easy access to their health information



- having one centralised medical record for individuals and healthcare providers

At baseline and follow up, the majority of respondents who indicated that they had a My Health Record were confident in their ability to use the My Health Record.

As the My Health Record can only be accessed through the myGov platform, a key aspect of confidence to the use the My Health Record is whether or not people have a myGov account. The findings demonstrate that the majority of respondents had a myGov account. This means that these people would be able to access and use their My Health Record. Respondents who did not have a myGov account said the reasons why they did not have one, included: being unaware that they could have one/had no information about it or that having an account was not a priority or not necessary.

The other aspect of confidence to use the My Health Record is the confidence that people have in the Government's capacity to maintain the confidentiality of their My Health Record and the security of the My Health Record system from external threats, such as hackers. Respondents at follow up were somewhat confident: in the ability of the My Health Record system to maintain their information as private, confidential and secure; that the My Health Record is secure from external threats such as hackers and that the Government/others would treat the medical information appropriately.

When asked whether they have a My Health Record, most respondents said they did not have a My Health Record, or were unsure if they had one.

Of the respondents who indicated that they did not have a My Health Record (or were unsure), only eight had opted out. The reasons given by these respondents for opting out included: unsure about how to use the My Health Record; did not see a need for it and concerns about the My Health Record's security.

Of those who indicated that they had a My Health Record at baseline and follow up, most had not set privacy settings, had not accessed their My Health Record in the last four weeks and were unsure of their intention to access their My Health Records in the future. These people also believed that to some extent they had been able to observe members of their treating team working better together because of the My Health Record.

At baseline and follow up, there were similar numbers of respondents who thought that a healthcare provider's use of the My Health Record would or would not influence the likelihood that they would use them as their healthcare provider of choice.

[How have outcomes for individuals, healthcare providers and other groups changed over time?](#)

A brief summary of preceding data (all data sources)

Individuals

There were approximately 2.6 million individuals registered for a My Health Record at baseline. 971,245 My Health Records were automatically created as part of the opt-out trials. An additional 80,444 My Health Records were created in the opt-in trial sites over the trial period. 1,726 of these My Health Records were created as a direct result of the opt-in trial activities. This is in comparison to the 596,345 My Health Records that were created in the rest of Australia between March and September 2016 under the usual opt-in registration arrangements.



More individuals have uploaded and viewed their My Health Record; and most of these individuals have not restricted access and have allowed MBS data to be added to their My Health Record. Most individuals who have a My Health Record reported that they do not intend to cancel it.

At the time of the follow up surveys, more people in both opt-in (18.5%) and opt-out (41%) trial areas had heard about the My Health Record than those in the rest of Australia (10.7%).

However, the focus group findings indicate that most individuals in the trial sites remain largely unaware of the My Health Record system and its features and benefits.

Little has changed for Aboriginal and Torres Strait Islander people over the trial period.

Healthcare Providers

Healthcare providers started with a relatively high level of awareness of the My Health Record. The number of organisations (n=292 across all trial sites) registered with the My Health Record system and the number of documents uploaded increased significantly, especially in opt-out sites. An increased number of healthcare providers have My Health Record use embedded in or linked to their existing information systems, therefore more healthcare providers have access to the My Health Record system at their workplaces.

A proportion of healthcare providers received training on the My Health Record system (significantly so in opt-out areas), although the percentage of healthcare providers who have been trained remains low (<15%). Healthcare providers who received training reported feeling confident to use My Health Record and explain it to others.

Although healthcare provider confidence in the confidentiality and security of the My Health Record system remains variable, healthcare providers have indicated their intention to continue to use the My Health Record system into the future.

In the trial sites, additional healthcare provider organisations have been registered with the My Health Record system.

For trial teams

Implementation teams have built up new contacts in and knowledge about healthcare provider segments in their area or within their hospital. New knowledge has been created (e.g. digital health capacity of services within their area have been mapped). They have reviewed their approaches, based on lessons learned in the early stages of the trials. They have established new working relationships with State Health Departments, especially the digital health groups.

Trial teams were still learning and revising strategies to engage healthcare provider segments as the end date of the trials approached.

Time series data from the System Operator

There was consistent growth in the number of My Health Records created across trial sites. However, due to the automatic registration process in the opt-out trial site there was a dramatic increase in the number of My Health Records created in June.



Also, there was steady growth in the number of healthcare providers across the trial period with a few exceptions, where bulk registrations of public hospitals occurred, this led to spontaneous increases in the number of registered healthcare providers e.g. opt-in trial sites in June and rest of Australia in late August early September. The opt-out trial sites performed well throughout the duration of the trial evaluation period and had statistically greater registrations than the rest of Australia.

The time-series demonstrated a gradual increase in Shared Health Summary uploads from baseline to May in all trial sites. There was an increase in the rate of uploads from May to the end of July in all trial sites. However, the opt-out trial sites had greater activity than the rest of Australia per healthcare provider. This increase in activity was probably associated with the ePIP which set Shared Health Summary upload targets for General Practices. The deadline for reaching these targets was the 31st July. The activity in all sites dropped off after the ePIP deadline; however, the activity in the opt-out trial sites was maintained at a higher level when compared to the rest of Australia. It is difficult to predict if this will continue long term given the temporal/seasonal nature of the activity. The opt-in trial site had a slower increase in activity than the rest of Australia, but hit a similar peak as the rest of Australia and has maintained this similarity after the ePIP deadline.

It is not possible to make projections of activity at this point due to the seasonal/temporal nature of the data. It is likely that there will be a plateau of activity between the deadlines for ePIP and further peaks, but as there has only been one iteration of this cycle in the reporting period for this evaluation, it is impossible to state where these plateaus and peaks will be in the future.

The number of Discharge Summary uploads per week in the opt-out trial sites increased dramatically in late July and then plateaued for the rest of the trial period. The rest of Australia maintained a continuous increase which did not plateau, though this increase was proportionally less than the opt-out trial sites. There was a dramatic increase in the number of Discharge Summaries uploaded in July in the opt-out trial sites. This increase in activity was maintained for the remainder of the trial period. This is mainly due to the availability of My Health Records, with healthcare providers being able to add data to individuals' My Health Records, who did not opt out, from the 15th July.

The number of Prescription Records uploaded by healthcare provider organisations in the rest of Australia and in the opt-in trial sites also maintained an increasing trend for the duration of the trial with few exceptions. The opt-out trial site Prescription Record uploads demonstrated a similar trend to Discharge Summaries, with a sudden increase in activity in mid-July, due to healthcare provider access to the My Health Records being activated.

Throughout the trial period there were drops in activity levels which coincided with public holidays. This occurred in mid-June with a reduction of Prescription Record uploads. Reduced activity levels were also seen at the time of the Queen's birthday public holiday, the Easter public holidays and Anzac Day.



Appendix 3 Analysis of the My Health Record System Operator data

Methods

Data

The My Health Record System Operator extracted de-identified data collected by the Department of Human Services in the daily operation of the My Health Record and provided it to the evaluation team. The *baseline period* covers usage data from the 1st to the 28th February 2016 for both the individual and healthcare provider analysis. The *follow up period* covers usage data from 5th September to 2nd October 2016 for individuals, and 29th August to 25th September 2016 for healthcare providers. Registration data and document counts are based on data that was current on 28th Feb 2016 for baseline, and 2nd October for follow up.

Variables were extracted from the data for individual registration and usage, and for healthcare provider organisation and usage (for details of the list of variables see Attachment 1). MBS uploads that examined specific types of healthcare provider attendances were also extracted (Table 1). Data from the My Health Record System Operator was provided in a range of formats. Individual registration and document count data was provided as 297 zip compressed files which contained a total of 1,151 percentage delimited separated files. Individual usage was provided as 34 zip files that contained 34 percentage delimited separated list files, and specifically for MBS 7 zip compressed files that contained a total of 4 comma delimited .csv files and 15 excel files. Healthcare provider registration was provided as 2 excel files. Healthcare provider usage was provided as 2 excel files. The files were imported into Stata and merged where appropriate.

Table 1. MBS items extracted in an aggregate process and assigned to the listed attendance types for the analysis

Health service	MBS items numbers
General Practitioner attendances	51, 43, 35, 20 , 3, 23, 36, 44, 2497, 2501, 2503, 2504, 2506, 2507, 2509, 2598, 2600, 2603, 2606, 2610, 2613, 2616, 2721, 2723, 2725, 2727, 4, 24, 37, 47, 170, 171, 172, 173, 193, 195, 197, 199, 160, 161, 162, 163, 164, 2100, 2122, 2125, 2126, 2137, 2138, 2143, 2147, 2179, 2195, 2199, 2220, 4001
Specialist / non GP attendances	52, 53, 54, 57, 58, 59, 60, 65, 92, 93, 95, 96, 99, 104, 105, 106, 107, 108, 109, 110, 112, 113, 114, 116, 119, 122, 128, 131, 288, 296, 297, 299, 300, 302, 304, 306, 308, 310, 312, 314, 316, 318, 319, 320, 322, 324, 326, 328, 330, 332, 334, 336, 338, 342, 344, 346, 353, 355, 356, 357, 358, 359, 361, 364, 366, 367, 369, 370, 384, 385, 386, 387, 388, 389, 410, 411, 412, 413, 414, 415, 416, 417, 501, 503, 507, 511, 515, 519, 520, 530, 532, 534, 536, 880, 2799, 2801, 2806, 2814, 2820, 2824, 2832, 2946, 2949, 2954, 3003, 3005, 3010, 3014, 3015, 3018, 3023, 3028, 3032, 3040, 3044, 6004, 6007, 6009, 6011, 6013, 6015, 6016, 10801, 10802, 10803, 10804, 10805, 10806, 10807, 10808, 10809, 10816, 10905, 10907, 10910, 10911, 10912, 10913, 10914, 10915, 10916, 10918, 10921, 10922, 10923, 10924, 10925, 10926, 10927, 10928, 10929, 10930, 10945, 10946, 10947, 10948, 5200, 5203, 5207, 5220, 5223, 5227, 5228, 5260, 5263, 5265, 5267, 598, 600
After-hours	5067, 5049, 5028, 5010, 5060, 5040, 5020, 5000, 5063, 5043, 5023, 5003, 597, 599
Managed care plans and health assessments (GP)	723, 721, 732, 729, 731, 701, 703, 705, 707, 715, 2517, 2518, 2521, 2522, 2525, 2526, 2546, 2547, 2552, 2553, 2558, 2559, 735, 739, 743, 871, 872, 900, 903, 2700, 2701, 2712, 2713, 2715, 2717
Managed care plans (non-GP)	132, 133, 141, 143, 145, 147, 135, 289, 137, 139, 291, 293, 359, 820, 822, 823, 855, 857, 858, 880

Quantitative data analysis

Descriptive statistics

Routine descriptive methods (including proportions and means) were used to describe the data at the level of the participation trial site for the comparison group, the rest of Australia.

Statistical Analysis

Pearson χ^2 test of association, t-tests and logistic regression analysis were conducted to determine differences in pre- and post-trial implementation periods and to test differences between the opt-in participation trials and the rest of Australia and the opt-out participation trials and the rest of Australia.

Analysis was conducted using StataSE® version 13 (StataCorp College Station, TX, USA) and MS Excel © was used to develop graphs and tables for the final report.

Increased participation in, and use of, the My Health Record System by users Participation

Individuals

There were 971,245 additional My Health Records created in the opt-out trial sites, compared to 596,345 new registrations in the rest of Australia, leading to a statistically significant 8-fold increase in opt-out trial areas over the rest of Australia (Table 2, Figure 1).

Table 2. Total number of My Health Records by trial site pre- and post-trial implementation in the opt-out trial sites compared to rest of Australia [n]

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
My Health Records	116,559	1,087,804	10.1	2,195,629	2,791,974	1.27	8.83

Bold = statistically significant difference

There were 80,444 additional My Health Records created in the opt-in trial sites compared to 596,345 in the rest of Australia leading to a 0.04 increase in opt-in trial registrations over the rest of Australia (Table 3, Figure 1).

Table 3. Total number of My Health Records by trial site pre- and post-trial implementation in the opt-in trial sites compared to rest of Australia [n]

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
My Health Records	263,542	343,986	1.31	2,195,629	2,791,974	1.27	0.04

Bold = statistically significant difference

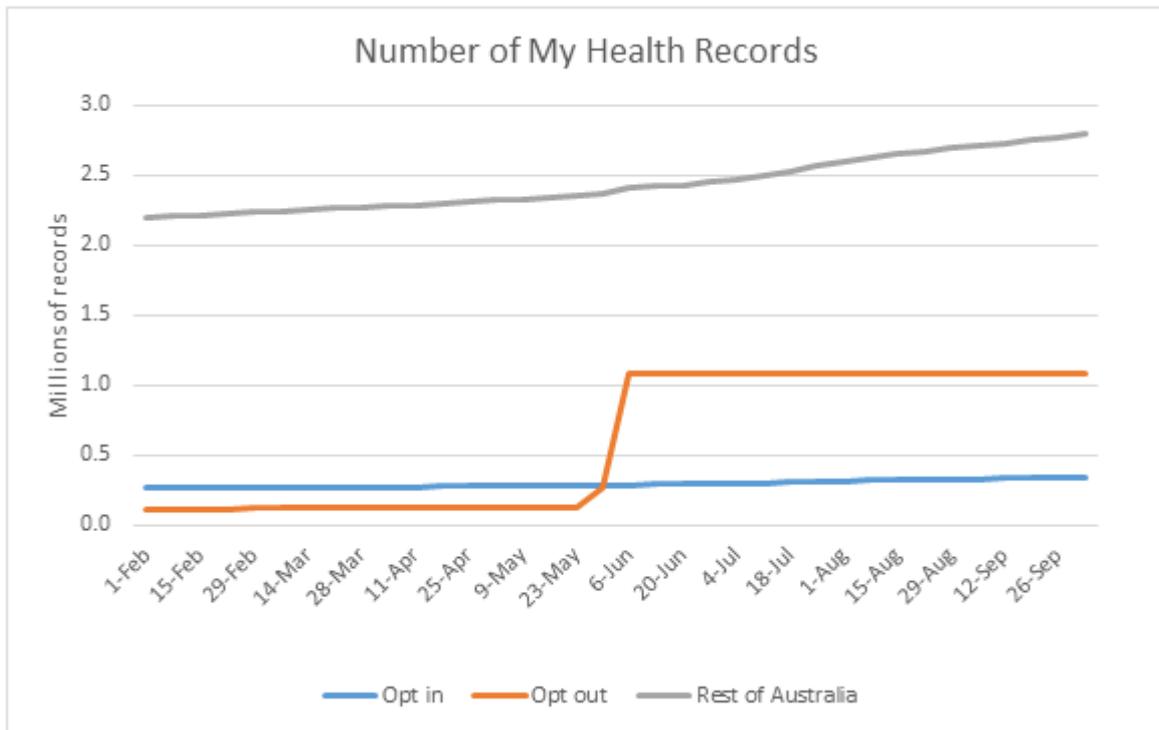


Figure 2. Number of My Health Records in each participation trial for the duration of the trial period

There are proportionally more Aboriginal and Torres Strait Islander people in North Queensland (one of the two opt-out trial sites) than in the rest of Australia. The proportion of individuals with a My Health Record who identified as Aboriginal and Torres Strait Islander in the opt-out trial areas was significantly higher than in the rest of Australia. There were no meaningful differences between the level of change in Aboriginal and Torres Strait Islander peoples’ My Health Record registration between opt-out sites and the rest of Australia (Table 4).¹⁴

Table 4. Number of Aboriginal and Torres Strait Islander peoples registered with My Health Records in the opt-out versus rest of Australia

A&TSI	Opt-out N=116,559	Opt-out N=1,081,811	Difference	Rest of Australia N=2,195,629	Rest of Australia N=2,791,974	Difference
	Baseline	Follow up		Baseline	Follow up	
Yes	6,648 (8.5%)	7,568 (8.3%)	-0.2%	61,905 (4.1%)	76,783 (4%)	-0.1%
No	71,451 (91.5%)	83,227 (91.7%)	0.2%	1,447,547 (95.9%)	1,822,707 (96%)	0.1%

Bold = statistically significant difference

There were no meaningful differences between the level of change in Aboriginal and Torres Strait Islander peoples’ My Health Record registrations between opt-in and the rest of Australia (Table 5).

Table 5. Number of Aboriginal and Torres Strait Islander peoples registered My Health Records in the opt-in trial areas versus rest of Australia

A&TSI	Opt-in N=263,542	Opt-in N=343,986	Difference	Rest of Australia N=2,195,629	Rest of Australia N=2,791,974	Difference
	Baseline	Follow up		Follow up	Follow up	
Yes	6,221 (4%)	8,331 (4%)	0%	61,905 (4.1%)	76,783 (4%)	-0.1%

¹⁴ Note: there are My Health Records where individuals have not chosen to nominate whether they are of Aboriginal and Torres Strait Islander descent or not.

A&TSI	Opt-in N=263,542	Opt-in N=343,986	Difference	Rest of Australia N=2,195,629	Rest of Australia N=2,791,974	Difference
	Baseline	Follow up		Follow up	Follow up	
No	150,993 (96%)	200,623 (96%)	0%	1,447,547 (95.9%)	1,822,707 (96%)	0.1%

Bold = statistically significant difference

Healthcare Providers

There were a number of healthcare provider organisations dropped from the analysis due to not having access to postcode data. There were 142 missing at baseline and 170 at follow up.

There were 131 additional healthcare provider organisations registered in the opt-out trial sites during the trials period. This equates to a 0.28 proportional increase in the opt-out trial areas over the rest of Australia (Table 6).

Table 6. Total number of healthcare providers registered by trial site pre- and post-trial implementation [n]

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Healthcare Providers registered	360	491	1.36	7,138	7,720	1.08	0.28

Bold = statistically significant difference

There were 161 additional healthcare provider organisations registered in the opt-in trial sites which equates to a 0.17 proportional increase in opt-in trial areas over the rest of Australia (Table 7).

Table 7. Total number of healthcare providers registered by trial site pre- and post-trial implementation [n]

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Healthcare Providers registered	677	843	1.25	7,138	7,720	1.08	0.17

Bold = statistically significant difference

65% of registered healthcare provider organisations were general practices. Pharmacies were the next most common (14%) (Table 8 and Figure 2).

Table 8. Healthcare provider organisation types registered in the My Health Record System by trial site as of September [n (%)]

	Opt-out N=491	Opt-in N=843	Rest of Australia N=7,720	Total
Aged Care	5 (1.02%)	21 (2.49%)	142 (1.84%)	168 (1.86%)
Allied Health	23 (4.68%)	31 (3.68%)	547 (7.09%)	601 (6.64%)
General Practice	285 (58.04%)	552 (65.48%)	5,025 (65.09%)	5,862 (64.74%)
Other	34 (6.92%)	51 (6.05%)	267 (3.46%)	352 (3.89%)
Pharmacy	88 (17.92%)	96 (11.39%)	1,091 (14.13%)	1,275 (14.08%)
Private Hospitals	7 (1.43%)	8 (0.95%)	149 (1.93%)	164 (1.81%)
Public Hospitals	39 (7.94%)	73 (8.66%)	318 (4.12%)	430 (4.75%)
Specialist	10 (2.04%)	11 (1.3%)	181 (2.34%)	202 (2.23%)

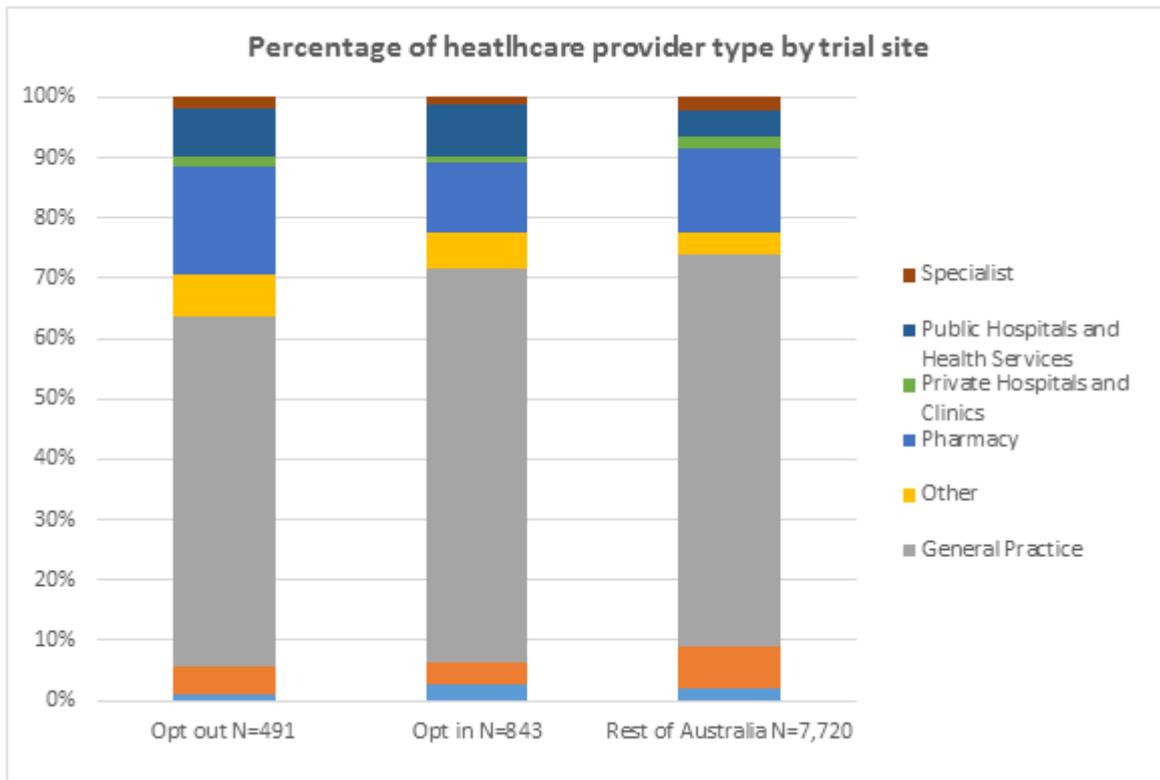


Figure 3. Percentage of healthcare provider type by participation trial at end of evaluation

Time-series

There was consistent growth in the number of healthcare providers across the trial period with a few exceptions where bulk registrations of public hospitals occurred, which lead to spontaneous increases in the number of registered healthcare providers, e.g. opt-in trial sites in June and rest of Australia in late August early September 2016 (Figure 3).

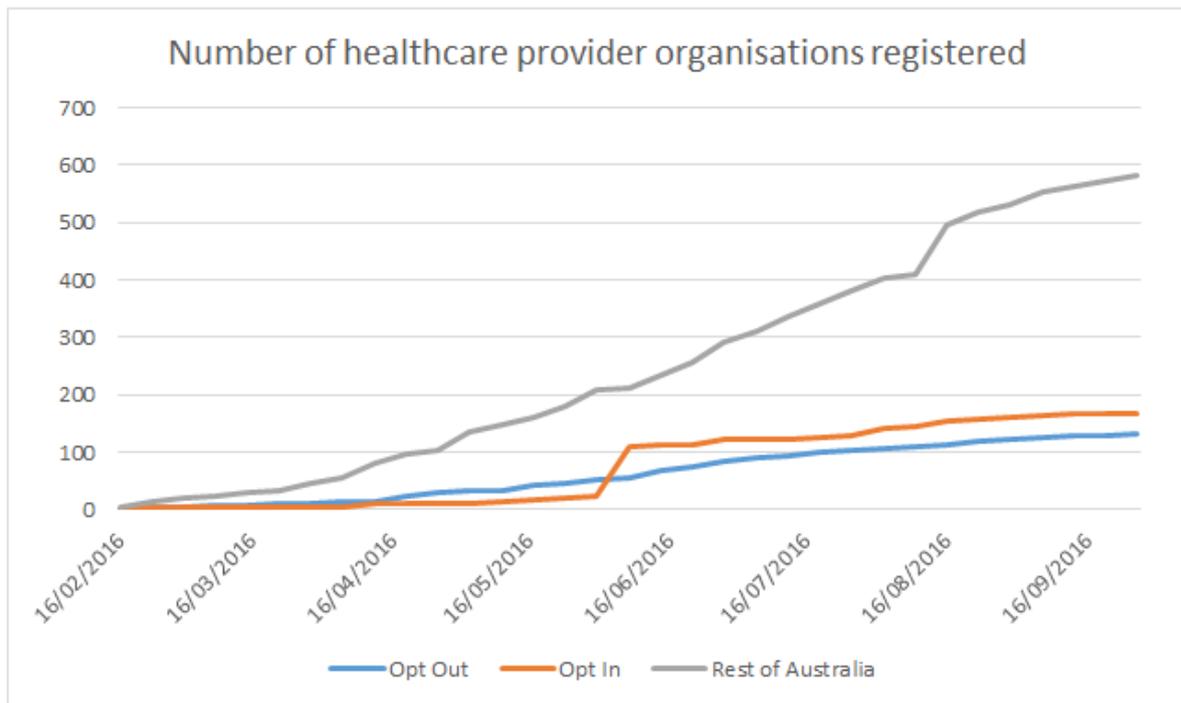


Figure 4. Number of additional healthcare provider organisations registered by participation trial over the period of the evaluation

From the proportional gain in registered healthcare providers it can be seen that the opt-out trial sites performed well throughout the trial period (Figure 4).

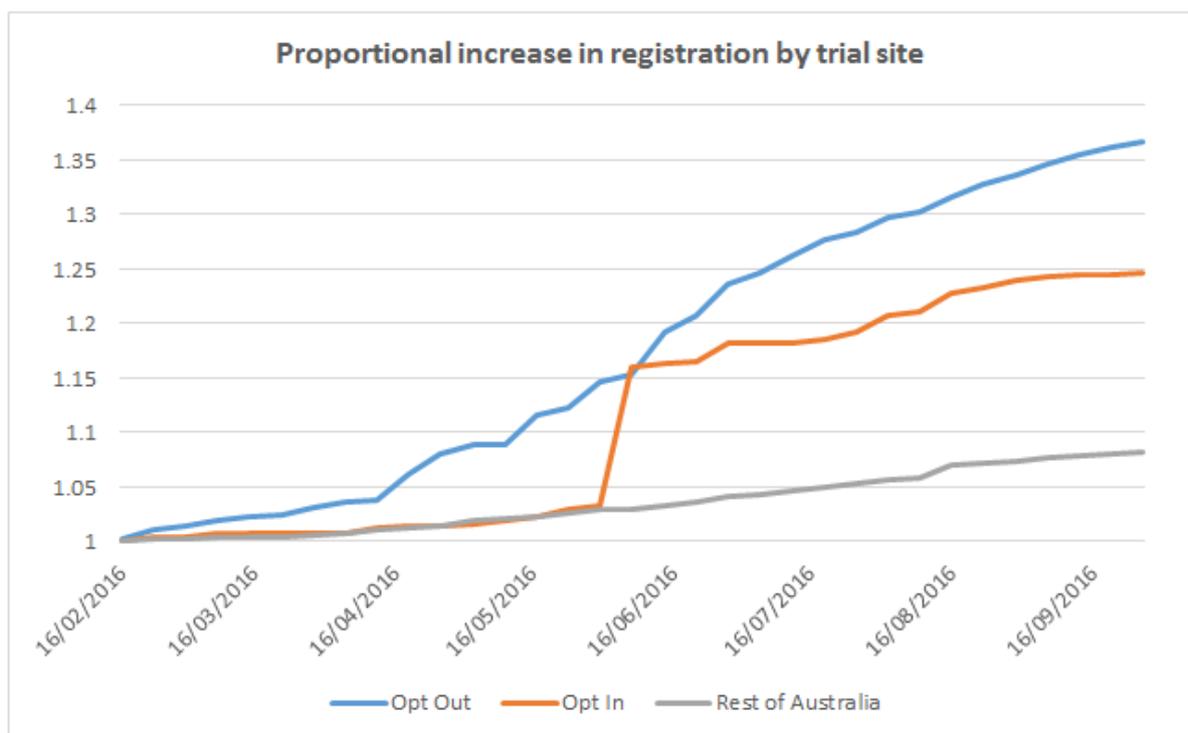


Figure 5. Proportional increase of additional healthcare provider organisations registered by participation trial over the period of the evaluation

The main healthcare provider types registered in the trial period were general practices, followed by pharmacies, and public hospitals and health services (Figure 5), this was consistent across the three trial sites.

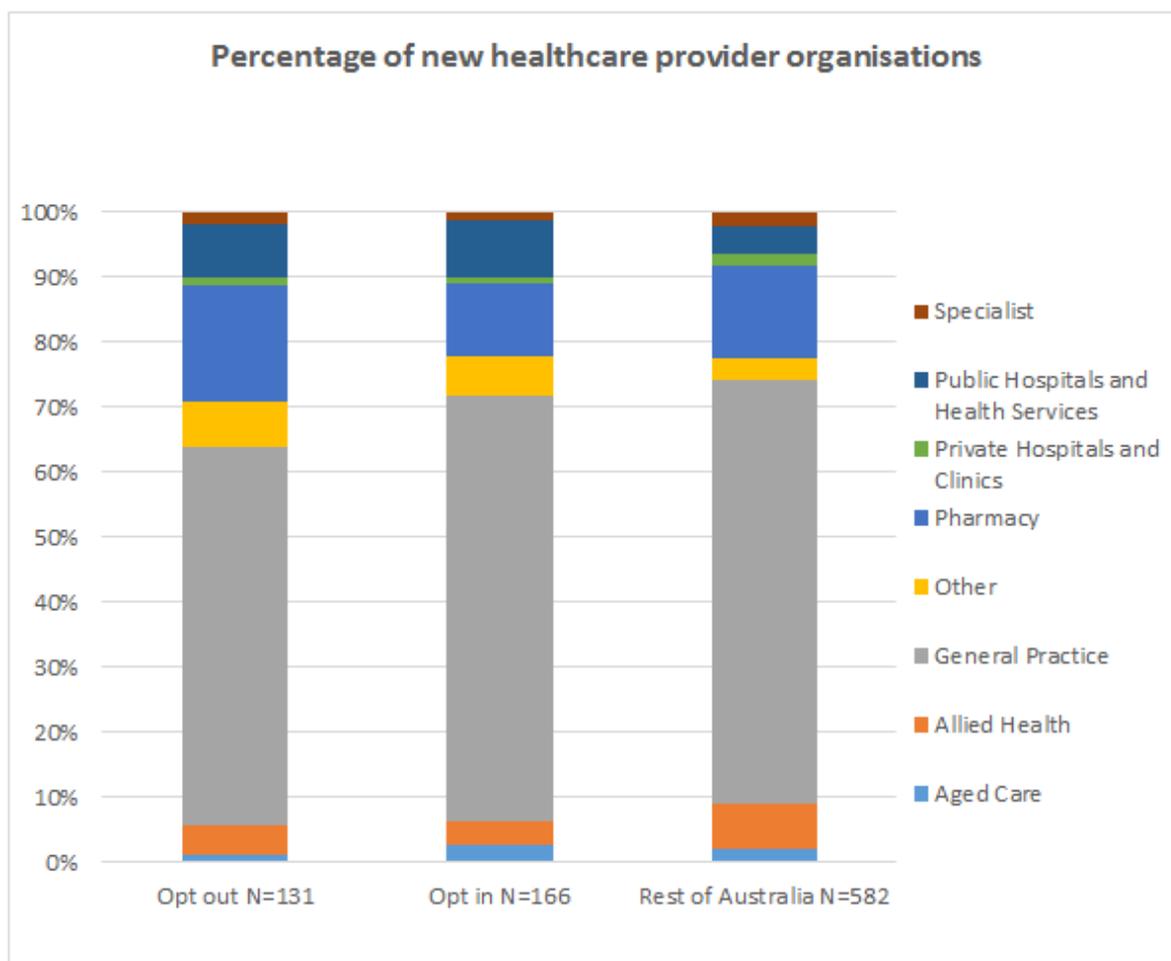


Figure 6. Percentage of new healthcare provider organisations by type and trial site that registered with the My Health Record system during the trial period

Use

Individual

Individuals contributed to the My Health Record in several ways, but particularly by allowing their My Health Records to be accessed by healthcare providers and not restricting access. The number of My Health Records that had restricted access to either documents or healthcare providers was less than 0.5% and this did not vary across participation trials and the rest of Australia (Table 9).

Table 9. Access limitations by the different participation trials

	Opt-out	Opt-in	Rest of Australia	Total
Restricted Access Code set				
Yes	568 (0.1%)	1,093 (0.3%)	7,971 (0.3%)	9,632 (0.2%)
No	1,081,243 (99.9%)	342,893 (99.7%)	2,784,003 (99.7%)	4,208,139 (99.8%)
Limited Document Access Code set				
Yes	221 (0%)	505 (0.1%)	3,716 (0.1%)	4,442 (0.1%)
No	1,081,590 (100%)	343,481 (99.9%)	2,788,258 (99.9%)	4,213,329 (99.9%)

Individuals uploaded a range of different documents to the My Health Record system, including Consumer Entered Health Summary, Consumer Entered Notes, Advance Care Directive Custodian Report, Advance Care Documents, Personal Health Observation, Personal Health Achievement, and

Child Parent Questionnaire. Together, there were 187 additional uploads carried out by individuals in the opt-out trial sites during the follow up period, compared to 2,235 in the rest of Australia. This equated to a 1.1 proportional increase in opt-out trial areas over the rest of Australia (Table 10).

While MBS item code information is uploaded directly from MBS, individuals allow this data to be added to their My Health Records. There was a significant increase in the number of MBS attendance items added to the My Health Record system in both the opt-out trial sites and the rest of Australia (Table 10).

Table 10. Total number of uploads by individuals and the number of MBS attendance items uploaded associated with an individual by the opt-out participation trial compared to the rest of Australia in the baseline and follow up periods

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Individual Uploads	72	259	3.6	1,469	3,704	2.5	1.1
MBS item uploads							
Managed Care Plan and Health Assessment (GP)	7,566	9,442	1.2	84,064	88,246	1.0	0.2
Specialist or non GP Attendance	17,815	23,637	1.3	193,973	226,580	1.2	0.2
After hours	2,378	4,801	2.0	29,794	50,026	1.7	0.3
Managed Care Plan (non-GP)	664	821	1.2	8,828	10,764	1.2	0.0
GP Attendance	58,480	84,208	1.4	628,669	787,762	1.3	0.2
Total MBS attendances recorded	86,903	122,909	1.4	945,328	1,163,378	1.2	0.2

Bold = statistically significant difference

There were 440 additional uploads carried out by individuals in the follow up period in the opt-in trial sites compared to 2,235 in the rest of Australia. This equated to a 1.5 proportional increase in the opt-in trial areas over the rest of Australia (Table 11). There was also an increase in the number of MBS attendance items added to My Health Records in the opt-in trial areas; however, this change was a 2.1 proportional increase over the rest of Australia (Table 11).

Table 11. Total number of uploads by individuals and the number of MBS items uploaded associated with an individual by the opt-in participation trial compared to the rest of Australia in the baseline and follow up periods

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Individual Uploads	149	589	4.0	1,469	3,704	2.5	1.5
MBS item uploads							
Managed Care Plan and Health Assessment (GP)	4,775	13,685	2.9	84,064	88,246	1.0	1.8
Specialist or non GP	9,402	27,744	3.0	193,973	226,580	1.2	1.8

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Attendance							
After hours	1,548	6,096	3.9	29,794	50,026	1.7	2.3
Managed Care Plan (non-GP)	304	1,113	3.7	8,828	10,764	1.2	2.4
GP Attendance	31,994	112,928	3.5	628,669	787,762	1.3	2.3
Total MBS attendances recorded	48,023	161,566	3.4	945,328	1,163,378	1.2	2.1

Bold = statistically significant difference

Individuals also viewed documents in their My Health Record, with the key ones being viewed and increased from baseline including; Consumer Entered Health Summary, Audit View, Diagnostic Imaging Report, Health Record Overview, Medicare Overview, Prescription Record View, and Prescription Dispensed View. Overall the level of viewing of these documents between baseline and follow up increased more in the opt-out trial sites than in the rest of Australia though these differences were low (Table 12).

Table 12. Total number of views by individuals by the opt-out participation trial compared to the rest of Australia in the baseline and follow up periods

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Consumer Entered Health Summary	99	968	9.8	1,901	10,072	5.3	4.5
Audit View	971	1,383	1.4	14,733	11,559	0.8	0.6
Diagnostic Imaging Report	1,042	3,879	3.7	19,183	42,679	2.2	1.5
Health Record Overview	3,970	16,527	4.2	72,416	186,320	2.6	1.6
Medicare Overview	2,229	3,700	1.7	36,399	42,215	1.2	0.5
Prescription Record View	1,346	3,354	2.5	24,190	36,401	1.5	1.0
Prescription Dispensed View	1,574	3,341	2.1	26,778	39,128	1.5	0.7

Bold = statistically significant difference

Similarly, viewing in the opt-in trial sites was increased more than in the rest of Australia, but these were lower than for the opt-out trial sites (Table 13).

Table 13. Total number of views by individuals by the opt-in participation trial compared to the rest of Australia in the baseline and follow up periods

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Consumer Entered Health Summary	229	1,253	5.5	1,901	10,072	5.3	0.2
Audit View	1,889	1,467	0.8	14,733	11,559	0.8	0.0
Diagnostic Imaging Report	2,468	5,575	2.3	19,183	42,679	2.2	0.0
Health Record Overview	8,693	23,759	2.7	72,416	186,320	2.6	0.2
Medicare Overview	4,269	5,383	1.3	36,399	42,215	1.2	0.1
Prescription Record View	3,118	4,408	1.4	24,190	36,401	1.5	-0.1
Prescription Dispensed View	3,341	4,737	1.4	26,778	39,128	1.5	0.0

Bold = statistically significant difference

Document Uploads by Healthcare Providers

Healthcare providers uploaded a range of different documents to the My Health Record system, including Shared Health Summaries, Event Summaries, Discharge Summaries, Prescription Records, Pathology and Diagnostic Imaging Reports. Prescription Records and Dispense Records were the most regularly uploaded documents by healthcare provider organisations at both the baseline period and follow up period.

In the opt-out trial sites, some kinds of documents increased significantly in volume between baseline and follow up, and increased significantly more compared to the rest of Australia. They included Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Records. Healthcare providers in the opt-out trial sites were more likely to access My Health Records and upload the first clinical document than those in the rest of Australia (Table 14).

There were increases in the number of Shared Health Summary uploads occurring within 24 hours of some MBS items, and these increases were significantly greater in the opt-out trial sites than the rest of Australia. In particular, Shared Health Summary uploads were markedly increased for GP attendances and managed care plans, and greater in the opt-out trial sites compared to the rest of Australia (Table 14).

Table 14. Total number of different types of documents uploaded by healthcare provider organisations in the opt-out participation trial compared to the rest of Australia in the baseline and follow up periods

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Shared Health Summary	75	3,332	44.4	4,983	37,814	7.6	36.8
Discharge Summary	519	4,817	9.3	18,088	27,180	1.5	7.8

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Event Summary	31	305	9.8	6,869	11,317	1.6	8.2
Dispense Record	5	32,365	6473.0	25,557	33,176	1.3	6471.7
Prescription Record	4,909	88,892	18.1	93,405	253,124	2.7	15.4
HPIO up first clinical document	354	6,642	18.8	10,908	39,621	3.6	15.1
Shared Health Summary uploads occurring within 24 hours of selected MBS items							
GP Attendance	53	1,593	30.1	1,521	10,917	7.2	22.9
Managed Care Plan and Health Assessment	9	363	40.3	537	2,797	5.2	35.1

Bold = statistically significant difference

Similarly, in the opt-in trial sites some kinds of documents significantly increased in volume between baseline and follow up, and increased significantly compared to the rest of Australia. These included Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Records. Similar to the opt-out trials, healthcare providers were more likely to access My Health Records and upload the first clinical document in the opt-in trial sites compared to the rest of Australia (Table 15). There were also increases in the number of Shared Health Summary uploads occurring within 24 hours of a GP attendance in the opt-in trial sites. However, there was a small decrease in the opt-in trial sites compared to the rest of Australia with regards to Shared Health Summaries associated with managed care plan visits (Table 15).

Table 15. Total number of document uploads by healthcare provider organisations in the opt-in participation trial compared to the rest of Australia in the baseline and follow up periods

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Shared Health Summary	180	4,073	22.6	4,983	37,814	7.6	15.0
Discharge Summary	150	786	5.2	18,088	27,180	1.5	3.7
Event Summary	29	322	11.1	6,869	11,317	1.6	9.5
Dispense Record	221	1,310	5.9	25,557	33,176	1.3	4.6
Prescription Record	3,652	15,433	4.2	93,405	253,124	2.7	1.5
HPIO up first clinical document	264	4,100	15.5	10,908	39,621	3.6	11.9
Shared Health Summary uploads occurring within 24 hours of selected MBS items							
GP	102	1,763	17.3	1,521	10,917	7.2	10.1

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Attendance							
Managed Care Plan and Health Assessment	93	375	4.0	537	2,797	5.2	-1.2

Bold = statistically significant difference

Comparing the number of MBS attendance items with no Shared Health Summary upload and those with one, MBS attendance items associated with attending a GP (either regularly or for a managed care plan) were the most likely to be associated with uploading a Shared Health Summary, both in the opt-out trial sites and the rest of Australia.

However, while the increases in opt-out sites and the rest of Australia were very similar, there was a slightly higher increase in number of uploads per MBS items in the opt-out trial sites compared to the rest of Australia (Table 16). In the follow up period, a GP attendance led to 1.9% of individuals with a My Health Record in the opt-out sites having a Shared Health Summary uploaded within 24 hours of their visit. This occurred for 1.1% of individuals with a My Health Record in the rest of Australia. It happened more often for individuals attending for a GP managed care plan: 3.7% of individuals with a My Health Record in the opt-out sites, and 2.5% of individuals with a My Health Record in the rest of Australia had a Shared Health Summary uploaded within 24 hours of their attendance (Table 16).

Table 16. Percentage of Shared Health Summaries that were uploaded within 24 hours of selected MBS items as a percentage of total MBS items of that type occurring in opt-out trial sites and the rest of Australia

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
GP Attendance	0.1%	1.9%	1.8%	0.2%	1.4%	1.1%	0.7%
GP managed Care plan	0.1%	3.8%	3.7%	0.6%	3.2%	2.5%	1.2%

Bold = statistically significant difference

In the opt-in trial sites, there was again increased probability of having a Shared Health Summary uploaded due to a GP attendance (1%) or a managed care plan (2.5%). However, the increase in the rest of Australia was slightly greater than in the opt-in trial sites for the managed care plan attendance (Table 17).

Table 17. Percentage of Shared Health Summaries that were uploaded within 24 hours of selected MBS items as a percentage of total MBS items of that type occurring in opt-in trial sites and the rest of Australia

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
GP Attendance	0.3%	1.6%	1.2%	0.2%	1.4%	1.1%	0.1%
GP Managed Care Plan	1.9%	2.7%	0.8%	0.6%	3.2%	2.5%	-1.7%

Bold = statistically significant difference

There was an increase in the number of Prescription Record uploads occurring within 24 hours of an MBS item and these increases were significantly greater in the opt-out trial sites than the rest of Australia. Prescription Record uploads were markedly increased for GP attendances compared to other MBS items (Table 18).

Table 18. Prescription Record uploads occurring within 24 hours of selected MBS items opt-out versus the rest of Australia

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
After hours	283	1,336	4.7	2,183	4,289	2.0	2.8
GP Attendance	3,363	54,306	16.1	76,567	147,603	1.9	14.2
Specialist or non GP Attendance	866	4,545	5.2	3,066	6,137	2.0	3.2
Managed Care Plan and Health Assessment	786	6,071	7.7	9,553	15,004	1.6	6.2
Managed Care Plan	11	62	5.6	60	104	1.7	3.9

Bold = statistically significant difference

There was an increase in the opt-in trial sites for Prescription Record uploads occurring within 24 hours of an MBS item. Again, GP attendances led to greater increases but these increases were much lower than the opt-out trial sites (Table 19).

Table 19. Prescription Record uploads occurring within 24 hours of selected MBS items opt-in versus the rest of Australia

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
After hours	67	152	2.3	2,183	4,289	2.0	0.3
GP Attendance	3,058	9,440	3.1	76,567	147,603	1.9	1.2
Specialist or non GP Attendance	109	258	2.4	3,066	6,137	2.0	0.4
Managed Care Plan and Health Assessment	484	1,058	2.2	9,553	15,004	1.6	0.6
Managed Care Plan	0	7	-	60	104	1.7	-

Bold = statistically significant difference

Time-series

The time-series demonstrates a gradual increase in the number of Shared Health Summaries uploaded from baseline to May in all trial sites (Figure 6).

There is an increase in the rate of uploads from May to the end of July in all trial sites; however, the opt-out trial sites had greater activity than the rest of Australia per healthcare provider. This increase in activity was probably associated with the PIP eHealth incentive which set Shared Health Summary upload targets for general practices. The deadline for reaching these targets for quarter one was the 31st July. The activity in all sites dropped off after the deadline. However, the activity in the opt-out trial sites has been maintained at a higher level over the duration of the trial, when compared to the rest of Australia. It is difficult to predict if this will be maintained long term given the temporal/seasonal nature of the activity. The opt-in trial sites had a slower increase in activity than the rest of Australia, but hit a similar peak in activity as the rest of Australia at the ePIP

deadline. These two sites (opt-in trial sites and the rest of Australia) have maintained this similar level of Shared Health Summary uploads since the ePIP deadline.

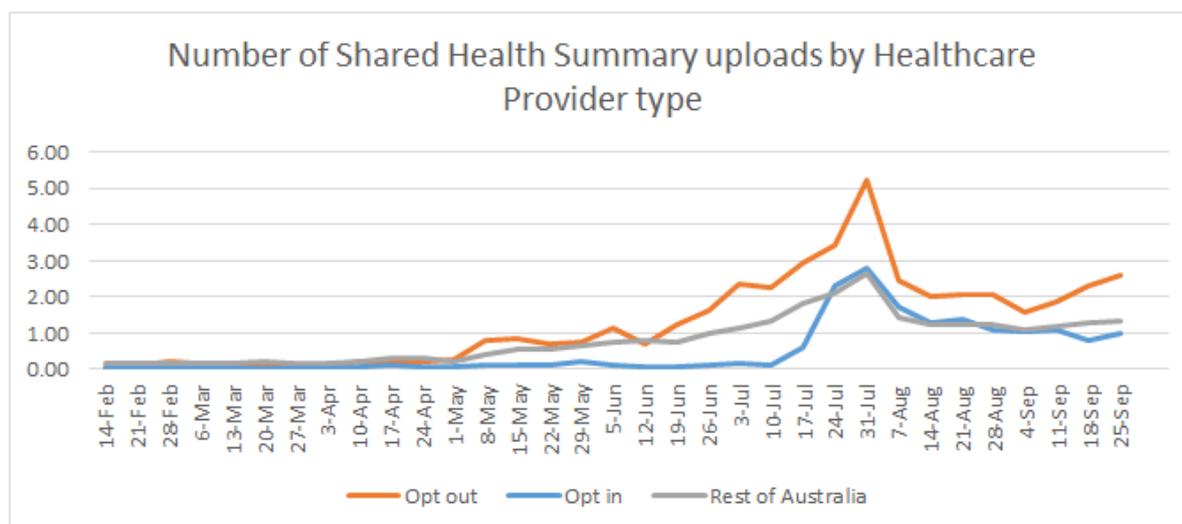


Figure 7. Number of Shared Health Summary uploads per week by healthcare provider organisation in the trial sites for the duration of the trial period

It is not possible to make projections of activity at this point, owing to the seasonal nature of the data. It is likely that there will be a plateau of activity between the deadlines for ePIP and further peaks, but as there has only been one iteration of this cycle in the reporting period for this evaluation, it is impossible to state where these plateaus and peaks will continue in the future.

The number of Discharge Summaries uploads per week in the opt-out trial sites increased dramatically in late July, and plateaued for the rest of the trial period (Figure 7). The rest of Australia has maintained a continuous increase which has yet to plateau, though this increase was proportionally less than in the opt-out trial sites (Table 14). There was a dramatic increase in the number of Discharge Summaries uploaded in July in the opt-out trial sites, this increase in activity has been maintained for the remainder of the trial period (Figure 7). This is mainly due to the availability of My Health Records, with healthcare providers being able to add data for individuals, who did not opt-out, from the 15th July. Interestingly the larger number of public hospitals in the opt-in trial sites did not result in a dramatic change in uploads and this may be due to a relatively lower number of individuals with My Health Records in opt-in sites compared to opt-out trial sites.

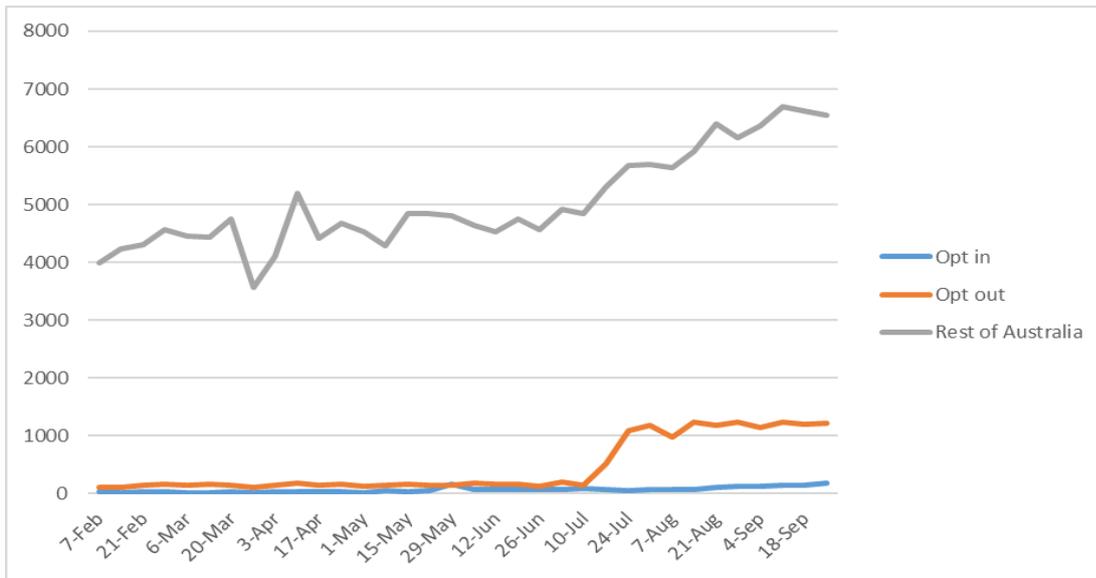


Figure 8. Number of Discharge Summary uploads per week by healthcare provider organisation in the trial sites for the duration of the trial period

The number of Prescription Records uploaded by healthcare provider organisations in the rest of Australia and in the opt-in trial sites also maintained an increasing trend for the duration of the trial with few exceptions (Figure 8). The opt-out trial site Prescription Record uploads demonstrated a similar trend to Discharge Summaries, with a sudden increase in activity in mid-July. This sudden increase may be explained in part due to the increase in healthcare providers accessing My Health Records to connect accounts in their computer systems, as access for upload to the automatically created My Health Records was only available from the 15th July. An increase in accesses of My Health Records to upload Shared Health Summaries for the ePIP (Figure 6) and an increase in the number of general practices registered on the My Health Record system (Figure 4) may also play a part in this increase.

There are also some drops in uploads of Prescription Records, especially noted in the rest of Australia in mid-June (and to a lesser effect in the opt-out trial sites) this may be in part due to a reduction in activity around a public holiday. However, the dramatic drop seen in the rest of Australia for the Queen’s birthday public holiday, which was mainly in the rest of Australia (not WA or Queensland) is not seen to such a great effect for other public holidays, although drops are noted around the Easter public holidays and Anzac Day (Figure 8).

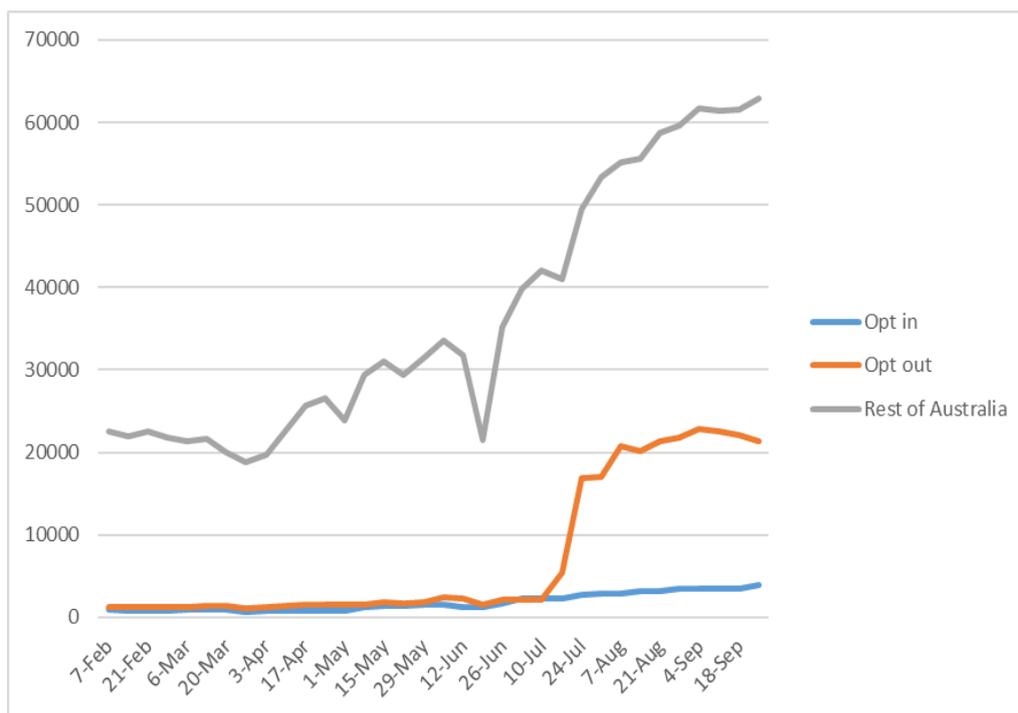


Figure 9. Number of Prescription Record uploads by healthcare provider organisation in the trial sites for the duration of the trial period

Document Accesses by Healthcare Providers

The level of accesses of documents increased dramatically during the trial period with accesses in the opt-out trial areas increasing significantly more than the rest of Australia (Table 20).

Table 20. Number of My Health Records accessed by healthcare providers and the number of My Health Records with no clinical documents accessed in the opt-out trial areas compared to the rest of Australia

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Total Unique My Health Records Accessed	3,145	74,129	23.6	77,523	228,814	3.0	20.6

Bold = statistically significant difference

The level of accesses of documents also increased dramatically during the trial period for the opt-in trial sites with accesses increasing significantly more than in the rest of Australia (Table 21).

Table 21 Number of My Health Records accessed by healthcare providers and the number with no clinical documents accessed in the opt-in trial areas compared to the rest of Australia

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Total Unique My Health Records Accessed	3,661	18,936	5.2	77,523	228,814	3.0	2.2

Bold = statistically significant difference

Some kinds of documents significantly increased in viewing activity between baseline and follow up and increased significantly more in the opt-out trial sites compared to the rest of Australia. These

included Discharge Summary, Medicare overview and documents created by other healthcare providers. However, healthcare providers in the opt-out trial sites were less likely to view Event Summaries than the rest of Australia (Table 22).

Table 22. Total number of different documents viewed by healthcare provider organisations in the opt-out participation trial areas compared to the rest of Australia in the baseline and follow up periods

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Shared Health Summary	30	514	17.1	265	3,888	14.7	2.5
Discharge Summary	6	257	42.8	148	967	6.5	36.3
Event Summary	6	13	2.2	22	308	14.0	-11.8
Prescription Dispense Record overview	26	238	9.2	319	1,524	4.8	4.4
Medicare Overview	0	1,313	-	68	3,373	49.6	-
Medicare DVA Benefits	10	123	12.3	545	970	1.8	10.5
Doc viewed of other HPIO	6	239	39.8	122	1,201	9.8	30.0

Bold = statistically significant difference

Several types of documents significantly increased in viewing activity between baseline and follow up, and increased significantly more in the opt-in trial sites compared to the rest of Australia. However, a number of these were different from the opt-out increases. The documents that were more likely to be viewed in the opt-in trial sites were the Medicare Overview and Medicare DVA Benefits Overview. These increases were mainly due to the low level of baseline activity. Healthcare providers in the opt-in trial sites were less likely to view Shared Health Summaries than the rest of Australia (Table 23).

Table 23. Total number of different documents viewed by healthcare provider organisations in the opt-in participation trial compared to the rest of Australia in the baseline and follow up period.

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
Shared Health Summary	42	353	8.4	265	3,888	14.7	-6.3
Discharge Summary	6	44	7.3	148	967	6.5	0.8
Event Summary	2	20	10.0	22	308	14.0	-4.0
Prescription Dispense Record overview	30	112	3.7	319	1,524	4.8	-1.0
Medicare Overview	1	929	929.0	68	3,373	49.6	879.4
Medicare	25	104	4.2	545	970	1.8	2.4

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
DVA Benefits							
Doc viewed of other HPIO	11	49	4.5	122	1,201	9.8	-5.4

Bold = statistically significant difference

My Health Record access also increased over the trial period in terms of the occurrence of MBS items. There were increases in access in the opt-out trial sites compared to the rest of Australia, with GP attendances having the greatest increase overall (Table 24).

Table 24. My Health Record accesses occurring within 24 hours of selected MBS items opt-out versus the rest of Australia

	Opt-out	Opt-out	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
After hours	29	6,254	215.7	398	15,922	40.0	175.7
GP Attendance	210	110,015	523.9	6,690	231,633	34.6	489.3
Managed Care Plan	72	25,044	347.8	1,642	58,793	35.8	312.0
Specialist or non GP Attendance	146	45,603	312.3	3,133	100,546	32.1	280.3
Managed Care Plan and Health Assessment	4	1,448	362.0	119	4,419	37.1	324.9

Bold = statistically significant difference

My Health Record access increased within the trial evaluation period around the occurrence of MBS items for providers in the opt-in trial sites. However, while these MBS attendances increased in opt-in trial sites the increase from baseline was less than the rest of Australia (Table 25).

Table 25. My Health Record accesses occurring within 24 hours of selected MBS items opt-in versus the rest of Australia

	Opt-in	Opt-in	Prop Change	Rest of Australia	Rest of Australia	Prop Change	Difference in prop change
	Baseline	Follow up		Baseline	Follow up		
After hours	30	1,096	36.5	398	15,922	40.0	-3.5
GP Attendance	1,775	25,412	14.3	6,690	231,633	34.6	-20.3
Managed Care Plan	358	6,382	17.8	1,642	58,793	35.8	-18.0
Specialist or non GP Attendance	543	9,507	17.5	3,133	100,546	32.1	-14.6
Managed Care Plan and Health Assessment	14	328	23.4	119	4,419	37.1	-13.7

Bold = statistically significant difference

Conclusions and recommendations

Individuals

There was an increase in the number of My Health Records across the opt-out and opt-in trial sites and the rest of Australia. As a result of the automatic creation of records under the opt-out model, the opt-out trial sites had significant increases, both in numbers and proportionally over the rest of Australia. The opt-in trial sites had only a small proportional increase over the rest of Australia. Proportional My Health Record registration of Aboriginal and Torres Strait Islander people did not change, regardless of the model of participation.

Individuals, were generally unlikely to restrict access to their My Health Record either by restricting documents or healthcare providers (less than 1% did so). Very few actively changed their uploading restrictions for MBS or PBS items and a large volume of MBS attendance items were recorded in their My Health Record. These increases were proportionally higher in both opt-out and opt-in trial sites compared with the rest of Australia. This means more information is available to healthcare providers when they view the Medicare overview in the trial sites.

Individuals are also able to upload their own personal health related documents to their My Health Record, but very few individuals availed themselves of this facility.

Individuals also viewed documents in their My Health Record. The key items viewed and increasing from baseline included the Consumer Entered Health Summary, Audit View, Diagnostic Imaging Report, Health Record Overview, Medicare Overview, Prescription Record View, and Prescription Dispensed View. The level of viewing of these documents between baseline and follow up increased more in the opt-out trial sites than in the rest of Australia, though these differences were low. Similar differences were seen in the opt-in trial sites compared to the rest of Australia, but these were lower than for the opt-out trial sites.

Healthcare Providers

There were additional healthcare provider organisations registered in all areas. These increases in registrations were consistent throughout the trial period, with only a few sudden increases due to bulk registrations of HPIOs. The majority of registered healthcare provider organisations in the My Health Record system were general practices. Pharmacies were the next most common. Both the opt-out and opt-in trial sites had a proportional gain greater than the rest of Australia.

The documents that significantly increased in volume in the opt-out trial sites between baseline and follow up (compared to the rest of Australia) included the Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Records. Similarly, documents increased significantly more in the opt-in trial sites compared to the rest of Australia.

Prescription Records and Dispense Records were the most regularly uploaded documents by healthcare provider organisations over both the baseline period and follow up period. These uploads occur with limited input from the healthcare provider as they mainly occur automatically once the My Health Record is attached to the localised software.

The increase in Shared Health Summary uploads is closely linked with the ePIP deadline. The increases were greater in the opt-out trial sites than the rest of Australia, and maintained a higher proportion following the ePIP deadline. The availability of My Health Records may have led to this prolonged increase and this may continue, though a longer follow up is needed to monitor for seasonal changes.

The number of MBS uploads associated with attendances examined increased between baseline and follow up. The proportional increases were greater in the opt-out trial sites compared to the rest of Australia. Of note, there were only minimal differences between opt-out and the rest of Australia in the percentage of MBS attendance items with a Shared Health Summary upload.

The level of accesses to documents increased dramatically during the trial evaluation period, with accesses in the opt-out trial areas increasing significantly more than the rest of Australia. There was an increase in the number of My Health Records accessed that had no clinical documents in them, with healthcare providers in opt-out and opt-in trial sites more likely than the rest of Australia to access My Health Records and upload the first clinical document. The level of accesses of documents also increased dramatically during the trial period for the opt-in trial sites, with accesses increasing significantly more than in the rest of Australia. As the level of accesses was increasing during the trial, the proportion of My Health Records viewed without a clinical document was likely to increase as well. This may change over time as more documents are uploaded to the My Health Record system, but the time frame for this evaluation was too short to examine this.

There were some types of documents that significantly increased in viewing activity between baseline and follow up, and these increased significantly more in the opt-out trial sites, compared to the rest of Australia, these included: Discharge Summary, Medicare Overview and documents created by other healthcare providers. However, healthcare providers in the opt-out trial sites were less likely to view Event Summaries than the rest of Australia. Similar trends were seen in the opt-in trial sites, but the document types were slightly different. Types of documents that were more likely to be viewed in the opt-in trial sites included Event Summary and Medicare Overview. Healthcare providers in the opt-in trial sites were less likely to view Shared Health Summaries than the rest of Australia.

Analysis of the National Infrastructure Operator data highlighted some interesting usage and participation differences from baseline and between opt-in and opt-out trial sites. The time from implementation to analysis makes long term predictions impossible, and some key variables should be monitored going forward.

Recommendations for future monitoring of activity

Shared Health Summaries are a key indicator for the Department. As part of the ePIP they play an important role in general practices. Given that there was only one PIP quarter in the evaluation period, it would be important to monitor both uploads and views of Shared Health Summaries continually, to establish if the increased upload is maintained in the trial sites, and whether this translates into increased views in the long term.

When more healthcare providers can upload radiology and pathology documents, these uploads should be monitored.

A key indicator of use is the healthcare provider's activity when an individual has an interaction with the healthcare provider. The proportion of MBS attendance items with an activity in the My Health Record system is a good measure of this type of use, and it would be beneficial to continue to monitor this measure.

Individuals are likely to view their My Health Record around the time of an attendance. For this reason, it would be important to monitor individual views about their attendances.

Appendix 4 Findings from the opt-out focus groups

Description of focus groups conducted

General population focus groups were held in the opt-out trial sites of Mackay, Townsville, and Cairns in the Northern Queensland (NQ) PHN, and in Katoomba, Springwood, Windsor, Penrith, and Werrington in the Nepean Blue Mountains (NBM) PHN.

Two groups were held with Aboriginal and Torres Strait Islander participants in remote and very remote settings: Mapoon in Cape York, and Thursday Island in the Torres Strait. These focus groups were co-facilitated by Apunipima staff in the case of Mapoon, and the Aboriginal and Torres Strait Islander liaison officer of the PHN in the case of the Torres Strait. People felt comfortable to speak up because they were encouraged and supported by people they knew, or who were well known in the community.

One Aboriginal focus group was held in the NBM PHN, co-facilitated by the Aboriginal Project Officer for that PHN.

A group with 15 participants was held in Townsville with recent migrants or refugees from Myanmar, Uganda, Democratic Republic of Congo, and Somalia. These groups were co-facilitated with interpreters for each language group present, ensuring understanding and cultural sensitivity.

Focus groups ranged in size from six to 15 participants. The total number of participants from all the above groups (general population, Aboriginal & Torres Strait Islander specific and culturally and linguistically diverse specific (CALD)) was 257. 140 participants attended focus groups held in NQ, and 117 attended focus groups held in NBM.

Demographics of the focus groups

The following analysis of demographic data (other than gender breakdown) is only for those participants who attended the general population focus groups recruited by the online research panel provider (106 in NQ, and 111 in NBM).¹⁵ During the screening process for drawing the sample, information about gender, age and income level was collected. The pie charts presented below show that, in the NQ focus groups, the gender balance was very like the general population in the region, while the NBM focus groups had a higher number of women than would be expected from population data. Data below compared to the general population for each region have been analysed against the Australian Bureau of Statistics 2011 *Census of Population and Housing* dataset for each region.

¹⁵ This data was not collected for Indigenous or CALD groups organised with the assistance of other agencies, with respect for cultural sensitivities.



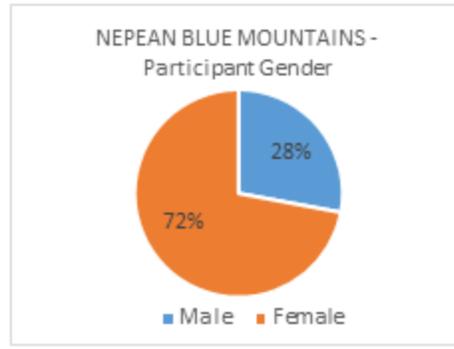
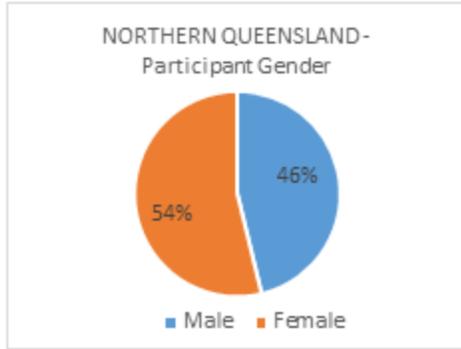


Figure 10: Northern Queensland Participant Gender.

Figure 11: Nepean Blue Mountains Participant Gender

The age distribution of participants was broadly similar to the general population in both PHN regions.

Table 26. Age bracket of participants (general population participants only)

Age Range	Northern Queensland	Nepean Blue Mountains	Total
18 – 34 years	27 (25%)	26 (23%)	53 (24%)
35 – 54 years	41 (39%)	52 (47%)	93 (43%)
55 – 64 years	17 (16%)	20 (18%)	37 (17%)
65+ years	21 (20%)	13 (12%)	34 (16%)
Total	106	111	217

Descriptive statistics

Participant Household Income

Participants were asked to indicate their household income. For NQ participants, the distribution of income levels was broadly similar to that of the Australian general population.

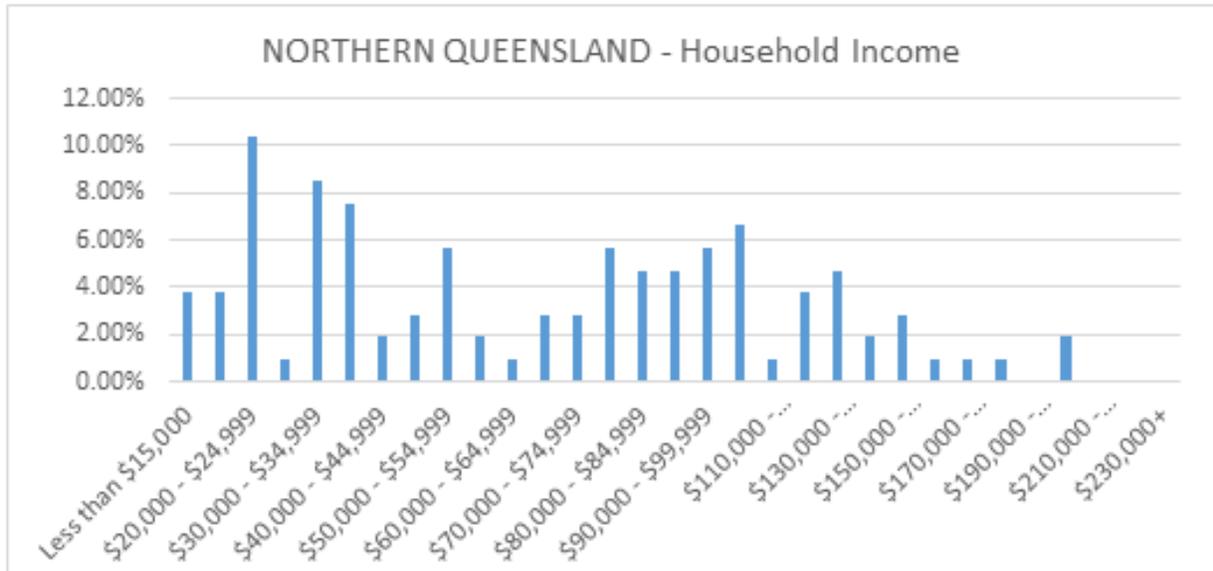


Figure 12: Household Income of Participants in Northern Queensland.

The distribution of income levels in NBM focus group participants broadly reflects that in the general population in that PHN region.

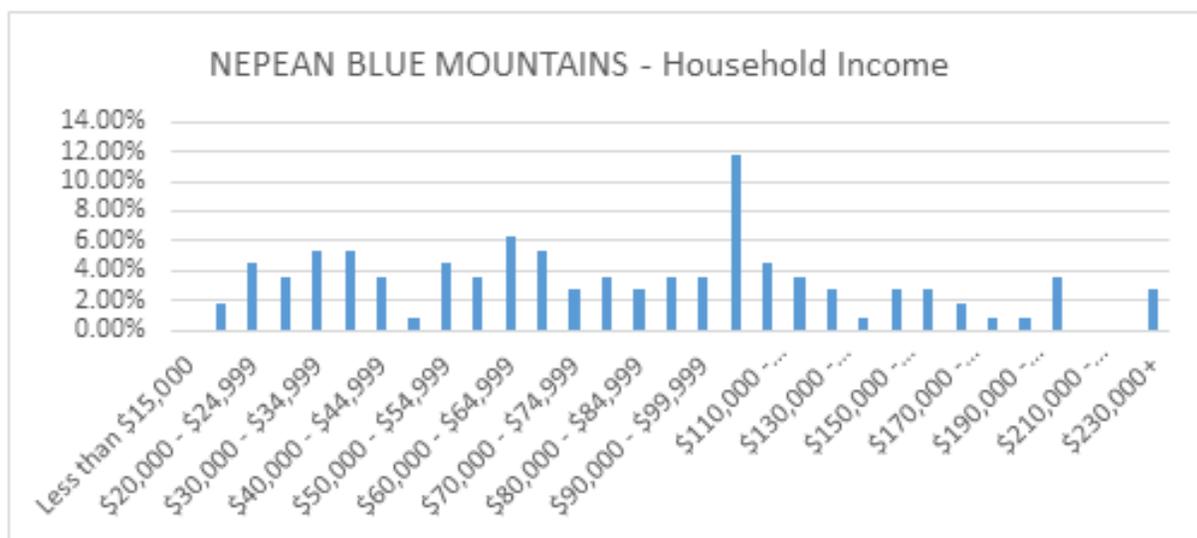


Figure 13: Household Income of Participants in Nepean Blue Mountains.

Participants' Nationality

In both the NQ and NBM focus groups, seven participants identified as being born overseas (see Table 2). The distribution of participants born overseas is approximately half that of the general population in both regions. To ensure adequate CALD participation in the evaluation, a CALD specific focus group was held in the NQ region.

Table 27. Participants born in Australia.

Region	Yes n (%)	No n (%)
Northern Queensland	99 (93%)	7 (7%)
Nepean Blue Mountains	104 (94%)	7 (6%)
Total	203 (94%)	14 (6%)

11 participants in the NQ focus groups said their parents were born in a country other than Australia. This was slightly fewer than in the NBM focus groups (n=20), as shown in Table 3. The proportion broadly reflects the general population in each region.

Table 28. Participants whose parents were born in Australia.

Region	Yes n (%)	No n (%)
Northern Queensland	95 (90%)	11 (10%)
Nepean Blue Mountains	91 (82%)	20 (18%)
Total	186 (86%)	31 (14%)

Identification as Aboriginal or Torres Strait Islander

The number of focus group participants who identified as being of Aboriginal or Torres Strait Islander descent was similar to the proportion in the general population in NBM PHN, but significantly lower in the NQ PHN (see Table 4). To ensure adequate participation in the evaluation, two Aboriginal and Torres Strait Islander specific focus groups were held in NQ and one in NBM.

Table 29. People who identify as Aboriginal and/or Torres Strait Islander descent in general population focus groups.

Region	Yes n (%)	No n (%)
Northern Queensland	5 (4.7%)	101 (95%)
Nepean Blue Mountains	3 (2.7%)	108 (97%)

Employment

A quarter of the participants in the NQ opt-out trial site, and a third in NBM, worked full-time (Table 5). Participants in both trial sites had a spread of employment status broadly similar to the general population in both locations.

Table 30. Number of participants by employment types.

Employment Type	Northern Queensland n (%)	Nepean Blue Mountain n (%)
Full-time	27 (25%)	37 (33%)
Part-time	15 (14%)	18 (16%)
Casual	8 (8%)	9 (8%)
Student - working casual/part-time	0 (0%)	2 (2%)
Unemployed	7 (7%)	3 (3%)
Home Duties	12 (11%)	18 (16%)
Pension	7 (7%)	4 (4%)
Student - working full time	1 (1%)	0 (0%)
Student - not working	4 (4%)	1 (1%)
Retired	20 (19%)	17 (15%)
Self Employed	5 (5%)	2 (2%)
Total	106	111

Location of participants in the PHN regions

The general population focus groups included only people from the cities where the groups were held or from locations within an hour's drive of those cities. This means, in the case of the NQ PHN, that people from rural areas further than one hour's drive away were not included for logistical and budgetary reasons. The findings may therefore overestimate the impact of communication and other engagement efforts during the trial, as it is safe to assume that those closest to the regional centres in the NQ PHN would be more likely to have timely mail services and access to community engagement activities.

In the case of NBM, its much smaller geographic footprint meant that recruiting participants from places up to one hour's drive from the venue represented good coverage of the region.

Demographic comparison between participants in focus groups and the population in the region

The evaluation team notes that all participants across both trial sites confirmed at the time of recruitment and again during the focus groups that they had lived in the trial area since February 2016, or before the start of the trial. The efforts to recruit a sample of people who were broadly representative of the general population in both PHN regions was largely successful, with the exception of the gender imbalance in the Nepean Blue Mountains area. The imbalance in both Aboriginal and Torres Strait Islander participants and in people from CALD backgrounds was expected, and was compensated for by adding the Aboriginal and Torres Strait Islander and CALD specific focus groups.



Accordingly, we are therefore confident that the views expressed in the focus groups, as a whole, provide a representative range of awareness, beliefs, understanding and intentions in relation to the My Health Record in the two trial sites.

Triangulation of data from these groups with the data from the larger population-based online surveys and the My Health Record System Operator data will provide the most solid and cross-validated evidence.

Overview of the focus groups findings

Questions asked during the focus group were those agreed in discussion with the Department in the evaluation framework, and later refined in consultation with the National Trials Team. Questions were first asked unprompted, and then later prompted by briefing participants about the nature and purpose of the My Health Record, or showing them the letter and brochure and then asking them to consider the questions again.

The answers to the questions are reported under the following headings:

- awareness and understanding of the My Health Record
- awareness of the benefits of the My Health Record
- awareness and understanding of the communication efforts during the trial about the My Health Record
- confidence in the confidentiality and security of the My Health Record system
- experience, participation in and use of the My Health Record
- enablers and barriers to individual use of the My Health Record
- individual views about what should happen next to improve understanding and use of the My Health Record

As there are no significant differences across the two opt-out trial sites and across CALD, Indigenous and remote Indigenous groups, we present the findings for all groups together, noting where necessary any differences that may have implications in the event of a decision to implement an opt-out approach.

Awareness and understanding of the My Health Record

Awareness of the My Health Record was low across all the locations where focus groups were held. Nearly all participants who attended the focus groups in NQ said that they were unaware of the My Health Record system, and they did not know about an opt-out trial taking place in their region. In NBM focus groups, participants also had a low level of awareness, with one or two people per group saying they had a PCEHR or a My Health Record. Participants were asked if they recalled receiving any form of communication from the Government about the My Health Record or the opt-out trials. Awareness of the communications from the Department or PHNs was also low for all focus groups, with two to three participants per group (an average group size was 12-13) in NQ recalling a letter about the My Health Record. Recall of receiving a letter was somewhat higher among NBM participants (about five per group).

“I don’t really know anything about it. The only thing I have seen is the image on myGov. I have never received a letter in the post” – Anonymous – Penrith

"I have never received a letter... My GP has never spoken about it. I have been to hospital a number of times for my husband and grandchildren, no one has ever spoken about it. I would need to know more about it. I feel weird about privacy and security" – Anonymous – Cairns

"I seem to recall a letter... I didn't see a problem with being on it so I didn't opt-out. I haven't accessed it or used it though..." – Anonymous – Mackay

"I got the letter a few months ago... I also remember receiving one for my husband and son, but not for my daughter. I have never said anything to my doctor about it. I looked at my record last night and there was nothing there. Reading the letter again, I did not realise that you had to ask. My husband said 'I don't want big brother knowing more than what they already know' – Anonymous – Windsor

In the remote settings of Mapoon and Thursday Island, awareness of the My Health Record and the opt-out trials was nil. All these participants advised that they were unaware of the My Health Record and its purpose. While there were some participants in the group who (prompted and unprompted) said they had received a letter, they all said they did not understand it and therefore took no notice of its content. All the participants said no healthcare providers in the region had discussed the My Health Record or the trial activities with them.

In the NBM Indigenous specific focus group, none of the participants recalled receiving a letter. One of them said he was illiterate. Most were aware of the My Health Record, and had been made aware by health or welfare professionals (either Indigenous support staff of the PHN, or staff from a local Aboriginal community centre) in face to face settings.

"Yeah I remember getting a letter or something but I didn't read it or pay attention to what it says" – Anonymous – Mapoon

"I haven't heard about this My Health thing. Who created the record and who can look at it? My doctor hasn't said nothing to me about it" – Anonymous – Mapoon

The focus group held in NQ with participants from CALD backgrounds (Myanmar, Uganda, Democratic Republic of Congo and Somalia) found that all 13 participants were aware of the My Health Record and understood its functionality and purpose. This level of awareness was not due to the letter and brochure mailed out. 10 participants remembered receiving the letter; three did not remember receiving the letter or brochure, but those who did receive it could not read it owing to language barriers. The reason for the high level of awareness in this group, as reported by participants, was the significant local and face to face efforts by the NQ PHN in organising intense briefings to members of these communities, and co-facilitating briefing with a local settlement service. The sessions focused on informing them of the features and benefits of the My Health Record and explaining how to use it. Participants described these sessions as highly valued because they were translated into their first language. When asked, many of these participants stated that, as a result of these briefing sessions, they had gone on to educate friends and relatives in their language group, noting varying levels of success.

"I attended a face to face information session. It told me about the My Health Record, it was very good I think it's a great idea" – Anonymous – Townsville



“My Health Record is online, it keeps your medical information, the [healthcare] providers’ care will be much better, sometimes you can forget your medication... it can help you easily get your medication...” - Anonymous - Townsville

Comments from those who did receive the letter and brochure (and for whom English was their first language) suggested that the letter left people with a variety of unintended messages. These included:

- ‘You are getting a My Health Record, but not now - sometime in the future.’ This left some people thinking ‘Well, I will wait till I get the next letter telling me I have a My Health Record.’
- ‘I don’t have to do anything the doctor will do it.’
- ‘My entire lifetime record will somehow be migrated to the new record’
- ‘I do not need to do anything,’ believing the My Health Record system would begin to automatically populate the My Health Record for them without having to speak with their healthcare provider or log-in to myGov to verify their identity, set permissions and link their account
- A number of participants who said they had received the letter said that the content of the letter set an expectation that they would be receiving follow up communications, in the form of another letter or targeted advertising such as TV commercials to advise them on the next steps to take, to activate or use the My Health Record.

Only four of 114 participants from the NBM focus groups reported following the instructions in the letter about ‘What do I need to do?’ (i.e. went to their GP and asked him/her to assist them to set privacy settings or upload advanced directives).

“I remember hearing about it through a TV campaign, between 9 and 12 months ago and I believe we got some correspondence through the mail about 5 months ago... I have not opted out” - Anonymous - Townsville

“I remember seeing in the brochure or a letter - that as you control it you can delete things you don’t want to be on there. So I just wondered then how helpful that would be, say, in the case of mental illness or double dipping stuff... If people can manipulate it anyway. I know there are privacy issues as it is your personal information” - Anonymous – Springwood

“I first heard about it in the neurology clinic, saw it as a poster. I thought it was something for only the doctors so they could share information... When the invite to participate in this research came through I jumped on to myGov to see what it was about and I couldn’t see any information so just left it. I didn’t realise it was something we could access” - Anonymous – Cairns

“Having the poster on the wall doesn’t necessarily mean that people are saying anything to you” - Anonymous – Penrith

I have seen a poster and received two letters in the mail. I have not gone on and used it or tried to as I was not sure what it was or if it would be confusing. I think it would be better if the GP’s advertised it more and made people aware of it” - Anonymous - Windsor

“I found it by accident on the myGov website. It was an option and reading it I thought it was a great idea to have records that all doctors could assess. I put in a few details but did not get



past that point. There was something in it that was a little confusing and I was unsure of, so I stopped” - Anonymous – Mackay

The majority of participants believed that healthcare providers shared records with each other by linked electronic methods, similar to that of the My Health Record. They expressed the view that they would not have registered for a My Health Record themselves and would have expected that their healthcare providers already would be sharing information with other healthcare providers in this way.

In both NQ and NBM nearly all participants who had visited a healthcare provider within the last six months stated that their healthcare providers had not discussed the My Health Record or the trial activities with them. Those whose healthcare providers did discuss the My Health Record with them, or who had initiated discussion about it themselves, were more often people who were chronically ill or had chronically ill dependents (elderly or children). Only a small number of participants approached their GP about the My Health Record, and most of these people stated that their doctor actively discouraged the use of it, refused to use it, or expressed scepticism about it.

Most participants from all cohorts (Aboriginal and Torres Strait Islander, CALD and general population) who were either aware or unaware of the My Health Record and its purpose believed that all healthcare providers, especially general practitioners, should have to use the My Health Record system in order for it to be beneficial to the public. Participants in NQ had difficulty in understanding why healthcare providers were not required by law to use the My Health Record. Participants also had difficulty in understanding why some healthcare providers would object to using the My Health Record system when the benefits to their patients are so clear. In NBM, people also felt that the My Health Record system would not work unless most healthcare providers used it. People also wondered why the Government had not acted to make it compulsory for healthcare providers to use it, as it was clearly costing taxpayers a lot of money to set it up and maintain it. There were three attitudes commonly expressed:

- either that it should be mandatory for all healthcare providers in all settings to use it
- that healthcare providers should have incentives to use it, or
- that it should be mandatory *and* incentives should be paid.

Perceived benefits of the My Health Record

As awareness and understanding levels were so low across all focus groups, the facilitators spent time explaining the design, scope and purpose of the My Health Record system and its implementation at the national and trial site levels. Once people understood the My Health Record, most people expressed only positive views about it. The exception was the small number of people, in both opt-out trial sites, who had lingering privacy and security concerns, or strong objections on philosophical grounds about the creation of a My Health Record without consent, or concerns about Government intrusion. All these people had opted-out.

Those who were positive about the My Health Record and its use by healthcare providers and individuals easily described the benefits of using the My Health Record without further prompting. Common benefits suggested by participants across both regions were:

- continuity of care for patients
- the My Health Record following the person wherever they go in the country



- decreasing the number of unnecessary tests
- reduction in time going to and interacting with healthcare providers
- potential reduction in out of pocket expenses for unnecessary consultations with healthcare providers
- a resource for an emergency presentation at hospitals
- a resource for recording allergies and medications
- a resource which would assist healthcare providers in reducing errors in clinical decisions
- a resource that allows you to make clear your decisions about end of life care and those wishes are available across the health system
- an aid to assist memory for people with multiple healthcare providers due to chronic illness
- an aid to assist all treating healthcare providers to know who is recommending what and prescribing what, what has been tried in the past and to what effect
- reduce the risk of adverse drug interactions

“I think it’s a great idea and would be excellent if all doctors used it around the country. I travel a lot and it would be perfect for me to be able to walk in to any clinic and have my information there ready to go” - Anonymous – Cairns

“You wouldn’t have to repeat yourself every time you saw a different doctor. You know, often you can’t get in to see your normal one so you may go somewhere else and you have to remember everything... I think it’s a really good idea. Just have to make sure its secure” - Anonymous – Townsville

*“Can you put your kids on there? It would be good for immunisations and allergies and that...”
Anonymous – Penrith*

“I think it’s a great idea and I am going to sign up. I had surgery last year and you have to put on all your surgeries and you can’t remember and for the hospital to just be able to go ‘click’ and to have it all there without having to have you there” – Anonymous – Springwood

“Don’t the doctors already do this? Seems rather silly that they wouldn’t be able to or don’t, it’s 2016” – Anonymous – Mackay

“I think all doctors should be required to use the system. It should be mandatory for them to use it and tell people about it. That’s the only way it will work...” – Anonymous – Cairns

Confidence in confidentiality and security of the My Health Record system

Most participants were positive about the Government’s ability to keep their information confidential. Many participants said they could not see how the information contained in the My Health Record could or would be used against them by the Government or other third parties. Some participants raised concerns that insurance companies or employers might gain access to their My Health Record, and it could potentially increase personal insurance premiums, or prevent them from gaining a particular type of employment.

When asked specifically about cyber security threats and hackers, the sentiment of most participants from both NQ and NBM regions was that all online databases and systems were prone to cyber security threats. They felt that the My Health Record was no different and that other online sources already



contain personal information like banking, retailers, and social media platforms. One or two participants in each group in both regions raised concerns about recent media reports on the 'dark web' and the sale of personal information, or the Census problems – issues of concern for some, but not most, participants in each region.

Although most participants in each region had not opted out of the My Health Record system, the small number of participants had actively opted out of the My Health Record, primarily citing security, confidentiality and distrust in the Government having access to their personal information as their main reasons.

Security and access concerns were raised in all groups, but after debate and discussion among participants, the consensus was that security was not a major concern, and the overall benefits outweighed the risks. The confidentiality of personal My Health Records was not seen as a major concern. A few participants remained concerned about security even after the facilitators explained the functionality of the My Health Record's privacy settings. There was total support for the concept of receiving alerts when healthcare providers were accessing their My Health Record, and being able to view an activity log of who had accessed their My Health Record.

"I think the benefits far outweigh the minute risk that someone may get your information. The benefits for not only us but for future generations. As you [a fellow participant] say, a new born baby will automatically be linked to the [My Health Record] system, basically, from birth to death. And for us, that are getting on a little bit now, who knows what is going to happen to us in the future with our health, dementia etc. etc. You go to one doctor and bang! Everything is online and you don't have to remember as much... So it is a great benefit, I feel" – Anonymous - Penrith

"People talk about the identity theft thing and I guess when I think about that I think, oh yeah that would not be nice. But... I am reasonably young so my whole life has been online. So I think, I know that my mum and my grandmother they have a lot of, 'oh I don't want to do my banking online as it's not safe', where I have only ever done my banking online. And so I don't think I have the same kind of security concerns as everybody else" – Anonymous - Windsor

"It is also going to be a target as all of the information is in one place. It is not a matter of hacking 100 thousand different doctors around the country. It is all there in one place which makes it a target... Perhaps we are all fortunate enough not to have issues in our medical records that might be embarrassing but what about, I don't know, someone might have had mental health issues or they might be in a position of power or a position of authority and don't want that information coming out" – Anonymous - Penrith

"I am a little less confident. Couldn't an insurance company just hire a doctor and get them to look through your record" – Anonymous - Mackay

"I am one person out of the 25 million, it's no different to internet banking. Anything online is not overly secure to cyber threats" – Anonymous - Townsville

"My background is IT and I believe that the strictness... security level for myGov is there and like you said if you need the phone and access to the phone to get the pin and it tells you if there has



been unauthorised access you will get a message. So general users like us, I do not think we should be worried” – Anonymous - Windsor

Concerns about confidentiality and security were expressed more often in the focus group in Mapoon. Many of the participants in this remote NQ community said they were wary of the My Health Record as another Government initiative to keep a watchful eye on their community. There were questions and apprehensions raised about exactly what type of information the My Health Record contained, and what level of detail those who did access it could view. They were wary about their family members or people other than registered healthcare providers having access to it. This was highlighted further in cases where a diagnosis of a mental health issue or sexual health related diseases might be present in the My Health Record. Questions and concerns were also raised by this group regarding law enforcement agencies having access to the My Health Record system. After clarifying that, as a personally-controlled record, they could set their own privacy settings and also access alerts and logs that detailed which healthcare providers had recently accessed the My Health Record, half the participants were satisfied with the level of security and ability of the My Health Record to keep their information confidential, while the other half remained skeptical.

“I don’t want my family being able to see My Health Record... who can see this information and access it?” – Anonymous Mapoon

“It’s no good if others can access the information... what about sexual health and mental health and that? ... I don’t want to share that information with no one” – Anonymous Mapoon

Use of the My Health Record

Only a very small number of participants in the focus groups in both NQ and NBM had used their My Health Record. The general sentiment from these users was positive. They praised the functionality and user friendliness of the My Health Record system, its usefulness when visiting healthcare providers and sharing information amongst them, as well as using their My Health Records’ as a tool to monitor their personal health, especially their medications. One participant from the CALD group said they were a user of the My Health Record system, and had proactively encouraged their child’s GP to view the My Health Record on an occasion when the child was ill. The GP was surprised at the usefulness of the My Health Record and it assisted in providing the child with the appropriate treatment.

“This woman said, she was at the GP, it was hard to access information for her son... the GP went straight to file and found information there... the GP she was seeing said ‘wow I found a lot of information here’... This is positive because the information that they had there helped with treating her son quickly”

– Anonymous - Townsville

“I have used the My Health Record, it’s pretty straight forward... you log-in by myGov and you can look at what your doctor has put in there about you... you can also make notes on yourself too... I like it, it works well for me” – Anonymous - Cairns

Of those who had visited a healthcare provider in the regions within the last six months, most said their healthcare provider had not mentioned or discussed the My Health Record with them. Further discussions around this point highlighted that most, if not all, participants believed that healthcare providers would already be using the My Health Record system, particularly if they were aware of the trials, and that all their patients would have a My Health Record unless they had opted-out. Most thought that they would



not need to prompt their healthcare provider to have their information uploaded to the My Health Record and thought it would be part of standard practice.

In discussing the kind of information the My Health Record contained, a number of participants in both regions made suggestions about the level of detail presented to the individual to make their experience more satisfying and relevant to their level of health literacy. The information in the My Health Record should be in plain English so that users could tell whether they were 'okay' or not, and whether or not they needed to go back to their healthcare provider. This should be the case for routine tests such as blood tests or general health checks.

As previously noted, given the low levels of awareness and understanding about the My Health Record, part of the focus groups in each region routinely became an 'information session' giving an overview of how the My Health Record works, and answering questions about its functionality and use in the health sector. All focus group participants (other than those who said they had actively opted out or intended to opt out) said the information they received in the focus group was extremely useful. Most participants said the focus group had encouraged them to look at the My Health Record system or seek further information about it. We note that this was not the original intention of the focus groups, but people with low awareness received more information and listened to the discussion. Many voiced their intention to prompt their GP about the My Health Record and have them start using it for their personal health.

“When the market research [company] called me I was like, oh yeah, I wonder if I can access that. So I logged in the other day and had a look to see what is actually in there and to see if it was set up properly. It had some of my past prescriptions dating back a couple of years and little bits and pieces and then there was a lot of blank stuff. I was a bit confused. I was not sure if I was meant to be telling the doctors that they need to update it. But I think it’s a good idea. I think it’s handy, as you don’t always see the same doctor and it’s nice if they have access to what [meds] you have been on prior and they can see your medical history and you can upload data with allergies and any information you want. So it seems good” – Anonymous - Windsor

“After this I will definitely be speaking with my doctor to check they are using the [My Health Record] system and get them to upload my records to it” – Anonymous - Mackay

“This session has been great; this is the type of information the public needs to understand what it is all about. They should do more things like this so people and doctors use the [My Health Record] system” – Anonymous - Cairns

Enablers and barriers to individual use of the My Health Record

The most commonly reported barrier to use of the My Health Record was having to access it via the myGov portal. Experiences with the myGov portal were mixed. A majority of those who had used the myGov portal to access other federal Government services such as Centrelink and the Australian Tax Office said the site was unresponsive, too complicated to navigate, and had an extremely difficult and arduous log-in process with complex usernames and passwords to remember. myGov therefore had a poor reputation with users and was a deterrent to attempting to access their My Health Record. Some others who had used myGov said they had not experienced these problems. While there were differences in opinion about myGov and the need to access the My Health Record via this portal, most



participants believed that, for people to be aware of, understand and use their My Health Record, improvements to the functionality and user friendliness of the myGov website needed to be a priority.

“myGov is clunky and pretty unresponsive. Every time I have tried to log on I have had issues. The password is so hard to remember and the username too, all letters and numbers... I have tried a few times but just end up getting mad and give up...” – Anonymous - Mackay

“I have had so much trouble with my log-in and passwords for myGov, I always lose it as it’s hard to remember and then they text you a code and all that... just so time consuming” – Anonymous - Townsville

People who had actively tried to use the My Health Record reported that, once accessed, the usability of the My Health Record itself was good. Only a few reported calling the 1800 number for assistance, but when they did the staff member was unable to answer their question satisfactorily.

There was concern among participants that some members of the community would not be able to access the My Health Record owing to their low levels of computer literacy, or limited access to a computer or the internet. This was echoed by participants in the remote community settings of Thursday Island and Mapoon. While many had smart phones, the connectivity by mobile networks or internet in the Cape York region was extremely unreliable. Very few of these participants reported having access to computers or knowing how to operate them.

The Indigenous participants in NBM did not report problems with connectivity or computer literacy – their issues were solely with accessing the myGov website. They stated that the biggest barrier to using the My Health Record was they could not see where it noted that they were registered with the Closing the Gap – PBS Co-Payment Measure¹⁶. Participants in this focus group suggested that there would be little incentive for them to use the My Health Record or ask their healthcare provider to do so if it was not linked in some way to the records of the Practice Incentives Program as it related to Closing the Gap.

“Most elderly people don’t have a computer or a smart phone... and if they do they can’t really use them well. I think this would be a hard system for them to access” – Anonymous - Springwood

“We don’t have good connections around here... it’s very on and off, if it’s bad weather you won’t get signal... mobile reception is hard to get sometimes” – Anonymous, Mapoon

“Wouldn’t you think it’s up to the Doctor to assist the elderly. I live in units with a number of elderly people and the letter would go in the bin as they didn’t understand it. 9/10 elderly people don’t even have a mobile” – Anonymous - Springwood

Some participants were concerned that requiring their healthcare provider to upload information to their My Health Record could have financial implications. Several participants in Mackay and NBM said there was little to no bulk billing available. They were therefore reluctant to ask healthcare providers for

¹⁶ To receive the benefits of this measure, Indigenous patients need to be registered and their prescribers need to be participating in the Indigenous Health Incentive under the Practice Incentives Program or be working in the Indigenous Health Service in rural or urban settings, or be medical specialists practicing in any settings who received a referral from a participating General Practitioner.



help to use their My Health Record because they were mindful of the time they spent with their doctors and needed to avoid the out of pocket expense of long consultations.

“There is very little choice in Mackay for doctors... especially bulk billed - pretty much non-existent. It’s a good idea but not if it’s going to cost me more at the counter of the doctors [surgery]” – Anonymous - Mackay

*“I would use it so long as it’s a free service and the doctors don’t ping me for extra time spent in their office”
– Anonymous - Cairns*

In both regions, participants commonly and strongly suggested that the greatest enabler to use the My Health Record would be information, education and promotion provided to them by their healthcare providers, in particular their general practitioner, or staff associated with the practice they attended. Most participants in all groups (apart from those who had actively opted-out), said that if GP practice staff conveyed messages about the features and benefits of the My Health Record and its use to them, they would be most likely to listen to this trusted source and seek to engage with the My Health Record system. This was also discussed and similarly reflected in the Aboriginal and Torres Strait Islander groups (NBM and NQ) and in the CALD specific group. These groups said their healthcare provider would be the person best placed to help them understand and use the My Health Record. Community elders and leaders were also suggested as people who could encourage and enable use of the My Health Record system. Another common, trusted (and convenient) source for information about the My Health Record was reportedly the local pharmacist - because people went to the pharmacy more often than the GP, relied on them for advice, and also went there when they were not sick.

Asked about their intentions to change healthcare providers if their present healthcare provider refused to use the My Health Record, participants gave mixed responses in both regions. About a quarter of all respondents thought they would change healthcare providers if they did not use the My Health Record system. Others would not change either because of good relationships and trust with their current healthcare provider, or due to lack of choice in rural, regional or remote settings. Participants in Mackay felt they could not be assertive about the use of their My Health Record or shop around, because they had little choice of healthcare providers.

Individual views about what should happen next to improve understanding and use of the My Health Record

Participants were asked what the Government could do better to assist them and their healthcare providers to understand, use, promote and communicate the My Health Record, both at a local and national level.

Apart from the small group of participants who had actively opted out of the My Health Record or intended to do so, the participants agreed and accepted that the My Health Record was a work-in-progress and the ultimate purpose and goal was laudable for both individuals and healthcare providers.

One of the most consistent lessons across both opt-out trial sites was that the initial communication with individuals in both regions - a letter sent via the post with a brochure attached - was ineffective in creating awareness and understanding of the My Health Record. As noted above, awareness, understanding and use of the My Health Record system was extremely low across both regions.



Participants who had received the letter and read it said the content of the letter did not provide enough information, or it was poorly worded, creating mixed and unintended messages.

The communication activities undertaken about the My Health Record were consistently criticised, especially the wording, content and 'one off' nature of the letter. Suggestions for how best to reach people like them were heavily focused on the need for face to face communication by trusted healthcare providers. The most frequent suggestions were these:

- face to face communication by doctors, practice staff and hospital staff
- face to face communication by pharmacist, as people go there more often than to the doctors, and not when they are sick
- face to face communication by community leaders in culturally and linguistically diverse communities and Aboriginal and Torres Strait Island communities
- the use of existing publicly funded days and places – e.g. Centrelink, Medicare mobile offices, public hospitals (but with adequately trained staff)
- targeted educational multi-media approaches including television commercials, YouTube, Facebook and other online advertising mediums
- prompts and reminders when you are on Government websites
- advertisements by print and broadcast mediums which feature trustworthy and credible sources, such as prominent healthcare providers, Indigenous footballer heroes, known figures credible in various age and geographic and demographic target groups
- avoiding using politicians to make sure people understand it's a health benefit not a political benefit that is being sought by the Government
- consider the use of email rather than post or with post as most people have emails and they are listed with Medicare

“Advertisements should be run which say things like, ‘you will soon get a letter, and it is important for you to read and act on it’ or ‘Make sure your address with Medicare is up to date’ – this will make sure people actually pay attention and do something about it” – Anonymous - Townsville

“It needs to be a demographic rollout. What you just said is great for people who go and see their GP. But for, and I am really stereotypical here.... but for your younger generation if it is not on Facebook or Instagram they will not even know it exists. Make it a Pokémon game...so it really needs to be targeted at the different ages groups” – Anonymous - Penrith

“See that letter there, we did a lot of behavioural economics at the ATO and a lot of other revenue agencies do that, and it is about, (holds up letter) a letter like that means absolutely nothing because it is just a whole heap of paragraphs. There is nothing there. There are no attention getters and that is what you need to have so you need to research about what makes people tick to get them to pick up the key points” – Anonymous - Penrith

In both regions where Aboriginal and Torres Strait Islander specific focus groups took place, participants had no recollection of receiving or seeing any informational materials at all or any culturally appropriate posters and pamphlets or youtube clips or TV ads. There was strong agreement in these groups that communications for their community should be very localised and relevant to their specific community and population and that there needed to be on-the-ground engagement with people locally in their development.



*“They need to make things which speak to our Mob, not just letters for everyone” – Anonymous
– Mapoon*

*“Having like the elders and that know about it so they can tell the kids and family and tell them
to go see their GP and ask about it would be a good thing” – Anonymous – Mapoon*

Participants strongly recommended that all communication activities should look to highlight and sell the features and benefits of the My Health Record, detailing how it is beneficial to the individual and healthcare providers. Participants felt that there should be big public education efforts as well as more localised efforts. The theory of ‘pester power’ does not appear to be playing out in practice because of: the low awareness of the My Health Record; expectations that healthcare providers would be doing it because it is a good thing to do; or reluctance to request or instruct a healthcare provider to set up a My Health Record (for a range of reasons). People suggested that the essence of that campaign should be: ‘soon you will have a My Health Record and receive information in the mail or by email and so on, please make sure you read the information. The choices you make about the My Health Record could have important implications for the health care you receive wherever in Australia you go.’

A frequent suggestion was to provide some form of follow up communication to the initial letter. Many of those who recalled receiving the letter in the opt-out regions said they were expecting some form of follow up communication - either by letter or e-mail - to advise them their My Health Record was now active and usable. Participants said this would be beneficial to act as a prompt and increase participation and use of the My Health Record.

Others who had unsuccessfully attempted to set up a My Health Record said that real-time follow up (e.g. live chat) or online follow up reminders would have prevented them from abandoning it.

*“There should be some sort of follow up letter or advertisement or something letter you know
your record is ready to use and to push you to do it” – Anonymous - Townsville*

*“I thought they would tell me more information after receiving the first letter... that one didn’t
have much in it” – Anonymous - Cairns*

*“If people read the pamphlet there would be information on there but it is probably more a case
how the information is delivered” – Anonymous - Springwood*

Overall participants were very positive about the My Health Record and its purpose once they understood it.

*“Sitting around doing what we have done tonight has been great, getting a lot more input, so I
will certainly be asking the doctor next week if he’s using it” – Anonymous - Springwood*

*“It is pretty good though, overall, the whole thing, it sounds pretty good. It sounds like it is a
step forward” – Anonymous - Townsville*

*“I can see all of the benefit of it and, you know, it would be great even for my family as I have
two special needs brothers and every time we have an emergency and we have to go to an
after-hours doctor and we have to tell them every single thing they can’t have, they don’t like...
It would be great for them. I think for my demographic [young adult] we probably wouldn’t do*



it. Just because it is just another thing that we just have just for the sake of having it” – Anonymous - Penrith

“I have not gone on and used it or tried to use it as I was not sure if it was one of those things that you need - all sorts of different information to link together or whether it would be a straightforward process or confusing like somethings are that you join online. But I think it would be better if you did advertise it a bit more and make people more aware of it. Because it seems that not many people know about it or how to use it or what to do because we are not sure how to get the information on there” – Anonymous - Penrith

Findings from the focus groups in the opt-in trial sites

Description of focus groups conducted

Focus groups were held at one location in Ballarat (Ballarat Hospital) and two locations in Western Australia (Morely and Perth CBD). The focus groups in Ballarat were from 3rd to 5th October 2016, and in Western Australia (WA) from 10th to 13th October 2016. Eight focus groups were held in the Ballarat trial site, and 10 focus groups in WA. In both locations, the participants were from the target population of the opt-in trials - both people who had accepted and declined the assisted registration process in their respective settings were invited. The focus groups ranged in size from two to 15 participants, and the total from all groups was 134. Two of the WA focus groups were booked and organised, but no-one attended on the day, probably because the target group were chronically ill individuals, mostly from elderly age groups.

There were 101 participants in the Ballarat focus groups, and 33 participants in the WA focus groups. The low participation rate in WA resulted from low numbers of patients who had agreed to be contacted to take part. Siggins Miller had access to the contact details of 73 patients who had previously agreed to be contacted to register participation in a focus group in WA, but of these 73, 18 declined to participate when contacted again, 10 could not be contacted by phone or email on several occasions in the lead up to the consultation period. Of the 45 who agreed, 12 did not attend on the day, or contacted Siggins Miller to advise they could not attend owing to medical appointments or illness.

Demographics of the focus groups

Owing to privacy legislation and the methods used to recruit focus group participants, minimal identifying information could be collected on demographics such as age, household income, nationality etc. Accordingly, the evaluation can report only the gender of participants in each location. The gender of focus group participants from Ballarat is presented in Figure 5 and Western Australia in Figure 6.

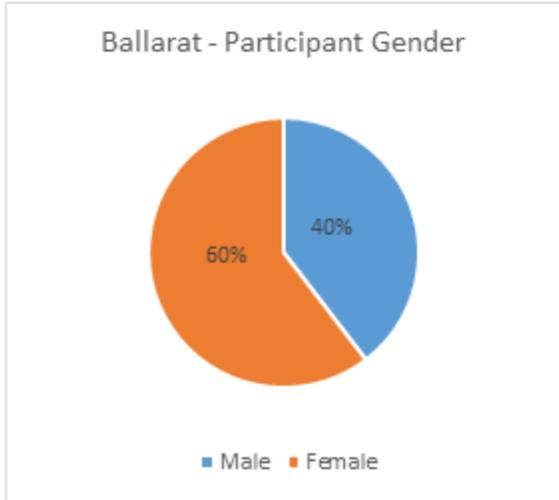


Figure 14: Ballarat Participant Gender.

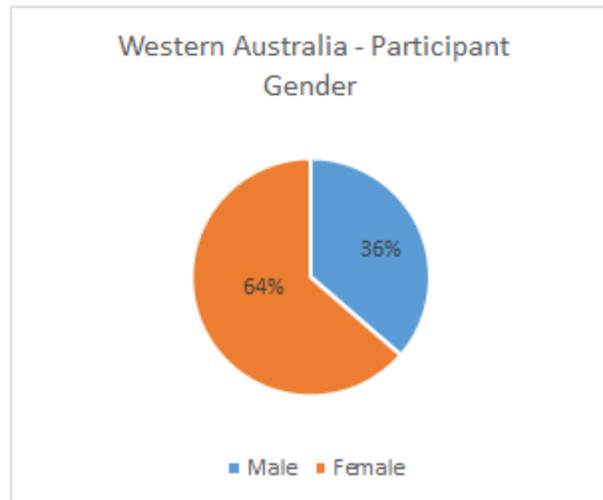


Figure 15: Western Australia Participant Gender.

Overview of the focus groups findings

Awareness and understanding of the My Health Record

The majority of participants from both opt-in trial sites - Ballarat Hospital and participating cdmNet practices in WA - had not heard about the My Health Record or the Personally Controlled Electronic Health Record before they were offered assisted registration in their respective trial settings. Only a very small number of participants recalled hearing of an electronic health record before being offered assisted registration, and these people said that their recollection and understanding of it was vague.

“About a month ago I signed up. I thought once I signed up then any doctors would be able to know exactly what was going on with me. I am going to sign my wife up... I didn’t know that I could look at my record”

– Anonymous - Ballarat

“The receptionist signed me up for ‘My Health’ and I haven’t heard anything about it since... I was more interested in getting in to see my doctor... I do remember her asking about signing up for ‘My Health’ – they didn’t give me any information. I picked up a pamphlet a few weeks back but I didn’t really read it, it was about ‘My Health’ though”

– Anonymous - Western Australia

“I filled out a form in the consulting appointment. I thought it was a very good idea and have never heard of it before”

– Anonymous - Ballarat

“I was on a care plan for one year – I saw a different doctor and he asked ‘Did I mind if I did this thing’ I said not at all if it does good things for my health... I am talking about the care plan, though - I didn’t know about the My Health Record part”

– Anonymous - Western Australia

Where did it come from? How come I am only hearing about it now? Shouldn’t the doctor’s surgery be saying... you know, or like a sign or something? If it’s been around for that long? Why haven’t I heard about it?”

– Anonymous - Western Australia

Participants from both opt-in trial areas presented views and anecdotes which reflect varying levels of understanding and awareness of the My Health Record post-contact with staff members who offered



them assisted registration. Most of these participants agreed that the process of assisted registration made them aware that a record/system existed and convinced them that it was a useful adjunct to a health plan or pre/post hospital admission. However, this was as far as their awareness and understanding of the My Health Record and its purpose went. Most participants reported seeing little to no information about the My Health Record before being approached about opting in to the My Health Record system.

The information presented to individuals and the approach from staff varied between trial sites. In Ballarat, almost everyone recalled seeing the sign-up form and brochure about the My Health Record. For many, this was accompanied by a verbal explanation. Others reported only being offered the paperwork. In the hospital setting, there was variation in the amount of personal explanation, depending on the location where they were approached (e.g. Emergency versus a day clinic versus a private ward). The next step (receiving a confirmation message - email or text - with their log-in details) was variously reported by participants in Ballarat. Many did not recall receiving any follow up after assisted registration. Others did receive a follow up, but had not yet acted (to log in). A minority (one-three) in each group had received a confirmation, logged in and set up their personal access.

In WA, many participants reported only verbal communication from staff about assisted registration and the My Health Record system. Others did note they were provided with some marketing material and information sheets about the assisted registration process including access codes and log-in instructions. There was a small number of participants, particularly in the WA site who said that even after the assisted registration process they were still not aware of the My Health Record system and its purpose, nor whether they had a My Health Record or not. A small number of participants noticed additional marketing or communication materials such as posters and brochures in both practice and hospital settings. Many in WA reported receiving no take home information or detail after being offered the assisted registration process.

“I had an appointment... and people were handing out the forms, though I was not sure what I was filling in and since then I got an email. And when I checked it, it said it had a code and when I looked at this the code had expired so I have not gone any further. My husband has medical problems so I think it’s a good idea”
– Anonymous - Ballarat

“I was introduced to it at my GP by a nurse that was handing things out – she asked if I would be involved in it – I put my hand up, unfortunately she didn’t give me any details on what it was about. I can’t recall how I took the next step ... When I first went to log on to the site I found it a nightmare... I had a pre-existing myGov, I would’ve done that 6 weeks ago... When I got in it was a bit of a jungle to get through – anyway there was nothing in there. I just assumed there was going to be stuff in there... I need to find out how I can get stuff in there, like ask my doctor or something... the nurse who signed me up didn’t give me much information at all... She was very vague about the entire process... Obviously, she got my attention anyway... something must have been exchanged because I took an interest but I didn’t walk out with any paper work”
– Anonymous - Western Australia

“I came to the hospital and they did not have a lot of information and I was waiting for more information. I filled out the form and got the response with the log-in number and that is where I stopped. I did not know you had to go on further with the record set up” – Anonymous - Ballarat



“I was approached by my GP and your records are put on a register so any practitioner can access them... I think it’s fabulous... I remember a few years ago they were going to do something similar but that didn’t take off... I think it’s really good for managing chronic disease”
– Anonymous - Western Australia

In terms of the key things which made participants decide to have a My Health Record or not, for most of them it was that, on the face of it, a record that travelled with them made sense, given that those in the WA trial site had been diagnosed with chronic conditions and often had to visit several healthcare providers.

The same key feature – ‘portability and accessibility’ of the My Health Record was important to Ballarat participants, most of whom had chronic diseases or serious illnesses that were often likely to involve treatment from multiple healthcare providers.

Confidence in confidentiality and security of the My Health Record system

Confidence in the My Health Record and its security was discussed by participants in the same way as focus groups in the opt-out trial sites. Participants reflected that nothing online was 100% safe from external threats and they believed that the benefits of having a My Health Record far outweighed the risk of their health information being compromised or accessed by hackers or third-parties. Many participants said that they could not see how their My Health Record would contain information which would be useful or valuable to anyone else.

“If they hack into the [My Health Record] system what would they be looking for anyway? Like what can the health information give them?” – Anonymous - Western Australia

“The big brother knows everything already. There are security concerns but they are not large enough not to use the My Health Record” – Anonymous - Ballarat

“I don’t really care; I am a diabetic but I don’t care if people know that – in terms of the Government keeping it safe I think they would be doing their best efforts but you know you can’t be 100% on it” – Anonymous - Western Australia

“I didn’t know you could set privacy settings so that certain [healthcare] providers couldn’t have access to different types of information... this should be communicated to people” – Anonymous - Ballarat

The great majority of participants said that little or no information about the personally controlled aspects of the My Health Record was provided to them at the point of assisted registration. In particular, in the focus group discussions, people were positive about the ability to set privacy settings such as authorising who could access and view the information in their My Health Record, or setting up alerts that notified the individual when someone had accessed, viewed or uploaded information to their My Health Record. In WA, most participants said they had been given no further information about the functionality of the My Health Record system, how to use it, how to view their My Health Record, how to upload information, update details, or how to use the My Health Record with their healthcare providers. People in the Ballarat groups had low levels of understanding about either the functionality or the content of the My Health Record.



Enablers and barriers to individual use of the My Health Record

In Ballarat, most participants said that the personal approach while they were attending the hospital had been the key factor in being aware of and agreeing to sign up for the My Health Record. In spite of the fact that they understood little about the My Health Record system, the majority felt the brief explanation and written information they received helped them see its benefit immediately. People who had declined to sign up were also invited to participate in focus groups, but none did. Consequently, the focus groups did not capture the views of people who had not signed up.

Participants from the WA trial region commented that the assisted registration process and information provided to them varied a great deal between individual practices. While a small number of participants said they received some limited information about the features and benefits of the My Health Record, as well as instructions on how to log-in and view their My Health Record, the clear majority said that practice staff administering the assisted registration process gave minimal and vague detail about the My Health Record and how to use it. Like Ballarat, they did comment that a personal approach in a practice setting would be a useful way of engaging individuals in the My Health Record system, particularly for elderly people who might not have access to a computer, smartphone, or the internet or had low levels of computer literacy. Many older participants reported regularly using a smartphone, but rarely if ever using a computer. They felt that, as an application, the My Health Record would be much more accessible to them.

For some older and sicker participants, the fact that the My Health Record was online had been a barrier to their doing anything more than filling in the form, and they did not have any interest in accessing the My Health Record themselves. Some people in this group, however, were interested in having others, such as a child or carer, access their My Health Record. Knowing that this third person access was possible was regarded as important to their potential use of it. Several participants in Ballarat (in all age groups) said the platform for My Health Record (access via myGov and not available as an application) was a barrier to use.

In both trial sites, very few participants across all groups had accessed the My Health Record. This appeared to be for two reasons: lack of knowing or understanding that they could access it themselves, and inconsistent automated follow up after completing assisted registration (not receiving a log-in and further instructions). All those who had accessed their My Health Record after receiving assisted registration (or prompted by their invitation to the focus group) said that no information had been uploaded to their My Health Record by a healthcare provider; and most of those who said they had accessed the My Health Record said they had not added any information themselves.

Many participants said they believed the My Health Record would be used only by healthcare providers to share information. Participants said the information provided to them really only explained the My Health Record's existence, and that it could be beneficial to their health plan (or in the case of Ballarat to their future hospital and GP contacts).

In WA, most participants reported that no detailed benefits of the My Health Record were described to them during the assisted registration process, and very few had discussed the use of the My Health Record with their treating team. Those few who had entered information into their My Health Record had entered only limited identifying detail, such as updating next of kin or contact details etc. In Ballarat, people most commonly reported one or two benefits - accessibility to multiple healthcare providers,



and reducing the need to repeatedly remember and report their health information (which they regarded as an enabler).

“I didn’t even know I could access this record as a consumer... the information provided to me didn’t tell me about that” – Anonymous - Western Australia

“I was keen to see what was in there and what it was all about. When I got home and eventually got in by myGov, I clicked on the My Health Record and couldn’t see anything in there so just logged out... I haven’t looked at it since” – Anonymous - Western Australia

“I at least thought I would be able to see something uploaded by the hospital in there when I logged-in to have a look, but so far I haven’t seen anything in there...” – Anonymous - Ballarat

“I can’t even really follow the instructions on the pamphlet... I was thinking it’s more of something that the doctors use...” – Anonymous - Western Australia

Over all, the main challenges participants reported in using the My Health Record were: their lack of awareness that they could access it; its location on the myGov site; concerns that other healthcare providers, (GPs or other hospitals) would not be using it; concerns about computer literacy; access to computers (among older participants); and concerns about poor internet connectivity in regional areas.

“I don’t have the internet or a computer so I am unsure how I would access the information, I am old and really not tech savvy, this may not be the best option for people like me” – Anonymous - Western Australia

“As far as computers are concerned it is no good say that they will send it to me on the computer as I have nothing to do with them. I don’t know the first thing about it” – Anonymous - Ballarat

“How user friendly is it? Are people who aren’t really tech savvy going to be able to drive it? Because if it is overly complex then the elderly people or people who aren’t particularly computer literate are not going to bother with it” – Anonymous - Ballarat

Participants were asked to reflect on what might encourage other individuals to access and use the My Health Record system. The most common response was to provide more detailed information about the personally controlled nature of the My Health Record - in particular, the functionality of the My Health Record system and how the individual can use it and control the privacy settings. Another key enabler was providing access to the My Health Record in ways other than via myGov, such as a user-friendly application.

“The focus needs to be on communicating the benefits and functionality of the [My Health Record] system to patients... Like if I had known that me, as a patient, could access the [My Health Record] system and look at my records I would’ve gone and used the system” – Anonymous - Western Australia

“People actually need to have explained in detail how the [My Health Record] system works and what it’s purpose is and how privacy settings can be changed... I think that will get a lot of people on board” Anonymous - Ballarat



Individuals' views about what should happen next to improve understanding and use of the My Health Record

The great majority of participants recognised the benefits of having a My Health Record once they were prompted with information on its features. The benefits included that the My Health Record could be accessible around the country; you could put your own information in the My Health Record as a useful adjunct to memory; decreasing avoidable duplication of tests; and reducing errors in treatment. They did not believe it would change the way that they related to their healthcare providers or the way the healthcare providers would relate to them.

Nearly all participants who attended the focus groups said that they would not change healthcare providers if theirs refused to use the My Health Record.

"I think it is only a good thing like if people can access it wherever, especially if you are away or anything like that" – Anonymous - Ballarat

"I think it is an excellent idea because I live in small town and have my treatment here and at one stage during my treatment I was in a different small town and I was critically ill and at that point if they could have accessed my records because I gave them the information and said you need to ring Ballarat they didn't and I nearly died...With my understanding of what this My Health Record is they would have been able to access my clinical history and everything might have been slightly different" - Anonymous - Ballarat

"I changed doctors... I wasn't happy with the doctor I had... When you go to talk to some doctors you don't get some support that you want... I think they get complacent... I looked around and found a new one and I am on the same level as him he doesn't talk down to me. He mentioned this My Health Record thing and I thought it was a good idea. When I was doing a lot of travelling I thought it would be great for this record being accessible by all healthcare providers... I am all for it – I think it's terrific" – Anonymous - Western Australia

"We do the grey nomad thing quite a bit and you know I have a chronic disease and it's just a pain having to remember everything and even all your scripts and that sort of thing. If I am not at home it just makes it harder to do everything to manage my conditions... So having this available to use would be really helpful for me and my wife" – Anonymous - Western Australia

Most participants wondered why use of the My Health Record system was not compulsory for healthcare providers. If it was beneficial for patients, why wouldn't healthcare providers use it? A small number of participants from Ballarat who, when this issue was raised, had some reservations about making use of the My Health Record system mandatory for all healthcare providers: it could add extra time to their workload, and there was a general resistance to 'mandatory' initiatives implemented by Government.

On the understanding that they were part of a trial process comparing different approaches, a majority of the participants felt an opt-out system would be more effective than assisted opt-in. A number believed the My Health Record system and its functionality would need to be stable and reliable for both individuals and healthcare providers before any national effort began (using either approach). In particular, individuals voiced concerns about the usability and functionality of the myGov website. Many were critical of its difficulty of use, making it a potential barrier or turn-off to increasing individual use of the My Health Record system - most commonly the portal's complex and arduous log-in process. Those



who voiced these concerns stressed the need to give individuals an early experience of success in using the My Health Record system. Otherwise those who had a poor user experience would be discouraged and lose confidence in the My Health Record system's ability to benefit them as individuals. Some suggested the use of prompts or reminders about the My Health Record while people were visiting the myGov site for other purposes, and chat line-type help while people were trying to set up or re-visit their My Health Record.

"If your doctors are not backing it there is no point in using it" – Anonymous - Ballarat

"If it is for the benefit of the Australian people where it will simplify things and make their health actually better and more accessible and easier for them to get treatment and see the right people and providers have better knowledge of what is actually going on with them personally. Then make it compulsory" – Anonymous Ballarat

"I think all doctors should have to use it... If it is so beneficial to the entire health system and saves time and money for everyone in the long run why doesn't the Government just tell the GP's they have to use it... it makes sense to do that" – Anonymous - Western Australia

"I think there are huge benefits for the government in making sure all [healthcare] providers use the [My Health Record] system... You know in emergency situations, having to get scripts renewed you know why should I have to go see the doctor for this and like you know I have eye specialists and they send me letters all the time and it just seems like a waste of time! I think this is a good idea for everyone to have one and for all the [healthcare] providers to use it cause it will save the Government money and that means it will save me money because I am a tax payer"

– Anonymous - Western Australia

To questions about how the Government could best communicate with the public to promote awareness, understanding and use of the My Health Record, all the participants gave similar responses: properly targeted public education campaigns tailored to various age groups and demographics; a number of different communication channels such as TV, radio, outdoor advertising, print, online and in particular social media; to reach a point of saturation where everybody not only knew about the My Health Record but was aware of the features and benefits of the My Health Record system, and was educated on how to use it.

Participants said that a potential national opt-out rollout needed to be supported by a planned communications campaign with consistent and clear messages that walked people through the process of automatic My Health Record creation for all Australians. Notify the populace by multiple media channels and methods that the automatic creation of a My Health Record would occur in X number of weeks. Individuals would then receive a communication about this process and told what they needed to do if they wanted to opt-out. Suggestions included a mass mail out to all eligible Australian's by hardcopy or email, similar to the opt-out trial sites. Participants believed individuals should be 'primed' before receiving information from the Government, so that when it arrived by letter or e-mail they paid attention to its content. The suggestions on the best way to communicate this process focused primarily on broadcast mediums such as television, radio, and on outdoor advertising such as billboards or advertising on public transport.

Participants also said that the most credible source of information, for their age group and cohort (primarily the elderly and all chronic disease patients) was their doctor. It was implied that for different



ages groups and those without a chronic disease/those who do not regularly see a doctor this may differ.

“There needs to be a big TV campaign, you know mass media. Just having a brochure, you won’t necessarily know what it’s all about or even pick it up. I know it’s a huge cost to Government but you need to get the message out there about the benefits for everyone” – Anonymous - Western Australia

“I would like to see some real-life experiences or examples on how it has worked for people. They need to make sure that they communicate properly to different groups... What works for people our age won’t work for the younger people and like people with young children and that” – Anonymous - Western Australia

“People pay attention to different media... radio, television, Facebook and the internet... for it to work you have to educate people in stages by all of these. It’s the only way you will reach everyone and get people on board, it’s a great idea!” – Anonymous Ballarat

“Poster and brochures in the hospital is great for people who are there and it can be a really useful way of letting people know about it but what about those who never go to hospital or the doctor, they need to know about it too, so they have to make sure they let everyone know about it by lots of advertisements everywhere and they should focus on educating people about the My Health Record” – Anonymous - Ballarat

Appendix 5 Interviews with healthcare providers (in the opt-out and opt-in trial sites)

Qualitative data analysis

The approach taken to the analysis of qualitative data from the interviews with healthcare providers in both opt-in and opt-out trial sites was based on Krueger's (1994, 2000)^{[1] [2]} Framework Analysis. The Framework outlines five key stages: (1) familiarisation, (2) identifying a thematic index, (3) charting, mapping, and (4) interpretation.

Individual narratives from the interviews were analysed and coded. Codes were words or devices for identifying themes and patterns in the data. To maximise inter-coder reliability in coding open-ended data a lead coder was appointed to oversee the research team to: segment the data; develop draft codes; have all consultants involved review the codes to ensure continuity and to check reliability; modify draft codes; and apply codes. The results would provide information on the prevalence of responses (or themes) from the interviews.

Results

Interviews with healthcare providers from the opt-out trial sites

This appendix presents the results of interviews conducted with healthcare providers in the opt-out trial sites of North Queensland (NQ) and Nepean Blue Mountains (NBM) during the consultation period 2nd August to 28th October 2016. 27 of those interviewed were from NQ, and 14 from NBM. Interviews were conducted with a range of professions, including GPs, nurses, pharmacists, practice managers and a clinical practice manager (see Table 1 and Figure 1 below). The views expressed are similar in both sites and are therefore presented together. Many GPs approached for interviews delegated the interview to a practice manager. It should be noted that while practice managers are not healthcare providers as such, they reported the views of healthcare providers in their practice.

Table 31. Number of participants by employment types.

Healthcare provider	Count
General Practitioner	11
Practice Manager	18
Nurse	6
Clinical Manager	1
Pharmacist	5
Total	41

^[1] Krueger RA (1994) Focus Groups: A Practical Guide for Applied Research. Thousand Oaks, CA: Sage Publications.

^[2] Krueger RA & Casey MA (2000) Focus Groups: A Practical Guide for Applied Research, 3rd ed. Thousand Oaks, CA: Sage Publications.



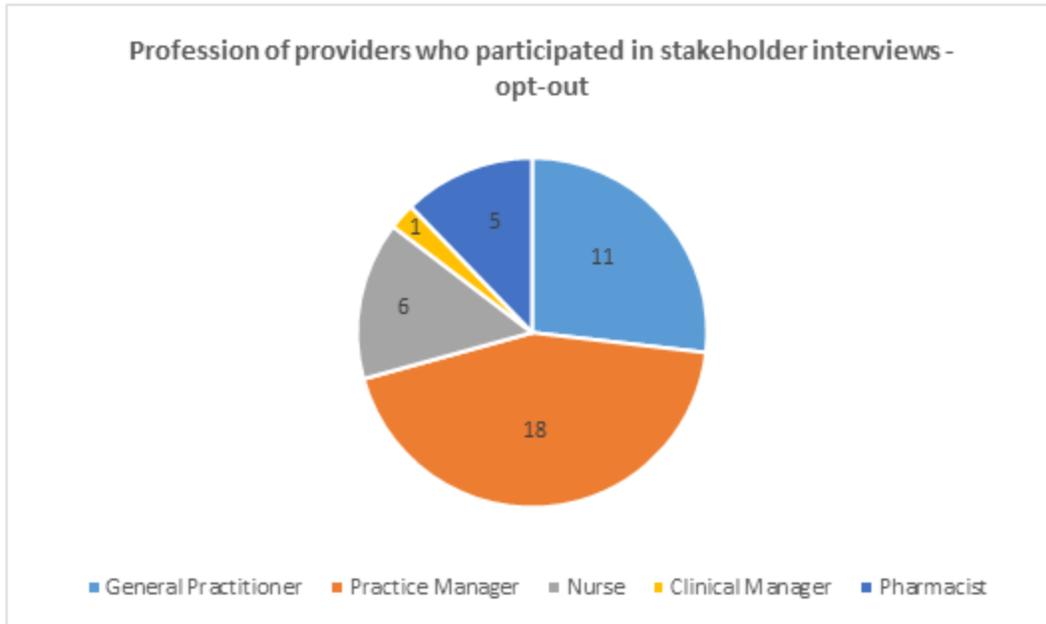


Figure 16 1. Profession of healthcare providers who participated in stakeholder interviews - opt-out

The interviews were conducted using a semi-structured interview protocol which asked interviewees' questions about the following:

- Awareness and understanding of the My Health Record
- Confidence in the My Health Record (confidentiality and security)
- Participation in, experience and use of the My Health Record
- Barriers and enablers of using the My Health Record system
- Stakeholders suggestions for future action

Awareness and understanding of the My Health Record

All healthcare providers interviewed to date were aware of and understood the purpose of the My Health Record system. 13 had used it before the trial began because they could see its benefits to their patients. One practice in the NBM region had tried to use the My Health Record system before 2016, but was unsuccessful in its attempt to access it.

All interviewees said they had received information, materials and resources for healthcare providers and their patients about the My Health Record system through various channels including post, emails and Primary Health Network (PHN) visits. nearly all said they had participated in trial activities in face to face training or visits from the PHN staff. Those who had participated in the trial activities all felt that the activities increased their understanding of the My Health Record and how to use it, and that in many cases it reduced the concerns they previously held about the My Health Record system. Most of those interviewed were not aware of the online training modules, and one person doubted that anyone would have time and motivation to learn about the My Health Record system in that way. Only five of those interviewed had used the online training modules.

Most healthcare providers could describe the potential benefits of the My Health Record system, but only a few could offer examples of clinical benefits. Considering the stage of the development of the



content of the My Health Record system to date this is not surprising. Those who could name benefits thought that the My Health Record could:

- reduce ‘doctor shopping’
- inform clinical decision making
- improve multidisciplinary team care
- facilitate medical information sharing among healthcare providers
- become a place where important health information was easily accessible
- be particularly useful when patients were travelling or presented to an Emergency Department. Some healthcare providers had seen benefits of their patients having a My Health Record. One healthcare provider had a patient who was able to access his medical information when he was travelling in another State. Another reported sharing information with the local hospital on their patient’s admission and discharge.

Most of those interviewed agreed that the automatic creation of My Health Records was essential to the My Health Record system’s long term effectiveness and coverage. Some said that it would take approximately six months or more to be able to see the benefits from the automatic creation of My Health Records. They felt that automatic creation would make it easier for people, since the registration process was tedious; providing assisted registration to individuals was time consuming; and the automatic creation of My Health Records would assist people who were computer illiterate or did not have a computer or poor internet access (e.g. elderly patients, or those in remote settings).

“Yes, I can see that it is very beneficial, especially when your regular GP is away and you have to come to a medical centre where the doctor has no details. I think being able to access it will give insight into a patient’s history that allows for proper treatment”- Pharmacist in NBM region

“If it’s used appropriately for benefit of consumers and benefit of country as a whole” - Pharmacist in Nepean Blue Mountains

“People are still trying to get their head around understanding it” - Pharmacist in NBM region

“Once there’s more information in there [the My Health Record system] available, I think there will be more benefit in using it” – Practice Manager in Nepean Blue Mountains

“When you go from one doctor to another doctor you have all the information. Supposedly if you go to Melbourne or Adelaide, you have them with you and the doctors have access to them.” - General Practitioner in North Queensland

“Admin wise having the Medicare linked to, or some of the Medicare linked, for some of the patient so you can actually view what item codes have been billed previously and therefore see where they are or where they are eligible for Medicare plan next or so on” – Practice Manager in North Queensland

“For example we had a patient who was planning to travel and he set up his record [My Health Record]. He was able to get his prescriptions from a doctor in another State without any problem. It worked.” - Practice Manager in Nepean Blue Mountains

Confidentiality and security of My Health Record

Of the healthcare providers interviewed, they were almost equally divided on whether or not they were comfortable that the My Health Record system could maintain the confidentiality of their patients’ data.



Those who said they felt confident that the My Health Record system was secure from external threats and safe from hackers cited the system's existing security measures are put in place to ensure an individual's My Health Record was protected. Many also stated that there was no unduly important personal information in the My Health Record that would be a useful or attractive target for hackers. Many commented that anything online is vulnerable to external threats, and the benefits of having and using the My Health Record system outweighed the risk of having health information accessed externally. Those who said they were not confident that the My Health Record system was secure gave reasons such as; they were not computer literate, the census "debacle", or they had concerns about the use of the data in the My Health Record system. For example patients may have information available that they would not otherwise have, such as doctors' notes about a patient, or information in referral letters to or from specialists. Those who had participated in the trial activities had greater confidence to use the My Health Record system and to explain it to their patients.

"I struggle to get into my own [My Health Record] record personally, so I think the security of the [My Health Record] system is pretty good" – GP in North Queensland

"If the government can't do it [keep a patient's record confidential and safe from external threats] no one can... If anyone or any group is going to be held accountable and cover themselves, it's the government" – Pharmacist in North Queensland

"I don't think there's any way out of it [security of technology]... or any sort of technology. We're all linked to the bank up to our eyeballs, the taxation office. It's a fact of life now but I don't think we can be confident in any of it. I totally believe that the benefits [of participation and use] outweigh the risks for healthcare providers and consumers." – Practice Manager in North Queensland

"I want to be confident and have faith in the security of the [My Health Record] system. The ones that I have encouraged to make their record [My Health Record] available are the elderly especially the ones that are active. You know they travel a lot so I think it's good for them to have one so other doctors can see their health status. They worry about the security of things online a lot though. I try to reassure them... nothing is safe these days" – GP in Nepean Blue Mountains

"I can't be 100%, but I'm reasonably confident that it's safe. And the information on the record [My Health Record] is not overly personal anyway so I am not sure what external third-parties or hackers would want with it anyway." – Practice Nurse in Nepean Blue Mountains

Participation in, experience, and use of the My Health Record

Of the 41 healthcare providers interviewed, 34 reported they (or healthcare providers in their practice) were using the My Health Record system to view or upload information. Some of those interviewed early in the consultation period said they had just connected to the My Health Record system in their practice. The seven interviewees who were yet to use the My Health Record said they felt the My Health Record system was underdeveloped and there was little to no demand from their patients to use the My Health Record system. All healthcare providers interviewed during the consultation period felt that a combination of demand by individuals for the use of the My Health Record and the availability of more clinically useful information in the My Health Record system would encourage other healthcare providers to use it. Suggestions for making information more available in the My Health Record system included reducing patients' control of their My Health Record (in particular, patients' capacity to limit healthcare providers' access to their information); and enabling healthcare providers access to pathology and radiology results through the My Health Record.



When asked whether the ePIP eligibility criteria affected their use of the My Health Record system, some said a little, but not to any great extent.

Of those interviewed, only one healthcare provider believed that their patients would seek another healthcare provider if they did not use the My Health Record system.

“Not (clinically useful) as yet. Primarily because I produce very good medical records and I am uploading my good medical records to the My Health Records of my patients when I see them. However, I am yet to find myself in a situation where anything uploaded by anyone else has been at all useful to me. There is a number of reasons for that. The first reason is; I already know my patients very well. The information that has been uploaded by the PBS for instance is not useful to me. The information loaded by the MBS is not useful to me. I am yet to see any pathology or radiology automatically uploaded to it. I have seen a hospital discharge summary occasionally uploaded to it but not consistently. And hospital or specialist correspondence from the public system is haphazard at best, even more so when related to the My Health Record.” - General Practitioner in North Queensland

“The My Health Record is only useful if everybody uploads every time. Because if they don’t, if everybody doesn’t do it every time.... Then we are in the exactly the same situation as we are now, no different, no better, no worse. Just one more button to click every time.” - General Practitioner in North Queensland

Barriers and enablers of using the My Health Record system

Most healthcare providers agreed that the availability of training, education and support provided by the PHN helped them use the My Health Record system. Many suggested that more training would be welcomed, and that information about training opportunities should be communicated to them more often. They described the need to ensure that healthcare providers were kept informed about My Health Record system upgrades, changes to the My Health Record system interface, functionality and requirements. Most of those interviewed reported that the resources they received to give to patients or clients (e.g. flyers, factsheets and brochures) were beneficial and helped educate individuals about the My Health Record, its use, features and benefits. Healthcare providers said more needed to be done outside of the practice setting to educate and raise awareness for their patients and all other individuals, as awareness and knowledge of the My Health Record was low. Some Practice Managers said they were using their own My Health Record to assist with training within their practice and in education for their patients. There were issues concerning their ability to train others in their practices because they did not have a HP-I and therefore could not access the My Health Record system, and would need assistance from the PHN.

A common barrier was the pace of the rollout of the National Broadband Network (NBN), with slow upload and download speeds noted as a major disincentive to use the My Health Record system. This was most commonly noted in regional areas of North Queensland.

Some healthcare providers were concerned about the increased time it would take to explain the My Health Record to patients, and also to upload information to the My Health Record system. None of the healthcare providers who raised this concern felt able to quantify the cost or the time taken or assign a monetary value to them. In contrast, other healthcare providers, in particular some practice managers, noted that ultimately the My Health Record system will save time for administrative, practice staff and



GP's as less time will need to be taken to track down discharge summaries and other information necessary to make clinical decisions.

"Come out and train us how to use it if they want us to use it" - Pharmacist in Nepean Blue Mountains

"Doctors are more supportive of it now that they are actively uploading and can see it has specific benefits for particular cohorts in the practice" - Practice Manager in Nepean Blue Mountains

"It's only a few clicks to access and upload" - Practice Manager in Nepean Blue Mountains

"People are still trying to get their head around understanding it" - Pharmacist in NBM region

"I think, you know, good quality face to face, just one on one education with all of the clinicians who use the [My Health Record] system would be a good thing. And, I think, probably to try to identify some protected time so the doctors can do that. We all have so much pressure on our time. So in order to identify protected time I think it would be helpful to have that time funded. So rather than doctors losing some money by doing it ...saying ok we will compensate you for the time doing to training. Then people would be more enthusiastic to embrace the training." - General Practitioner in North Queensland

"The [My Health Record] system is not designed for General Practice. It's designed by IT people.... And not in the speed or context required for General Practice" - General Practitioner in North Queensland

"The only thing we are assisting them [patients] with is creating a log in for the myGov App. A lot of them already had My Health Record but were unsure of how to actually access it. So that is where we helped them with their log in and link it with My Health Record, then they can access it that way." - Practice Manager in North Queensland

Most of those interviewed did not see any risks in the automatic creation of My Health Records. Some of their patients had expressed concerns about the security and privacy of their My Health Records, but many of these individuals reflected similar views about the safety and security of *any* personal information held online. Most healthcare providers felt equipped to answer any enquiries or concerns their patients expressed after receiving training and resources from the PHN. One healthcare provider was not confident to answer patients' concerns or enquiries because they had not received training, and suggested that having a helpline would be useful.

Some healthcare providers expressed concerns (some of which are common myths) about the My Health Record system that could be barriers to use:

- Concerns about litigation, especially when a healthcare provider accesses a patient's My Health Record in an emergency situation. The main concern expressed was whether a patient could "then turn around at a later time and say their privacy was breached, if the patient had not previously provided them with access to their record [My Health Record]".
- Concerns about the pathology/imaging results provided to patients. GPs were concerned about the potential for patients to misinterpret their pathology/imaging results when the reports become viewable to patients. For example, further follow up tests and discussions with the GP might be required however patients might not visit their GP after receiving the results. Also, GPs



are concerned whether they will be possibly liable if they are not providing adequate follow up of the results when patients did not return for a follow up visit after viewing their results in their My Health Record.

- Concerns about the inaccuracy or incomplete nature of the My Health Record, given that not all healthcare providers are uploading information consistently.
- A fear that information in the My Health Record system could be used to “police people”.
- A concern that the privacy legislation in relation to the My Health Record system might need to be strengthened so that the information in the My Health Record cannot be used in legal matters such as insurance claims.
- The need to obtain consent every time a practice is going to upload information as advised by some PHN staff during the training provided to some practices.

“If everybody did it all the time then I would only have to look in the My Health Record and it would be there now that’s when it becomes really useful and the Australian health system would save tens of billions of dollars. If it worked like that. But you have to make people do it... But it is not like that at all. We are nowhere near it. We are a long way from that. But I get it that this is the starting point, so if I don’t upload good stuff then I can be damn sure no one else is going to. So I am doing my bit, I am uploading good stuff and we will see if at some point it gets to a tipping point where people are using it routinely. And once we get to that point and certainly once we get to the point where the specialists are on board. Now they won’t do it they will just - they can hardly get over writing a hand-written letter let alone using My Health Record. They are just not going to do it. Which means we are probably 20 years away from getting it to work properly as the older specialist just retire.” - General Practitioner in Northern Queensland

Stakeholders’ suggestions for future action

Healthcare providers in the opt-out trial sites said a more concentrated and concerted effort needed to be made in awareness raising activities with individuals so that they could make informed decisions about their My Health Record. Awareness raising activities should include information about what the My Health Record contained, and the benefits to the individual.

Suggestions were made to streamline the registration process for individual members of the general public. Additionally, it was suggested to make accessing a My Health Record easier. An example of a new access model may include a My Health Record Number and Pin linked to an individual’s Medicare card.

A number of healthcare providers stated the Government should also develop a way for individuals to give permission to their healthcare providers to upload documents to their My Health Record easily.

All healthcare providers interviewed in the opt-out trial sites believed that training and education activities should be continued and increased, in particular face to face training, which was commonly regarded as the most efficient and effective way of getting healthcare providers up to speed and on board with the use of the My Health Record system.

Other suggestions included (some of which are already available):



- Making sure that the My Health Record system is a good IT platform that has been tried and tested.
- An IT helpline for the My Health Record system for healthcare providers to access so they did not have to use their individual IT providers to resolve error messages.
- Creating a standardised template to ensure information uploaded to the My Health Record system is consistent.
- Providing more resources/materials for individuals to be displayed/distributed in their practice.
- Communicating to healthcare providers about the importance of their role in explaining and/or assisting patients to use the My Health Record.
- Collaborating with existing professional networks and professional peak bodies/associations (e.g. Pharmacy Guild) to ensure My Health Record is used effectively.
- Establishing helplines where healthcare providers are able to seek legal advice regarding the My Health Record system and get assistance/support.
- Making patients' information in the My Health Record system accessible and easy to find.
- Providing mentorship where healthcare providers who have previous experience in using the My Health Record system can mentor and support others in using it.
- Continue and/or increase financial incentives for doctors to use the My Health Record system in their practice (e.g. Medicare billing codes).
- A proper legal process needs to be set up for people who wish to access other's information in the My Health Record system for legal matters.
- Publish or present some of the outcomes from the pilot so people could understand what is going on, give real life examples of positive outcomes or avoidance of poor outcomes to make it real for people.

Interviews with healthcare providers from the opt-in trial sites

This appendix presents the results of interviews with healthcare providers in the opt-in trial sites in Western Australia (WA) and the Ballarat Health Services (BHS) during the consultation period 29 August to 28 October 2016. A total of 49 healthcare providers were interviewed, 33 healthcare providers from WA and 16 from BHS. Interviews were conducted with a broad range of professions including a GP, nurses, clinical practice managers, practice managers, practice and hospital administration staff (see Table 2 and Figure 2 below). The views expressed in both sites are similar and are therefore presented together. Many GPs approached for interviews delegated the interview to a practice manager. It should be noted that while practice managers are not healthcare providers as such, they reported the views of healthcare providers in their practice.

Table 32. Profession of healthcare providers who participated in stakeholder interviews - opt-in trial sites

Healthcare provider	Count
General Practitioner	1
Practice Manager	8
Nurse	19
Healthcare providers working in the hospital	8
2IC	5

Healthcare provider	Count
Receptionist/Administration staff	8
Totals	49

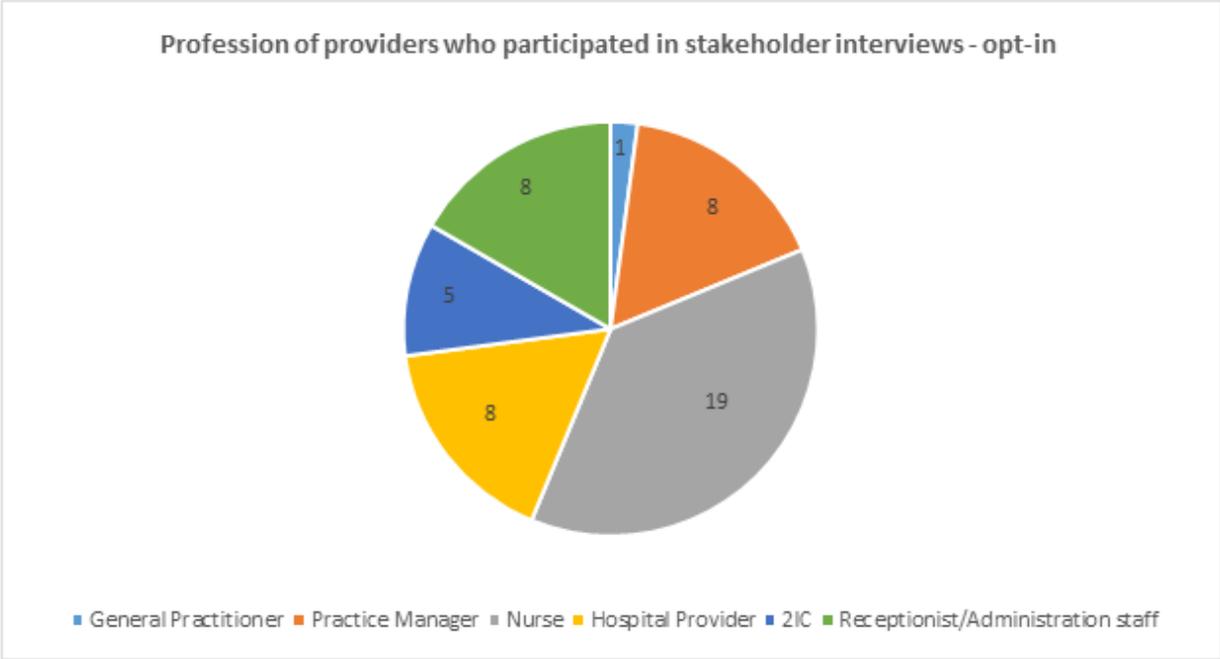


Figure 17. Profession of healthcare providers who participated in stakeholder interviews - opt-in

The interviews were conducted using a semi-structured interview protocol which asked interviewees questions about the following:

- Awareness and understanding of the My Health Record,
- Confidence in the My Health Record (confidentiality and security),
- Participation in, experience and use of the My Health Record,
- Barriers and enablers of using the My Health Record system, and
- Stakeholders suggestions for future action.

Awareness and understanding of the My Health Record

All 49 healthcare providers interviewed in the two opt-in trial sites were aware of and understood the purpose of the My Health Record system; and 17 had some awareness of the previous Personally Controlled Electronic Health Record (PCEHR) before the trial began. One practice manager from WA said she had attempted to enable her previous practice to use the PCEHR without success: it was reported to ‘fall through’ because the practice did not have compliant software.

Only one of the healthcare providers said they had not received information, materials and resources about the My Health Record system through various channels (post, emails, in-house training, and workshops). Most had participated in trial activities in the form of face-to-face training from their Practice Manager (WA) or Project Team (Ballarat). Only a small number of healthcare providers had used the online training modules to help them understand the My Health Record system, and several healthcare providers in WA said they would have used the online training if they were aware it was available. Most healthcare providers reported that the trial activities had given them adequate

knowledge to offer assisted registration to patients. However, some in both opt-in trial locations said further training would have helped them answer the sometimes-detailed questions patients raised. In Ballarat, five of the receptionist/administration staff who were providing assisted registration felt that they had a low understanding of the detail of what the My Health Record entailed.

“Patients who like the idea feel it will make their lives easier eg when travelling as they believe if they have health issues whilst away, the information about their condition will be readily available. People with complex health issues seem to feel that this will ease the burden of responsibility for them to explain when communicating with health professionals.” Nurse – Ballarat Health Services.

“We went to a seminar not long about that [opt-in/opt-out trials]. So we had the CDMnet, we trialled that a few years ago and that sort of fell flat as well too because we had such an old software system that we were continuously getting run errors and so the doctors then said “no, we’re not going this anymore” - Practice Manager – Western Australia

“Look I am 100% for it, it is so beneficial. We have so many patients here that attend hospitals and specialists and to be able to upload health summaries and, you know, shared health summaries it is so easy. It would just be so amazing if everyone could come on board with this. But you know there are always the ones that are quite negative about it that I don’t think fully understand, or want to understand this. So we do use a lot of paper. And that’s another thing about it – it would eliminate a lot of paper.” - Practice Manager – Western Australia

“If you want to check for extra information, it’s one click away” - General Practitioner – Western Australia

“Improve information sharing between health practitioners & reduce need for patient to repeatedly provide information when visiting various health practitioners” - Nurse – Ballarat Health Services

Confidence in the My Health Record (confidentiality and security)

Over half of the interviewees felt confident that the My Health Record system could maintain the confidentiality of their patients. 22 of those interviewed reported confidence that the My Health Record system was secure from external threats and safe from hackers. Their reasons for this confidence were their belief that the Government or the My Health Record system operator would ensure appropriate security measures, they assumed that the Government would have ensured that security measure were in place. It would be like the security measures applied by banks to online banking. Some said they were not confident, owing to the accessibility of the My Health Record to multiple healthcare providers, limited awareness of the security measures, the online nature of the My Health Record, and the loss of confidence in the Government’s ability to manage the security of big datasets following the 2016 Census. Many said anything online was vulnerable to external threats, but they believed that benefits of having and using the My Health Record far outweighed the risk of any potential confidentiality and security risk.

In the BHS, some staff were concerned that patients would have access to the full name of treating staff from information provided in the My Health Record. This concern was driven by a perception that knowing a staff member’s full name could potentially be used in a malicious manner by disgruntled or



unwell patients. Two interviewees who worked in the BHS were concerned that their medical history would be viewed by their colleagues in the Emergency Department if they required urgent treatment within the hospital. The privacy of staff members was also raised as a concern for staff who were receiving medical treatment while working in the associated department or ward.

“Well I’m confident but I know a lot of people aren’t. I mean they look at what’s happened with the census. That’s what we’ve had a lot of patients talk to us about. That “Oh look what happened with the census”, but then again, you know... Look I’m confident. We can only explain to certain patients, you know, this is the way of the future but they’re either for it or they’re not and we just can’t force them.” - Practice Manager – Western Australia

“I am not overly confident in the security of many online processes” – Receptionist - Ballarat Health Services

“Nothing is really safe from hackers and the likes these days, I don’t believe that should stop people from having a record [My Health Record] or using the [My Health Record] system though... anything can be breached online” – Practice Nurse – Western Australia

Participation in, experience and use of the My Health Record

Of the 48 healthcare providers interviewed, 11 said they were uploading information to the My Health Record system, and four of them were also viewing information from the My Health Record system. 24 of the interviewees were providing assisted registration, but were not also viewing or uploading to the My Health Record system. All the healthcare providers interviewed said they or their practice were using the My Health Record system in some capacity, but some did not have access to the clinical aspects of the My Health Record because of their positions (e.g. Practice Manager, 2IC receptionist).

Most had a positive view of the My Health Record, and predicted that it would be of clinical benefit to healthcare providers and patients in the future with increased healthcare provider uptake and individual use. Most could describe the potential benefits, which included:

- support for the elderly
- ease and speed of accessing medication information
- access to hospital discharge summaries
- portable medical records for patients who travel
- to inform clinical decision making in the event of an emergency or during a presentation to an Emergency Department.

Over all, these healthcare providers felt that a combination of individual’s awareness and demand for the use of the My Health Record, as well as the availability of more clinically useful information in the My Health Record system, would encourage other healthcare providers to use it. To promote future use of the My Health Record system, some suggestions included:

- reducing patients’ control of the My Health Record
- increased use by all members of the treating team
- increased general practitioner use in managing chronic disease
- continued healthcare provider education and training, particularly face to face training for doctors
- continued financial incentives to healthcare providers.



When asked whether the ePIP eligibility criteria changed their practices' use of the My Health Record system, ten said it was a contributing factor, one said it did not make a difference, and the remainder did not know.

All healthcare providers believed their patients would not seek another healthcare provider if they did not use the My Health Record system. Conversely, one Practice Manager said she would actively encourage a patient to consider accessing an alternative doctor within the practice if one of their doctors was not able to access the My Health Record.

We've had a few patients come in wanting to register and wanting to upload their shared health summaries and we've had a few doctors that have been against it and [patients] have actually swayed the doctors into doing it [using the My Health Record].” - Practice Manager – Western Australia

“If it contained more clinical information other than basics e.g. full consultation notes that can be transferrable to other medical centres.” - Practice Manager – Western Australia

“We've made our own photocopied and laminated forms for patients to hand to the nurse or doctor to prompt the doctors and nurses to upload.” Practice Manager – Western Australia

“I would like to see more information available, such as Specialist Reports, pathology results and other investigation reports, mostly to make that information more accessible to my multiple [health]care providers.” Nurse – Western Australia

Barriers and enablers of using the My Health Record system

Many of the healthcare providers interviewed in the opt-in trials sites noted barriers to the implementation of the trial activities. In particular, the difficulty of signing up patients to the My Health Record due to the very low level of awareness about the initiative and the My Health Record system amongst the target population groups in each trial site. In both trial sites, the staff tasked with conducting the assisted registration process said very few patients who were approached knew about the My Health Record, its purpose and functionality. This contributed to a lengthier assisted registration process as the My Health Record had to be explained in detail to the patient to first get understanding and then consent to be registered with the My Health Record system.

Many of those interviewed reiterated that the training they received was not detailed enough for them to convey the features and benefits to individuals. More comprehensive and useful resources, including promotional material and targeted public education campaigns would have been useful in helping staff explain the My Health Record and its benefits to their patients. Additionally, there needed to be a sufficient quantity of printed materials provided to each practice, to distribute amongst individuals who wanted to read the information. They also noted the need to develop more resources for patients from culturally and linguistically diverse backgrounds, the disabled, and the hearing and sight impaired.

In both Ballarat and WA, practice managers, nurses, and hospital administration staff involved in providing assisted registration also noted that a major barrier to the success of assisted registration was that the doctors had not been adequately targeted with information and resources to gain their buy-in, understanding and trust of the My Health Record system. In particular, they noted that the barriers to buy-in by doctors were more pronounced with older doctors, who had more general resistance to using IT systems.



Individuals who had low levels of computer literacy, access to a computer or smart phone and the internet, were harder to engage in the assisted registration process.

Several concerns were raised in the hospital setting about the effect of assisted registration on current workload. Some said they only had time to give patients a brief overview of the My Health Record because of other competing demands of their work environment (such as an Emergency Department, or busy practice setting). Several healthcare providers also raised concern that the increased administration time it takes to provide assisted registration to patients was a barrier to ongoing sustainable efforts to promote the My Health Record. Healthcare providers in the Ballarat opt-in trial site also noted that the Emergency Department was an inappropriate environment to provide assisted registration or information about the My Health Record to patients who were in pain, sick and under stress.

All healthcare providers said training was a key enabler in their participation in the My Health Record, and that information about training opportunities should be made available to them. While most people interviewed had received face to face training and education, they said that if they had known of the online training, it would have been a useful mechanism to gain the needed awareness and understanding of the My Health Record system.

In the Western Australia trial site, if their practice was busy, or if they were under-resourced on a particular day, assisted registration was not conducted as time and staffing would not permit. Importantly however, if there had been higher levels of individual's awareness and understanding of the My Health Record, this would have decreased the time they spent in explaining it to patients.

"Information session, that was good. I would like more formal hands on training in the future... I prefer face to face training as I absorb it better." – Nurse – Western Australia

"Lack of awareness about the record [My Health Record] from our patients has meant the nurses have had to spend a lot of time bringing them up to speed to get them on board with the concept. The elderly especially... they are always apprehensive about computers and the like" – General Practitioner – Western Australia

"Patient awareness is an issue that could be improved – most people don't bother to seek information about the My Health Record. They [patients] think that it is the responsibility of healthcare providers to keep their [health] record, and many people would not think it is their own responsibility." – Oncologist – Ballarat Health Services

"We have found that in Emergency it has been fairly futile trying to engage sick patients in the My Health Record information. I don't believe that ED is an appropriate environment to provide extra information to patients who are in pain, sick and under stress – from our experience they have showed little interest. It is difficult also for our staff to spend additional time on this process if the patient requires further information, has queries, etc." - Receptionist – Ballarat Health Services

Asked about My Health Record system or technical barriers and enablers, the majority of healthcare providers were positive about the functionality and user-friendliness of the My Health Record platform. The common barriers which were noted by healthcare providers in both sites more commonly reflected hardware or connectivity issues onsite.



“Only thing I can think of is because it is through the CDMnet I am guessing... CDMnet is so slow on our computer system to access the reports and that sort of thing. They come through very slowly. Not sure if it’s the hardware or the software. Computers will shut down about 4 or 5 times a day.” – Nurse - Western Australia

Stakeholders’ suggestions for future action

While the majority of the healthcare providers were positive about the My Health Record and its features and benefits for both themselves and individuals, all of those interviewed from the opt-in trial sites believed that participation in the My Health Record system should move to an opt-out model. They believed that given the barriers experienced during the opt-in trial that the opt-out model must be supported by extensive and targeted public education and awareness raising campaigns.

The more detailed advice they provided about the public awareness and education campaigns included the following suggestions:

- Specific and targeted public education and awareness raising campaigns for all sectors of the community including the elderly, Aboriginal and Torres Strait Islanders and those from Culturally and Linguistically Diverse backgrounds.
- Allowing localisation of materials to suit the local context.
- Materials to promote the benefits of the My Health Record for those who are healthy and do not present to the health system often as well as those who are frequent users of the health system.
- Campaigns should be delivered by several different media channels (television, radio, print, online and social media) as well materials that assist practice managers to educate their healthcare providers in the practice setting.
- Interviewees suggest that the Government should seek to streamline the process for individuals to register and access their My Health Records.
- Government should develop a way for individuals to be able to give permission for healthcare providers to upload documents to their My Health Record easily.
- Training and education activities should be continued and increased. Healthcare providers noted the importance of ensuring that training, in the first instance is delivered face to face and that it is targeted at those who will be using the My Health Record system and promoting the My Health Record and its use to individuals. While the online training was recognised by some healthcare providers, all stated that for the My Health Record system to work to its full potential for both individuals and healthcare providers, face to face engagement and training is required.

“I think if everyone had a record [My Health Record] created for them automatically it would reduce the time burden which is being put on to us here at the practice level to engage the patients and get them to sign up to the record [My Health Record]... also just because they sign up, doesn’t mean they will use it personally.” – Nurse – Western Australia

“Make it opt-out and then give the patient the choice to not have one. Opting-in to the [My Health Record] system is a time-consuming process no matter who does it, be it the patient or a staff member on behalf the patient... Opting out could be as easy as clicking a button saying no I don’t want this” – Administration staff - Ballarat



“It would be much more appealing for GP’s to use if everyone just had a record [My Health Record]... you know even if a consumer doesn’t use the record [My Health Record] it can still be useful to healthcare providers as it allows for the information to be shared... everyone should have one, they just need to know what it’s all about” Practice Nurse – Western Australia



Appendix 6 Findings from the survey of individuals

Methods

Sampling

The sample was drawn from a large online panel provided by the ISO accredited company I-View. To minimise response bias, panel members were randomly asked to participate in the study without specifying the topic of the survey. Respondent selection in the trial and non-trial sites was guided by the postcodes covered by the participating PHNs (Attachment 1). Recruitment across both trial and non-trial sites was stratified by age, gender and nationality to ensure a nationally representative sample was recruited across all sites. Upon completion, respondents would receive panel-specific credits/points. The credits/points are based on the length of the survey, and in this instance, a 10-minute survey offers respondents 100 panel-specific credits/points that equates to \$1. Questions were developed and piloted by the evaluators internally and in consultation with the Department of Health (the Department). Computer Assisted Telephone Interviewing (CATI) was conducted to supplement online surveys in Ballarat because the potential pool of respondents to an online survey was known to be too small to achieve the required sample size.

For the purpose of determining the sample size required, it was estimated that uptake of the My Health Record by individuals would differ in the opt-out trial sites compared to both the opt-in trial sites and the rest of Australia by over 95% (based on a 1.4% opt-out in the UK). However, it was estimated that there would be a difference of 30% between the opt-in trial sites and the rest of Australia (based on data from other similar projects)¹⁷. Based on the smaller difference of 30% and using a sample power of 0.8 and an alpha error of 0.05, we estimated that a sample size of 1,081 distributed evenly over the three trial arms (363 per trial arm) was required to test this difference. Based on previous experience, we expected that 60% of the people who agreed to be re-contacted for follow up would be available and willing to do the survey again. This would mean that the evaluator was able to track changes in this cohort over time. Assuming the current proportion of the population with a My Health Record at baseline was 13% and adjusting for a loss to follow up of 40%, the aim was to recruit 700 respondents per trial arm at baseline, to ensure 363 per trial arm in the follow up.

The questionnaire was developed and piloted by the evaluators internally and in consultation with the Department. At the end of the baseline survey, respondents were asked to indicate whether they would be willing to be contacted for follow up by the evaluator. The baseline survey was conducted between 18th February and 8th March 2016. The follow up surveys were conducted between 2nd September and 28th September.

Approach to quantitative analysis

Statistical analysis was conducted to evaluate the difference between opt-out trial participation and the Rest of Australia and between opt-in participation and the rest of Australia. Routine descriptive methods and tests of association were conducted to determine differences between the trial sites. Statistical analyses were conducted using StataSE[®] version 13 (StataCorp College Station, TX, USA) and Microsoft Excel © was used to develop graphs and tables for the final report.

¹⁷ Royal, R., Hambleton, S., and W Walduck, A. Review of the Personally Controlled Electronic Health Record, Department of Health, Editor. 2013.

Approach to qualitative analysis

The approach to the analysis of qualitative data generated by the survey of individuals was based on Krueger's Framework Analysis (1994, 2000)^{18,19}. The Framework outlines five key stages: familiarisation, identifying a thematic index, charting, mapping and interpretation. Qualitative data in the survey was analysed by coding the information provided by the respondents. Codes were used as a means or device for identifying categories and patterns in the data. The analysis of qualitative data was overseen by a lead coder and the process involved:

- segmenting the data;
- identifying key categories and patterns in the data (coding);
- discussing emerging categories and patterns across multiple coders;
- moderating categories and patterns in line with group discussion; and
- summarising data according to key categories.

Results

Demographics

3,579 people participated in the baseline survey, and 3,295 (92%) of them agreed to take part in the follow up survey. 1,918 (54%) took part in the follow up survey during the period allocated to collect data. There was an approximately equal distribution of the sample across the three trial sites²⁰. The respondents were 1,068 females (55.7%) and 850 males. Their average age was 53 years. The opt-in group was slightly older than the rest of Australia group (this difference was statistically significant). The study participants were older than the estimated July 2015 adult population, with fewer participants aged 18-35 years (15.4% vs 32% in the Australian population), and a larger number of adults aged 50-64 years (32.7% vs 24% in the Australian population). Overall household characteristics were broadly similar to 2012-13 Australian Bureau of Statistics estimates of household composition.

Table 33. Socio demographic characteristics of participants from the survey of individuals in the follow up survey

	Opt-out N=694	Opt- in N=775	Rest of Australia N=449	Total sample N=1,918
Age; mean (SD)	54.5 (14.2)	52.4 (15.3)	49.8 (17.4)	52.6 (15.5)
Age Group				
18-34	71 (10.8%)	121 (15.6%)	102 (22.7%)	298 (15.4%)
35-49	154 (22.2%)	214 (27.6%)	128 (28.5%)	496 (25.9%)
50-64	279 (40.2%)	238 (30.7%)	110 (24.5%)	627 (32.7%)
65+	186 (26.8%)	202 (26.1%)	109 (24.3%)	497 (25.9%)
Gender				
Female	402 (57.9%)	440 (56.8%)	226 (50.3%)	1,068 (55.7%)
Male	292 (42.1%)	335 (43.2%)	223 (49.7%)	850 (44.3%)
Family structure				
I live alone	125 (18.0%)	145 (18.7%)	98 (21.8%)	368 (19.2%)
Couple living alone	312 (45.0%)	291 (37.6%)	149 (33.2%)	752 (39.2%)
Couple with dependent children	149 (21.8%)	220 (28.4%)	114 (25.4%)	483 (25.2%)

¹⁸ Krueger RA (1994) Focus Groups: A Practical Guide for Applied Research. Thousand Oaks, CA: Sage Publications.

¹⁹ Krueger RA & Casey MA (2000) Focus Groups: A Practical Guide for Applied Research, 3rd ed. Thousand Oaks, CA: Sage Publications.

²⁰ The 3 trial sites = 1 x Opt-out trial site/group (NQ PHN and NBM PHN); 1 x Opt-in trial site/group (WAHPA and Ballarat Health Services); 1 x comparator site/group (the Rest of Australia)

	Opt-out N=694	Opt- in N=775	Rest of Australia N=449	Total sample N=1,918
Single parent with dependent children	21 (3.0%)	25 (3.2%)	20 (4.5%)	62 (3.2%)
Non-related adults sharing house/ apartment/flat or other	21 (3.0%)	21 (2.7%)	20 (4.5%)	62 (3.2%)
Other	61 (8.8%)	65 (8.4%)	42 (9.4%)	168 (8.8%)
Prefer not to say	5 (0.7%)	8 (1.0%)	6 (1.3%)	19 (1.0%)
Family Groupings				
Couple families	312 (64.7%)	291 (54.3%)	149 (52.7%)	752 (57.8%)
Families with Children	170 (35%)	245 (46%)	134 (47%)	549 (42%)
Income				
to 40K	174 (25.1%)	222 (28.6%)	123 (27.4%)	519 (27.1%)
40-100K	272 (39.2%)	262 (33.8%)	170 (37.9%)	704 (36.7%)
100+K	136 (19.6%)	197 (25.4%)	102 (22.7%)	435 (22.7%)
Education				
Up to High School	261 (37.6%)	269 (34.7%)	136 (30.3%)	666 (34.7%)
Certificate/Diploma	263 (37.9%)	239 (30.8%)	139 (31.0%)	641 (33.4%)
Bachelor/PostGrad	162 (23.3%)	264 (34.1%)	170 (37.9%)	596 (31.1%)
Prefer not to say	8 (1.2%)	3 (0.4%)	4 (0.9%)	15 (0.8%)
Aboriginal and Torres Strait Islander	21 (3.0%)	23 (3.0%)	15 (3.3%)	59 (3.1%)
English Language				
English Only	657 (94.7%)	719 (92.8%)	397 (88.4%)	1,773 (92.4%)

In the opt-out trial sites, there were statistically significant differences in the population compared to the rest of Australia: fewer participants lived alone; more participants were in the 50-64 years age group; participants tended to have a lower level of qualification; were more likely to have children; and there were more females. There were no differences in income, and in the proportion of Aboriginal and Torres Strait Islander peoples.

In the opt-in trial sites, there were statistically significant differences in the population compared to the rest of Australia: more participants were in the 50-64 years age group, and there were more females. There were no differences in the number of families with children, the type of household composition, income, education and proportion of Aboriginal and Torres Strait Islander peoples.

Follow up analysis

Increased awareness and understanding of the system amongst users

About a quarter of the respondents had heard about the My Health Record system since the initial survey in March 2016. Participants in the opt-out trial areas were more likely ($p < 0.05$) to have had exposure to awareness raising information about My Health Record than the rest of Australia. Over 40% of respondents in the opt-out group had been exposed to awareness raising information about the My Health Record system compared to 11% in the rest of Australia. There were no differences in the number of participants registered for myGov in the opt-out trial sites compared to the rest of Australia. There were no statistical differences in the two areas between a participant's expectation that their healthcare provider would share their information with other healthcare providers. Conversely, the majority of participants (> 65%) expected their healthcare provider to share their information with other healthcare providers.

Table 34. Awareness of and participation in the My Health Record – opt-out [n(%)]

	Opt-out	Rest of Australia	Difference %	Opt-out	Rest of Australia	Difference	Difference of difference % (SE)
	Baseline	Baseline		Follow up	Follow up		
Registered with myGov	475/694 (68.02%)	323/449 (71.91%)	-3.9%	499/694 (71.17%)	340/449 (75.72%)	-4.6%	-0.7% (3.8)
Aware of My Health Record at baseline	299/694 (43.08%)	171/449 (38.08%)	5.00%				
Made aware of My Health Record during trial period				282/649 (41%)	48/449 (11%)	30%	
Expect your healthcare provider to share your info with other healthcare provider	484/694 (69.74%)	295/449 (65.70%)	4.0%	516/694 (74.35%)	296/449 (65.92%)	8.4%	4.4% (4.0)

Participants in the opt-in trial areas were more likely ($p < 0.05$) to hear information about My Health Record than the rest of Australia. Approximately 18.5% of respondents in the opt-in trial sites had heard about the My Health Record system between baseline and follow up compared to 10.7% in the rest of Australia.

Table 35. Awareness of and participation in the My Health Record – Opt-in [n (%)].

	Opt-in	Rest of Australia	Difference	Opt-in	Rest of Australia	Difference	Difference of difference (SE)
	Baseline	Baseline		Follow up	Follow up		
Registered with myGov	470/775 (62.0%)	323/449 (71.9%)	-9.92%	495/775 (63.85%)	340/449 (75.7%)	-11.9%	-2.0% (3.8)
Aware of My Health Record	292/775 (37.7%)	171/449 (38.1%)	-0.04%				
Made aware of My Health Record during trial period				143/775 (18.5%)	48/449 (10.7%)	7.8%	
Registered for a My Health Record	104/775 (13.4%)	81/449 (18.0%)	-4.6%	142/775 (18.3%)	95/449 (21.2%)	-2.8%	1.8% (2.4)
Expect your healthcare provider to share your info with other healthcare provider	558/775 (72.0%)	295/449 (65.7%)	6.3%	542/775 (69.94%)	296/449 (65.9%)	4.0%	2.3% (3.9)

The myGov website (22.0%) was the most common source of exposure about the My Health Record system, followed by a healthcare provider (21.6%) and national media (17.1%). Other Government websites were the least common source (3.6%). The most common sources were relatively consistent across trial sites.

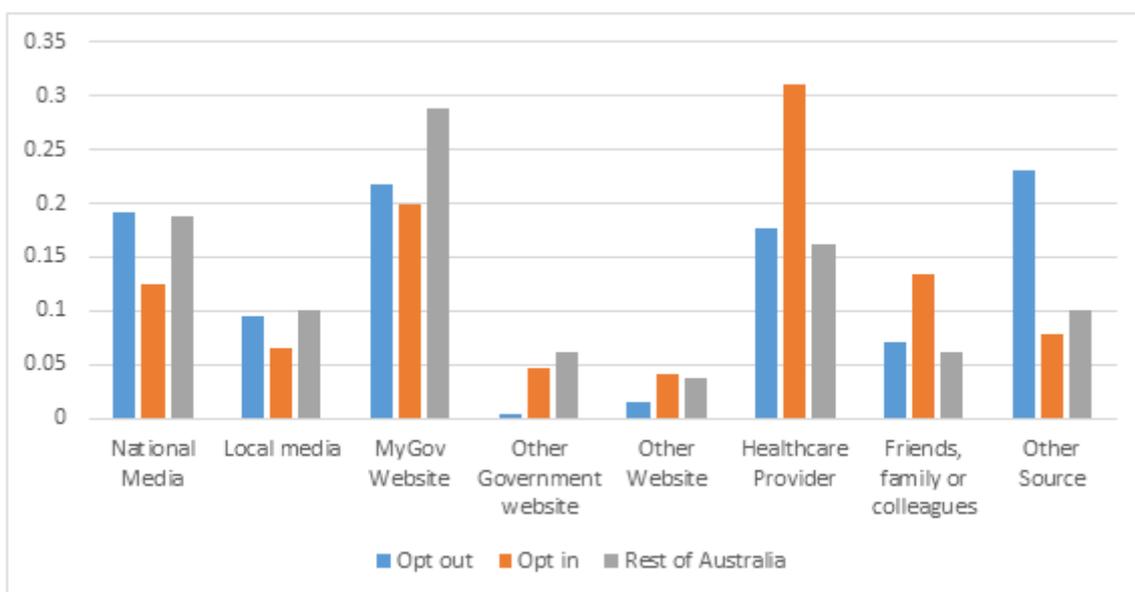


Figure 18 .Proportion of participants receiving information from different sources by trial site.

Increased participation in, and use of, the My Health Record System by users in the survey

There were significant differences in the proportion of respondents who attempted to create a My Health Record between the trial sites. Respondents from the opt-out trial sites were more likely to report that they had a My Health Record (31%) compared to the rest of Australia (21%).

All Medicare registered persons in the opt-out trial sites who didn't have a My Health Record would have received a letter about the participation arrangement. At follow-up, 42% of respondents without a My Health Record recalled receiving a letter that a My Health Record was being created for them.

Table 36 number of participants with or without a My Health Record who received a letter informing them that a My Health Record was been created for them

	Received letter	Didn't/unsure if they received letter	Not eligible to receive a letter
Stated they have a My Health Record	42/103 (40.8%)	61/103 (59.2%)	0/103 (0%)
Stated they did not have a My Health Record	250/591 (42.3%)	337/591 (57%)	4/591 (0.7%)

Overall, there were no significant differences in the demographics of respondents who had a My Health Record across the trial sites. In general, participants with a My Health Record were more likely to be younger. The proportion of respondents stating they had a My Health Record was highest in the 18-34 years age group (28%), decreasing with increasing age group to 20% in the 65+ year's group.

People were more likely to have a My Health Record if they were: living in a single parent household (30%); a couple with children (28%); or a group household (27%). People who had a household income between \$40,000-\$50,000 and those with an income above \$200,000 were most likely to have a My Health Record. Respondents who had attained a higher level of education were more likely to have a My Health Record, with 29% of people with post graduate qualifications reporting they were registered compared to 11% of respondents who had primary school education. This finding was statistically significant ($p < 5\%$). Uptake differed significantly based on internet

connection. People with fast internet were more likely to have registered than people without internet (20% vs 7%).

Overall there was an increase in the number of people who accessed their My Health Record from baseline to follow up. There was a significant increase in the number of participants using their My Health Record in the opt-out trial sites compared to the rest of Australia). However, there were no significant differences in the number of participants using their My Health Record in the opt-in trial sites compared to the rest of Australia.

Table 37. Activity in and attitude towards their My Health Record for participants in the opt-out trial sites compared to the rest of Australia that are registered for a My Health Record [%]

	Opt-out	Rest of Australia	Difference	Opt-out	Rest of Australia	Difference	Difference of difference (SE)
	Baseline (N=105)	Baseline (N=81)		Follow up (N=215)	Follow up (N=95)		
Used My Health Record in last 4 weeks	105/694 (15.1%)	81/449 (18%)	-2.9%	215/694 (31%)	95/449 (21.2%)	9.7%	12.6%
More informed about healthcare you received	19%	32%	-13.7%	23%	27%	-4.8%	8.8% (8.4)
More involved in decision making	20%	22%	-1.8%	15%	22%	-7.1%	-5.2% (7.8)
More aware about your health	20%	30%	-9.2%	23%	21%	1.5%	10.7% (8.2)

Table 38. Activity in and attitude towards their My Health Record for participants in the opt-in trial sites compared to the Rest of Australia that are registered for a My Health Record [%].

	Opt-in	Rest of Australia	Difference	Opt-in	Rest of Australia	Difference	Difference of difference (SE)
	Baseline	Baseline		Follow up	Follow up		
Used My Health Record in last 4 weeks	105/775 (13.5%)	81/449 (18%)	-4.5%	142/775 (18.3%)	95/449 (21.2%)	-2.9	1.6
More informed about healthcare you received	28%	32%	-4.2%	23%	27%	-5.5%	-1.3% (8.9%)
More involved in decision making	21%	22%	-1.1%	15%	22%	1.8%	2.9% (8.3)
More aware about your health	24%	30%	-5.6%	23%	21%	8.5%	14.1% (8.7)

There were no significant differences in whether participants felt more informed about their health or the healthcare they received, or more involved in health decision making in the opt-out trial sites compared to the rest of Australia or the opt-in sites compared to the rest of Australia. Overall of the respondents who were registered for a My Health Record: 23% felt they were more informed about the healthcare they received; 20% felt they were more involved in decision making; and 25% felt they were more aware about their health.

Of the My Health Record activities by participants, only prescription views had increased significantly between the baseline and follow up period for opt-out trial sites over the rest of Australia; however, given the low number of respondents who replied to this question, it is difficult to interpret the true significance of this finding and whether it is a true difference or just an artefact of the low numbers.

Table 39. Activity of participants who are registered for a My Health Record and have accessed their record in the last four weeks [%].

	Opt-out N=12	Rest of Australia N=10	Difference	Opt-out N=22	Rest of Australia N=15	Difference	Difference of difference (SE)
	Baseline	Baseline		Follow up	Follow up		
Viewed healthcare provider document;	42%	50%	-8.3%	50%	20%	30.0%	38.3% (25.9)
Viewed prescription info;	25%	70%	-45.0%	36%	27%	9.7%	54.7% (24.5)
Uploaded document	8%	30%	-21.7%	5%	20%	-15.5%	6.2% (20.0)
Found the My Health Record useful	67%	90%	-23.3%	73%	67%	6.1%	29.4% (22.7)

There were no statistically significant differences in the viewing and uploading activities reported by participants in the opt-in sites compared to the rest of Australia.

Table 40. Activity of participants that are registered for a My Health Record and have accessed their record in the last four weeks [%]

	Opt-in N=11	Rest of Australia N=10	Difference	Opt-in N=18	Rest of Australia N=15	Difference	Difference of difference (SE)
	Baseline	Baseline		Follow up	Follow up		
Viewed healthcare provider document;	30%	50%	-20.0%	39%	20%	18.9%	38.9% (26.4)
Viewed prescription info;	50%	70%	-20.0%	22%	27%	-4.4%	15.6% (26.2)
Uploaded document	0%	30%	-30.0%	17%	20%	-3.3%	26.7% (19.8)
Found the My Health Record useful	30%	90%	-60.0%	50%	67%	-16.7%	43.3% (24.2)

Overall, the number of participants accessing their My Health Record was very low in the 4-week period before the baseline questionnaire and the follow up questionnaire. Also there was little difference between the types of activities occurring across the trial sites.

Choosing a healthcare provider based on access to My Health Record

There were no statistically significant differences between the opt-out trial sites and the rest of Australia with regards to the likelihood of choosing a healthcare provider based on their use of the My Health Record system (Table 39). There were no differences in change in this attitude from baseline to follow up.

Table 41. Choosing a healthcare provider based on access to My Health Record [%].

	Opt-out N=649	Rest of Australia N=449	Difference	Opt-out N=649	Rest of Australia N=449	Difference	Difference of difference (SE)
	Baseline	Baseline		Follow up	Follow up		
Increase likelihood	21%	20%	1.0%	27%	23%	3.6%	2.6% (2.9)
Not affect your decision	57%	57%	-0.1%	55%	57%	-1.3%	1.2% (0.8)
Decrease likelihood	3%	3%	0.1%	4%	3%	0.3%	0.2% (0.03)
Don't know	19%	20%	-1.0%	15%	17%	-0.9%	-1.6% (2.5)

There were no statistically significant differences between the opt-in trial sites and the rest of Australia with regards to the likelihood of choosing a healthcare provider based on their use of the My Health Record system (Table 40). Also there were no differences in change in this attitude from baseline to follow up.

Table 42. Choosing a healthcare provider based on access to My Health Record [%].

	Opt-in N=775	Rest of Australia N=449	Difference	Opt-in N=775	Rest of Australia N=449	Difference	Difference of difference (SE)
	Baseline	Baseline		Follow up	Follow up		
Increase likelihood	23%	20%	3.3%	24%	23%	1.1%	-2.1 (2.8)
Not affect your decision	57%	57%	-0.6%	56%	57%	-0.4%	0.2% (0.7)
Decrease likelihood	3%	3%	0.3%	4%	3%	0.1%	-0.02 (0.03)
Don't know	17%	20%	-3.0%	16%	17%	-0.9%	2.1% (2.4)

A quarter of all respondents stated that if a healthcare provider used the My Health Record system it would increase their likelihood of using that healthcare provider, this was an increase from baseline, though not statistically significant. The majority of respondents (56%) stated the use of the My Health Record system by their healthcare provider would not affect their decision (Table 39 and Table 40).

Increased confidence to use the system amongst users

Users were asked about their confidence in the My Health Record system to maintain their data confidentially and securely. There was no difference in change in attitudes over the trial period between participants in opt-out trial sites and the rest of Australia (Table 11).

Table 43. Confidence using My Health Record – opt-out [%].

	Opt-out N=649	Rest of Australia N=449	Difference	Opt-out N=649	Rest of Australia N=449	Difference	Difference of difference (SE)
	Baseline	Baseline		Follow up	Follow up		
Changing privacy settings	68.2%	72.7%	-4.5%	56.2%	74.4%	-18.1%	-13.6% (8.6)
Viewing documents	73.3%	57.4%	-5.1%	78.4%	67.1%	-9.7%	-4.6% (8.4)
Uploading documents or updating health information	60.7%	73.4%	-12.7%	40.9%	52.4%	-11.5%	1.2% (9.0)
Updating details regarding your health	68.8%	79.5%	-10.7%	50.7%	67.4%	-16.7%	6.0% (8.5)
Using My Health Record with healthcare provider	51.9%	61.6%	-9.7%	52.1%	60.3%	-8.2%	1.5% (9.1)
Cancelling My Health Record	74.8%	77.4%	-2.6%	38.8%	49.3%	-10.5%	-7.9% (8.5)

Similarly, there was no difference in change in attitudes over the trial period between participants in opt-in trial sites and the rest of Australia (Table 42).

Table 44. Confidence using My Health Record – opt-in [%].

	Opt-in N=775	Rest of Australia N=449	Difference	Opt-in N=775	Rest of Australia N=449	Difference	Difference of difference % (SE)
	Baseline	Baseline		Follow up	Follow up		
Changing privacy settings	78.3%	72.7%	5.6%	68.2%	74.4%	-6.2%	-- 11.8%(8.6)
View documents	81.5%	57.4%	3.1%	69.6%	67.1%	2.5%	-0.5% (8.4)
Uploading documents or updating health information	72.7%	73.4%	-0.8%	52.2%	52.4%	-0.2%	0.5% (9.0)
update details regarding your health	79.3%	79.5%	-0.3%	66.9%	67.4%	-0.5%	0.2% (8.5)
Using My Health Record with healthcare provider	70.0%	61.6%	8.5%	61.6%	60.3%	0.1%	-8.4% (9.3)
Cancelling My Health Record	80.8%	77.4%	3.4%	52.5%	49.3%	3.2%	0.2% (8.8)

While there was no difference between the rest of Australia, opt-in or opt-out trial sites, 35% of respondents reported feeling confident in the My Health Record system to maintain their information confidentially and securely. Those who were registered with My Health Record were more confident that their information was secure with 56% stating they were confident or very confident compared to 35% of those who were not registered. A smaller proportion of people who were registered reported being not confident or really not confident (14% vs 34%). A larger proportion of respondents from the opt-out sites reported they were 'really not confident' (13%), compared to 7% in the opt-in trial sites and the rest of Australia.

A quarter of respondents (24%) felt confident that the system was secure from external threats with no difference between the rest of Australia, opt-in or opt-out trial sites. A similar proportion (28%)

was confident in the Government’s capacity to keep personal information confidential with no difference between the rest of Australia, opt-in or opt-out trial sites.

Generally speaking, participants were unsure or not confident in the ability of the My Health Record system to maintain their information as confidential and secure, in the Government’s capacity to protect their My Health Record data secure from external threats, and in the Government’s capacity to keep their personal information held in the My Health Record confidential. Just over a third of the population indicated that they were confident or really confident. Overall participants trusted the Government and others somewhat to always treat their medical information appropriately.

Table 45. Confidence in security measures around the My Health Record System.

	Really confident	Confident	Not sure	Not confident	Really not confident
How confident are you in the ability of the My Health Record system to maintain your information as confidential and secure?					
Opt-out	39 (6.1%)	211 (32.9%)	201 (31.4%)	99 (15.4%)	91 (14.2%)
Opt-in	45 (6.5%)	228 (33.1%)	231 (33.6%)	127 (18.5%)	57 (8.3%)
Rest of Australia	19 (4.9%)	125 (32.1%)	141 (36.2%)	72 (18.5%)	33 (8.5%)
How confident are you in the Government’s capacity to protect your My Health Record data secure from external threats?					
	To a great extent	Very much	Somewhat	Very little	Not at all
Opt-out	18 (2.8%)	150 (23.5%)	196 (30.8%)	148 (23.2%)	125 (19.6%)
Opt-in	29 (4.1%)	153 (21.9%)	228 (32.6%)	187 (26.8%)	102 (14.6%)
Rest of Australia	11 (2.8%)	104 (26.5%)	125 (31.8%)	95 (24.2%)	58 (14.8%)
How confident are you in the Government’s capacity to keep your personal information held in the My Health Record confidential?					
	To a great extent	Very much	Somewhat	Very little	Not at all
Opt-out	22 (3.4%)	173 (26.6%)	186 (28.6%)	136 (20.9%)	134 (20.6%)
Opt-in	24 (3.3%)	187 (25.8%)	227 (31.3%)	186 (25.6%)	102 (14%)
Rest of Australia	11 (2.7%)	115 (27.9%)	128 (31.1%)	100 (24.3%)	58 (14.1%)
To what extent do you trust that the Government/others will always treat your medical information appropriately					
	To a great extent	Very much	Somewhat	Very little	Not at all
Opt-out	30 (4.6%)	126 (19.1%)	292 (44.4%)	119 (18.1%)	91 (13.8%)
Opt-in	47 (6.5%)	155 (21.4%)	324 (44.7%)	118 (16.3%)	81 (11.2%)
Rest of Australia	17 (4.1%)	81 (19.4%)	201 (48.2%)	71 (17%)	47 (11.3%)

There was no difference in participants’ intention to use their My Health Record between trial sites into the near future. Approximately half of all respondents (47%) plan continue to use their My Health Record at the same level, though there were no differences across trial sites. Very few respondents intended to cancel or decrease use of their My Health Record.

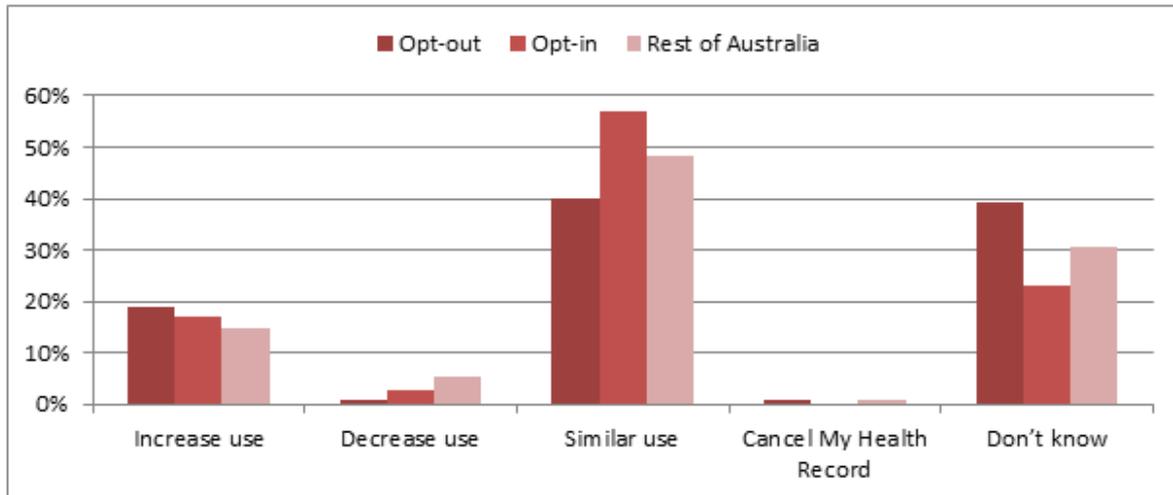


Figure 19. Percentage of participants that plan to use their My Health Record in the next 4 months by trial site.

At the time of the first survey, two thirds of participants reported having taken up to 15 minutes to register for a My Health Record account. A further 23% required 16-30minutes to set up their account. There were no differences between trial sites. The second survey includes only the opt-in and rest of Australia groups. Respondents in the opt-in group appeared to set up their accounts faster than the rest of Australia group although this difference was not statistically significant.

Results of Qualitative Analysis

Not all the questions from the follow up were asked in the baseline survey of the evaluation. They were added to gather more information from the results of the baseline survey.

We firstly describe the overall findings for each qualitative question from the follow up survey. Where possible, we then compared the results found from the follow up survey with the baseline survey. However, it should be noted that the frequency and proportion reported in the tables below for the follow up survey could not be directly compared against those reported at baseline, as proportion calculated at baseline accounted for people who did not respond in the follow up survey.

The findings for each question in the follow up survey were then analysed by different demographic groups: age groups; whether individuals identified as Aboriginal and/or Torres Strait Islander whether people spoke a language other than English at home; and their location. Patterns of results emerged when analysed by different demographic groups and were then compared with the overall pattern of results. They were also compared against the findings of the baseline survey which were also analysed by different demographic groups.

Note: When responses to the qualitative questions (i.e. open-ended questions) could be classified under two different categories, they were then coded in those two categories. Therefore, the total number of responses described in the following section does not reflect the total number of respondents who answered the question. Rather, it represents the total number of concepts or categories respondents provided to answer a question. It should also be noted that the percentages reported within each question can only be interpreted for that question as they account for the percentage of total number of categories expressed in response to a question, rather than the total number of people who responded to the question. Responses that did not directly address the questions asked or were not able to be interpreted were categorised as “Other”.

Results for each open-ended question in the survey of individuals are described as a whole, highlighting the key categories and responses provided. The findings are then broken down and presented in demographic groups to identify any observable differences or key findings within: age group, locations, Aboriginal and Torres Strait Islander background; and whether respondents spoke another language at home.

Reasons for not having a myGov account

Those who indicated that they did not have a myGov account were asked to provide reasons for not doing so. At follow up, a total of 401 people responded (Table 44). The most common themes for not having a myGov account were: the respondents were not aware or informed about myGov (n=128, 32%); having a myGov account was unnecessary (n=83, 21%); and creating an account was not a priority n=53, 13%). The categories of responses in the follow up results are consistent with those found at baseline. There were some at baseline who indicated that they did not have access to the Internet/a computer as a reason for not having a myGov account. The top four reasons for not having a myGov aligned with those reported at baseline.

Table 46: Reasons for not creating a myGov account (n,%).

Baseline			Follow-up		
Category	n	%	Category	n	%
Lack of awareness/information	464	52%	Lack of awareness/information	128	32%
Having a myGov account is unnecessary	196	22%	Having a myGov account is unnecessary	83	21%
Creating a myGov account is not a priority	78	9%	Creating a myGov account is not a priority	53	13%
Difficulties accessing/registering a myGov account	31	3%	Difficulties accessing/registering a myGov account	36	9%
Privacy and security concerns	24	3%	Unsure	33	8%
Unsure	24	3%	Privacy and security concerns	16	4%
Was not prompted by the Government/healthcare providers	13	1%	Having a myGov account increases Government access/control over individual information	2	0%
Lack of Internet/computer access	8	1%	Was not prompted by the Government/healthcare providers	2	0%
Having an account increases Government access/control over individual information	5	1%	Concerns about the effectiveness and usefulness of the myGov account	1	0%
Concerns about the effectiveness and usefulness of the myGov account	4	0%	Other (e.g., might enrol, not entitled to Medicare benefits; partner has an account; prefer face to face interaction)	47	12%
Other (e.g., no opportunity, might enrol, not entitled to Medicare benefits/not entitled to create an account, partner has an account)	51	6%			
Total	898	100	Total	401	100%

Some quotes from respondents who provided reasons for not creating a myGov account were:

"Because I don't really have any health issues so I don't really see health professionals enough to need one"

"I have never heard of myGov. Why do I need one?"

"Haven't been too aware of this and how to get on the system."

"I don't need one and I don't trust the Government to keep my information secure."

"It's another way for 'big brother' to keep an eye on me."

"I didn't have any idea it [existed] until you surveyed me last time. I googled it to see what it was and was surprised to find [what] it was about and I still haven't done anything."

"Have seen how useless my husband's account is. Too slow and hard to use."

"I have tried to set it up on several occasions and have failed. I need some help."

"Because I don't believe all the problems of these records have been fully worked out in NSW - not sure."

"Tried several times to enrol but it kept cutting out on me so I gave up."

"Nobody asked me to have one."

"I am not in receipt of any Government benefits."

Age group: Similar patterns of findings also emerged in the follow up survey when compared to the baseline. Most who responded were aged 50-64 years. Younger populations (18-34 years) were more likely to say that they did not see a need to have a myGov or felt it was not a priority to have one in both follow up and at baseline (Table 45). Older populations were also more likely to say that they experienced difficulty accessing or registering for a myGov account.

Table 47 Number of responses per category identified against age groups (for baseline and follow up).

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
Lack of awareness/information	67	91	183	123	Lack of awareness/information	5	19	48	56
Having a myGov account is unnecessary	39	37	75	45	Having a myGov account is unnecessary	9	19	36	19
Creating a myGov account is not a priority	17	19	27	15	Creating a myGov account is not a priority	7	11	24	11
Difficulties accessing/registering a myGov account	2	4	10	15	Difficulties accessing/registering a myGov account	2	5	16	13
Privacy and security concerns	1	6	13	4	Unsure	5	8	14	6
Unsure	5	6	8	5	Privacy and security concerns	0	1	11	4
Was not prompted by the Government/health care providers	0	3	3	7	Having a myGov account increases Government access/control over individual information	0	1	1	0
Having a myGov account increases Government access/control over individual	0	2	2	1	Was not prompted by the Government/health care providers	0	0	0	2

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
information									
Lack of Internet/computer access	0	2	3	3	Concerns about the effectiveness and usefulness of the myGov account	0	0	0	1
Concerns about the effectiveness and usefulness of the myGov account	2	0	1	1	Other	6	5	23	13
Other	15	8	20	8					
Total	148	178	345	227	Total	29	50	125	69

Other demographic groups: Similarly, at baseline there were no observable differences in reasons for not creating a myGov account between those who identified as Aboriginal and Torres Strait Islander, those who spoke a language other than English, and between locations across the trial and comparison sites. A lack of awareness or information, seeing a myGov account as unnecessary or not a priority, and having difficulty accessing and registering for a myGov were commonly mentioned across the three demographic categories.

Tables of results for other demographic groups are presented in below in Tables 16 to 18.

Table 48 Number of responses per category identified against respondents' identification as an Aboriginal and/or Torres Strait Islander for baseline and follow up.

Baseline				Follow Up			
Category	No	Prefer not to say	Yes	Category	No	Prefer not to say	Yes
Lack of awareness/information	446	4	14	Lack of awareness/information	126	0	2
Having a myGov account is unnecessary	185	4	7	Having a myGov account is unnecessary	79	1	3
Creating a myGov account is not a priority	71	2	5	Creating a myGov account is not a priority	50	0	3
Difficulties accessing/registering a myGov account	29	0	2	Difficulties accessing/registering a myGov account	34	0	2
Privacy and security concerns	22	1	1	Unsure	16	0	0
Unsure	24	0	0	Privacy and security concerns	32	0	1
Was not prompted by the Government/healthcare providers	13	0	0	Having an account increases Government access/control over individual information	2	0	0
Lack of Internet/computer access	8	0	0	Was not prompted by the Government/healthcare providers	1	0	1
Having an account increases Government access/control over individual information	4	0	1	Concerns about the effectiveness and usefulness of the myGov account	1	0	0
Concerns about the effectiveness and usefulness of the myGov account	4	0	0	Other	45	1	1
Other	48	0	3				
Total	854	11	33	Total	260	2	11

Table 49: Number of responses per category by respondent's identification of whether they spoke another language at home (for baseline and follow up).

Baseline				Follow up			
Category	No, only speak English	Prefer not to say	Yes	Category	No, only speak English	Prefer not to say	Yes
Lack of awareness/information	428	1	35	Lack of awareness/information	122	0	6
Having a myGov account is unnecessary	182	2	12	Having a myGov account is unnecessary	80	1	2
Creating a myGov account is not a priority	70	0	8	Creating a myGov account is not a priority	49	0	4
Difficulties accessing/registering a myGov account	31	0	0	Difficulties accessing/registering a myGov account	34	0	2
Privacy and security concerns	20	0	4	Unsure	29	0	4
Unsure	21	0	3	Privacy and security concerns	14	0	2
Was not prompted by the Government/healthcare providers	13	0	0	Having an account increases Government access/control over individual information	2	0	0
Lack of Internet/computer access	7	0	1	Was not prompted by the Government/healthcare providers	1	0	1
Having an account increases Government access/control over individual information	5	0	0	Concerns about the effectiveness and usefulness of the myGov account	1	0	0
Concerns about the effectiveness and usefulness of the myGov account	4	0	0	Other	43	0	4
Other	45	1	5				
Total	826	4	68	Total	253	1	19

Table 50: Number of responses per category against the trial sites and the Rest of Australia for baseline and follow up.

Baseline						Follow up					
Category	NQ	NB M	Balla rat	WA	Rest of Australia	Category	NQ	NB M	Balla rat	W A	Rest of Australia
Lack of awareness/information	90	67	164	74	69	Lack of awareness/information	18	13	54	25	18
Having a myGov account is unnecessary	29	38	51	43	35	Having a myGov account is unnecessary	13	15	22	19	14
Creating a myGov account is not a priority	15	12	19	15	17	Creating a myGov account is not a priority	9	7	14	5	18

Baseline						Follow up					
Category	NQ	NB M	Balla rat	WA	Rest of Austr alia	Category	NQ	NB M	Balla rat	W A	Rest of Austr alia
Difficulties accessing/ registering a myGov account	5	5	8	4	9	Difficulties accessing/ registering a myGov account	8	4	7	9	8
Privacy and security concerns	8	5	6	2	3	Unsure	4	3	10	5	11
Unsure	2	3	4	3	12	Privacy and security concerns	6	4	1	4	1
Was not prompted by the Government/ healthcare providers	1	3	7	1	1	Having a myGov account increases Government access/control over individual information	0	0	0	0	2
Lack of Internet/ computer access	0	2	5	1	0	Was not prompted by the Government/ healthcare providers	0	0	1	1	0
Having an account increases Government access/ control over individual information	2	1	0	1	1	Concerns about the effectiveness and usefulness of the myGov account	0	1	0	0	0
Concerns about the effectiveness and usefulness of the myGov account	0	0	0	1	3	Other	8	12	14	5	8
Other	8	11	12	14	6						
Total	160	147	276	159	156	Total	48	46	123	48	62

Reasons for not registering for a My Health Record (previously known as a PCEHR)

A total of 555 people provided reasons for not registering for a My Health Record, with a total of 562 responses recorded in the follow up survey. The reader should note that only people who had not registered for a My Health Record in the opt-in trial sites (Ballarat and Western Australia) and in the comparison site (Rest of Australia) were asked to provide reasons at follow up.

Of the 562 responses, 24% indicated that they were unaware or uninformed about the My Health Record system (n=134), and 21% believed that having a My Health Record was unnecessary (n=117). Creating a My Health Record was not a priority for 13% (n=71), while 7% had privacy and security concerns (Table 49). Those who reported that they were not interested in having a My Health Record also indicated that their doctors were not using the My Health Record system. A few

mentioned that the difficulty to register for a My Health Record was due to difficulty accessing myGov.

The categories found from the follow up surveys are consistent with those found at baseline (Table 49). Similarly, the top four reasons for not having a My Health Record aligned with those reported at baseline.

Table 51: Reasons for not registering for a My Health Record for baseline and follow up (n, %).

Baseline			Follow up		
Category	n	%	Category	n	%
Lack of awareness/information	1933	64%	Lack of awareness/information	134	24%
Having a My Health Record is unnecessary	227	8%	Having a My Health Record is unnecessary	117	21%
Creating a My Health Record is not a priority	189	6%	Creating a My Health Record is not a priority	71	13%
Privacy and security concerns	157	5%	Difficulties accessing/registering a My Health Record	46	8%
Not interested in creating a My Health Record	135	4%	Privacy and security concerns	39	7%
Difficulties accessing/registering a My Health Record	88	3%	Not sure	35	6%
Not sure	75	3%	Not prompted by Government/healthcare providers	19	3%
Not prompted by Government/healthcare providers	51	2%	Having an account increases Government access/control over individual information	12	2%
Concerns about the effectiveness and usefulness of the My Health Record	25	1%	Concerns about the effectiveness and usefulness of the My Health Record	9	2%
Don't know the benefits of having a My Health Record	36	1%	Not interested in creating a My Health Record	7	1%
Other (e.g., prefer pen and paper version, no opportunity, lack of support from healthcare providers)	119	4%	Other (e.g., does not have Medicare, can't afford it)	73	13%
Total	3,035	100%	Total	562	100%

Some quotes from respondents who provided reasons for not creating a My Health Record were:

“Because I haven’t needed one. I don’t have any health concerns so I haven’t actually been to any healthcare provider for a few years.”

“Don’t see the point because I already have my regular doctor and there is no need to access info beyond him.”

“Cause I’m not unwell so it’s not a high priority. If I had a lot of illnesses or any illness, then I’d do it.”

“I do not really know if I am registered or not. I have a myGov account as I am on a Government Aged Pension, but I do not recall specifically registering for a My Health Record. I do not know if this is a compulsory requirement, but I do not remember registering.”

“Don’t think it’s necessary and I also have a lack of awareness about it.”

“Didn’t receive any info that told me I had to sign up and that it would benefit me.”

“I just wasn’t aware that I had to and I have no idea what it is.”

“I don’t mind my health records being given to certain health professionals that may need it at a particular time, but I’m still unconvinced about the security of e-health records generally.”

“Because I had trouble last time with setting it up so I didn’t bother and it all seemed to[o] complicated and I didn’t see any benefit.”

“Every time I attempt to set up, I get contradictory info in regards to verification.”

“I thought they were doing it through the doctor’s surgery. I didn’t know I had to do it.”

“I don’t trust the Government to keep it private in the future. Please refer to the last census data and the retention of names.”

“My doctor does not input into My Health [Record] and says that he has not had training (I don’t think he would be bothered!).”

“I have quite a bit of trouble with the myGov webpage when I have to contact Centrelink and this has put me off attempting to complete a My Health Record.”

Age group: In both follow up and baseline studies, most respondents were aged 50- 64 years. When compared to the baseline survey, younger people (18- 34 years) were more likely to feel that having a My Health Record was unnecessary in the follow up survey. Most people aged 18-34 years indicated that they were uninformed or unaware of the My Health Record.

As at the baseline, lack of awareness or information about the My Health Record was most often reported as the reason for not having a My Health Record in the follow up study for those above 35 years old. The total number of responses/ reasons for not creating a My Health Record and by age groups are presented in

Table 50 for baseline and follow up surveys.

Table 52: Number of responses per category for each age group for the baseline and follow up study.

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
Lack of awareness, information	462	496	594	381	Lack of awareness, information	12	41	35	46
Having a My Health Record is unnecessary	45	59	82	41	Having a My Health Record is unnecessary	23	37	32	25

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
Creating a My Health Record is not a priority	49	58	55	27	Creating a My Health Record is not a priority	16	18	22	15
Privacy and security concerns	26	41	59	31	Difficulties accessing/registering a My Health Record	5	10	9	15
Not interested in creating a My Health Record	23	37	44	31	Privacy and security concerns	5	13	19	8
Difficulties accessing/registering a My Health Record	16	20	25	27	Not sure	7	8	9	11
Not sure	27	25	15	8	Not prompted by Government/healthcare providers	2	2	7	8
Not prompted by Government/healthcare providers	4	6	18	23	Having an account increases Government access/control over individual information	1	2	8	1
Concerns about the effectiveness and usefulness of the My Health Record	4	4	9	8	Concerns about the effectiveness and usefulness of the My Health Record	3	1	1	4
Don't know the benefits of having a My Health Record	7	9	11	9	Not interested in creating a My Health Record	0	0	3	4
Other	18	28	33	40	Other	14	14	20	24
Total	681	783	945	626	Total	88	146	165	161

Other demographics: There were no observable differences in reasons provided by respondents who had not registered for a My Health record between those who identified as Aboriginal and Torres Strait Islander and those who spoke a language other than English at home. The pattern of results for these two demographic groups were similar to the patterns of results as a whole. That is, lack of awareness or information about the My Health Record was the most common reason cited for not having a My Health Record. This was consistent with the results found at baseline when compared against the same demographic groups.

Consistent with the baseline results, the most common reason expressed for not having a My Health Record in the follow up study was not being informed about or aware of it. Contrary to the baseline results, most people in the rest of Australia (the comparison site) reported that they saw having a My Health Record as unnecessary. Results for the demographics are described in Table 51. These tables describe the total number of responses from baseline to follow up, per category of the main reason for not having a My Health Record plotted against age groups, location, respondents' identification as having an Aboriginal and/or Torres Strait Islander background, and whether respondents spoke another language at home. Note that people in NQ PHN and NBM PHN (opt-out sites) were not asked to provide reasons for not registering for a My Health Record.

Table 53: Number of responses per category against respondents' identification as an Aboriginal and/or Torres Strait Islander for baseline and follow up

Baseline				Follow up			
Category	No	Prefer not to say	Yes	Category	No	Prefer not to say	Yes
Lack of awareness/information	1846	16	71	Lack of awareness/information	130	2	2
Having a My Health Record is unnecessary	220	1	6	Having a My Health Record is unnecessary	116	0	1
Creating a My Health Record is not a priority	176	3	10	Creating a My Health Record is not a priority	66	0	5
Privacy and security concerns	143	5	9	Difficulties accessing/registering a My Health Record	42	0	4
Not interested in creating a My Health Record	127	2	6	Privacy and security concerns	39	0	0
Difficulties accessing/registering a My Health Record	84	1	3	Not sure	35	0	0
Not sure	67	5	3	Not prompted by Government/healthcare providers	19	0	0
Not prompted by Government/healthcare providers	49	1	1	Having an account increases Government access/control over individual information	10	0	2
Concerns about the effectiveness and usefulness of the My Health Record	24	0	1	Concerns about the effectiveness and usefulness of the My Health Record	9	0	0
Don't know the benefits of having a My Health Record	35	0	1	Not interested in creating a My Health Record	7	0	0
Other	115	1	3	Other	72	0	1
Total	2,886	35	114	Total	545	0	15

Table 54 : Number of responses per category identified against whether respondents spoke another language apart from English at home for baseline and follow up

Baseline				Follow up			
Category	No, I only speak English	Prefer not to say	Yes	Category	No, I only speak English	Prefer not to say	Yes
Lack of awareness/information	1,750	16	167	Lack of awareness/information	117	0	17
Having a My Health Record is unnecessary	210	2	15	Having a My Health Record is unnecessary	111	0	6
Creating a My Health Record is not a priority	178	0	11	Creating a My Health Record is not a priority	64	0	7
Privacy and security concerns	146	0	11	Difficulties accessing/registering a My Health Record	42	0	4

Baseline				Follow up			
Category	No, I only speak English	Prefer not to say	Yes	Category	No, I only speak English	Prefer not to say	Yes
Not interested in creating a My Health Record	128	2	5	Privacy and security concerns	33	0	6
Difficulties accessing/registering a My Health Record	79	0	9	Not sure	32	0	3
Not sure	70	2	3	Not prompted by Government/healthcare providers	17	0	2
Not prompted by Government/healthcare providers	47	0	4	Having an account increases Government access/control over individual information	12	0	0
Concerns about the effectiveness and usefulness of the My Health Record	22	0	3	Concerns about the effectiveness and usefulness of the My Health Record	7	0	2
Don't know the benefits of having a My Health Record	33	1	2	Not interested in creating a My Health Record	7	0	0
Other	105	1	13	Other	68	0	5
Total	2,768	24	243	Total	510	0	52

Table 55. Number of responses per category against the trial sites and the Rest of Australia for baseline and follow up

Baseline						Follow up					
Category	NQ	NB M	Ballarat	W A	Rest of Australia	Category	NQ	NB M	Ballarat	WA	Rest of Australia
Lack of awareness/information	400	353	405	415	360	Lack of awareness/information	0	0	54	41	39
Having a My Health Record is unnecessary	42	45	61	45	34	Having a My Health Record is unnecessary	0	0	36	37	44
Creating a My Health Record is not a priority	32	54	41	32	30	Creating a My Health Record is not a priority	0	0	39	19	13
Privacy and security concerns	33	33	25	27	39	Difficulties accessing/registering a My Health Record	0	0	16	14	17
Not interested in creating a My Health Record	22	29	33	19	32	Privacy and security concerns	0	0	16	12	11
Difficulties accessing/registering a My Health Record	11	25	13	17	22	Not sure	0	0	9	7	19
Not sure	14	14	9	11	27	Not prompted by Government/healthcare providers	0	0	11	4	4

Baseline						Follow up					
Category	NQ	NB M	Ballarat	W A	Rest of Australia	Category	NQ	NB M	Ballarat	WA	Rest of Australia
Not prompted by Government/healthcare providers	8	15	8	9	11	Having an account increases Government access/ control over individual information	0	0	4	3	5
Concerns about the effectiveness and usefulness of the My Health Record	8	3	4	0	10	Concerns about the effectiveness and usefulness of the My Health Record	0	0	1	5	3
Don't know the benefits of having a My Health Record	7	6	6	8	9	Not interested in creating a My Health Record	0	0	4	1	2
Other	23	19	33	21	23	Other	0	0	14	29	29
Total	600	596	638	604	597	Total	0	0	204	172	186

Reasons for intending to cancel their My Health Record in the next four months

Those who indicated that they would cancel their My Health Record in the next four months were asked to provide reason(s) for doing so. Only three people provided reasons for their intention to cancel their My Health Record in the next four months. One reported that the information contained in their My Health Record was incorrect and another felt it was useless. The third respondent felt that having a My Health Record increases the Government's ability to monitor them.

How the members of your treating team worked better as a team because of the My Health Record?

Some respondents indicated that they had observed that having a My Health Record meant that members of their treating team had worked better together. These respondents were asked to further explain their response. A total of 76 respondents described how the members of their treating team worked better as a team because of the My Health Record.

Of the 76 respondents, 52% felt that the record had allowed their treating team members access to the same information (n=39). People also indicated that the My Health Record assisted their clinicians in their clinical decision making because they had all the information they needed without having to rely on the patient's memory or having the patient repeat their medical history. Six respondents provided 'other' responses such as: they intended to find more information about the My Health Record or did not see the use of the My Health Record at the time of being surveyed. Table 54 presents the frequency and proportion of responses by category expressed by respondents who described how their treating team would worked better as a team because of the My Health Record.

Table 56: How the My Health Record enabled members of treating team to work better as a team?

Category	n	%
Having a shared understanding of patient's health information	39	52%
Assists in clinical decision making without relying on patient's memory	12	16%
Create communication between GP / Specialists / allied health	7	9%
Not sure	5	7%

Category	n	%
Easy access to medical information without relying on patient's memory	5	7%
None	1	1%
Other (e.g., not using it yet, I would get more information)	6	8%
Total	75	100%

Some quotes from respondents described how the My Health Record enabled members of their treating team to work better as a team were:

"They work better because they can share information between each other so they are on the same page."

"All had access to the same info without me having to keep repeating myself."

"They're not chasing each other up about my medical conditions because they now share info."

"Better access to my medical history which has improved my care to doctors."

"GP, Specialists, Physio, [and] OT are all working to give me better quality of life, and day to day living."

"When I require medication, if my doctor is not available, I can rely on another doctor to prescribe rather than having to go through my whole record again."

"Because of ease of communication."

"They are aware of ongoing issues and previous history without the need for me to repeat it every time."

"Easy to share information."

Owing to the small number of people who responded to the question, we only compared participants' responses to their location (Table 55). Most people who described how the My Health Record had enabled their treating team to work together better as a team were from the comparison site (rest of Australia). Across all locations, most people felt that their treating team members would have a shared understanding of their health when everyone has access to the same information through the My Health Record.

Table 57: Number of responses for describing how the My Health Record would enable treating team members to work better as a team, by trial and non-trial sites and category.

Category	NQ	NBM	Ballarat	WA	Rest of Australia
Having a shared understanding of patient's health information	5	7	6	6	11
Assists in clinical decision making without relying on patient's memory	2	3	2	4	1
Create communication between GP / Specialists / allied health	2	4	1	1	4
Not sure	1	1	0	1	2
Easy access to medical information without relying on patient's memory	0	0	1	2	1
None	0	0	0	1	0
Other (e.g., not using it yet, I would get more information)	1	3	1	0	1
Total	11	18	11	15	20

Main purpose of having a My Health Record

All respondents were asked to provide their opinions about the main purpose of having a My Health Record, and a total of 1,885 respondents provided opinions. A total of 1,931 responses were recorded.²¹ Of the 1,931 responses, 24% indicated that their My Health Record allowed healthcare

²¹ More than one opinion/response was possible per respondent.

providers to share health information with each other (n=462). 16% said that it created a centralised health record for individuals and healthcare providers (n=310), and 16% were unsure of its purpose. Another 17% felt that the My Health Record provided healthcare providers easy access to their individual health information, particularly when they were hospitalised or injured while travelling in Australia.

Compared to results from the baseline, similar categories emerged from the data in the follow up survey. Table 56 presents the frequency and proportion of categories expressed by respondents about the main purpose of the My Health Record.

Table 58: Main purpose of having a My Health Record in baseline and follow up surveys

Baseline			Follow up		
Category	n	%	Category	n	%
Easy access to an individual's health information for healthcare providers	971	27%	To share information between healthcare providers	462	25%
Don't know	819	23%	Easy access to an individual's health information for healthcare providers	334	18%
Have one centralised health record for individuals and healthcare providers	703	20%	Have one centralised health record for individuals and healthcare providers	310	17%
To share information between healthcare providers	370	11%	Don't know	285	16%
For individuals to better monitor their own health	200	6%	To provide high quality healthcare	116	6%
For individuals to have the ability to personalise and control over the access/view of their health information	117	3%	To have access to up-to-date and accurate information for individuals and healthcare providers	105	6%
To provide high quality healthcare	94	3%	To increase Government's access to information about individuals health in order to control and monitor them	97	5%
To have access to up-to-date and accurate information for individuals and healthcare providers	85	2%	For individuals to better monitor their own health	58	3%
To increase Government's access to information about individuals health in order to control and monitor them	80	2%	For individuals to have the ability to personalise and control over the access/view of their health information	48	3%
Other (e.g., no reason, no, waste of money, expressed concerns about privacy)	100	3%	Other (e.g., no purpose, waste of money, expressed concerns about privacy)	116	6%
Total	3,539	100	Total	1,931	100%

Some quotes from respondents described the main purpose of the My Health Record:

"So if my GP is not available and I need treatment any other practitioner can check my medical records and the treatment I am having, the medicine I am taking so if I forget is not important."

"The main purpose of having My Health Record is to facilitate access by qualified medical staff to access my records if absolutely necessary to avoid any over-servicing."

"So that data kept and shared between healthcare providers which might be particularly useful for those that move around."

"I think it makes a lot of sense and has a lot of safety in that people are being able to be prescribed medication as sometimes [if] I were to turn to a GP or a specialist they could access that and see what medication I am on which would be useful. Also, for keeping records if you've had tests and things."

"So there is consistency in treatment, prescriptions etc. in more integrated ways right across medical practitioners, specialists, hospitals etc. and less likely for mistakes to be made"

“So that when you have an accident or you have to enter the hospital for any reasons the doctors can get access to your medical history and medications that you're taking. This will be available all over Australia.”

“To have record of when certain appointment or practice have been made and to know when the next one is due like pap smear test, blood test.”

“A one-stop shop of health records for individuals, to enable better patient care (if all records can be seen in one location).”

“It allows anyone to check your health issues i.e. in an emergency when unable to communicate your health record can provide critical information like chronic conditions, allergies, past surgeries etc. I don't find it really does this though”

“Easy access to personal records no matter what and where Health Professional I am visiting.”

“So all your healthcare providers including myself have access to my records and can treat me accordingly”

“To improve one's chances in life and assist healthcare to take care of myself and others in a better, more informed manner.”

“If you are anywhere in Australia, you can access any medical record if you fall ill or involved in an accident.”

Age group: Consistent with the results from the baseline, most respondents aged 18- 34 years thought the main purpose of having a My Health Record was to have a centralised medical record and provide easy access to medical information for healthcare providers (Table 57). People from other age groups in the follow up survey most commonly said the purpose of the My Health Record was to share information between healthcare providers. Most respondents from other age groups in the baseline survey thought the main reason was to allow healthcare providers easy access to their health information.

Table 59: Number of responses per category by age groups in the baseline and follow up studies

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
Have easy access to health information for healthcare providers	202	232	306	231	To share information between healthcare providers	55	122	166	119
Don't know	132	196	279	212	Have easy access to health information for providers	64	79	100	91
Have one centralised health record for individuals and healthcare providers	229	217	168	89	Have one centralised health record for individuals and healthcare providers	74	97	91	48
To share information between healthcare providers	70	104	132	64	Don't know	30	62	91	102
For individuals to better monitor their own health	84	51	47	18	To provide high quality healthcare	18	32	44	22

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
For individuals to have the ability to personalise and control over the access/view of their health information	35	32	35	15	To have access to up-to-date and accurate information for individuals and healthcare providers	6	22	33	44
To provide high quality healthcare	22	23	27	22	To increase Government's access to information about people's health in order to control and monitor them	6	30	35	26
To have access to up-to-date and accurate information for individuals and healthcare providers	21	17	29	18	For individuals to better monitor their own health	18	18	14	8
To increase Government's access to information about people's health in order to control and monitor them	5	27	30	18	For individuals to have the ability to personalise and control over the access/view of their health information	13	10	15	10
Other	17	26	29	28	Other (e.g., no purpose, waste of money, expressed concerns about privacy)	17	29	42	28
Total	817	925	1,082	715	Total	301	501	631	498

Other demographic backgrounds: There were no observable differences between responses from those who identified as Aboriginal and Torres Strait Islander, those who spoke a language other than English at home, and those in different sites. Consistent with the pattern of results as a whole, the most common responses were that: the main purpose of the My Health Record was to share information between healthcare providers, followed by to provide easy access to health information for their healthcare providers.

Tables 28 to Table 60 describe the total number of responses for the baseline and follow up surveys, per category of the main reason for having a My Health Record, based on identification as an Aboriginal and Torres Strait Islander, language spoken at home and trial site location.

Table 60: Number of responses per category against respondents' identification as an Aboriginal and Torres Strait Islander for baseline and follow up surveys

Baseline				Follow up			
Category	No	Prefer not to say	Yes	Category	No	Prefer not to say	Yes
Have easy access to health information for healthcare providers	916	13	42	To share information between healthcare providers	446	2	14
Don't know	784	14	21	Have easy access to health information for healthcare providers	321	2	11
Have one centralised health record for individuals and healthcare providers	673	4	26	Have one centralised health record for individuals and healthcare providers	300	3	7
To share information between healthcare providers	358	1	11	Don't know	278	0	7
For individuals to better monitor their own health	187	1	12	To provide high quality healthcare	116	0	0
For individuals to have the ability to personalise and control over the access/view of their health information	111	0	6	To have access to up-to-date and accurate information for individuals and healthcare providers	100	2	3
To provide high quality healthcare	87	3	4	To increase Government's access to information about people's health in order to control and monitor them	88	2	7
To have access to up-to-date and accurate information for individuals and healthcare providers	81	0	4	For individuals to better monitor their own health	54	0	4
To increase Government's access to information about people's health in order to control and monitor them	73	3	4	For individuals to have the ability to personalise and control over the access/view of their health information	47	1	0
Other	92	2	6	Other (e.g., no purpose, waste of money, expressed concerns about privacy)	108	2	6
Total	3,362	41	136	Total	1858	14	59

Table 61: Number of responses per category against respondents' identification of whether they spoke another language apart from English at home for the baseline and follow up surveys.

Baseline				Follow up			
Category	No, I only speak English	Prefer not to say	Yes	Category	No, I only speak English	Prefer not to say	Yes
Have easy access to health information for healthcare providers	901	6	64	To share information between healthcare providers	436	1	25
Don't know	759	10	50	Have easy access to health information for healthcare providers	307	4	23
Have one centralised health records for individuals and healthcare providers	633	3	67	Have one centralised health record for individuals and healthcare providers	107	0	9
To share information between healthcare providers	348	1	21	Don't know	269	1	15
For individuals to better monitor their own health	178	2	20	To provide high quality healthcare	45	0	13
For individuals to have the ability to personalise and control over the access/view of their health information	104	0	13	To have access to up-to-date and accurate information for individuals and healthcare providers	281	2	27
To provide high quality healthcare	85	2	7	To increase Government's access to information about people's health in order to control and monitor them	100	0	5
To have access to up-to-date and accurate information for individuals and healthcare providers	79	0	6	For individuals to better monitor their own health	45	1	2
To increase Government's access to information about people's health in order to control and monitor them	74	0	6	For individuals to have the ability to personalise and control over the access/view of their health information	89	0	8
Other	86	2	12	Other (e.g., no purpose, waste of money, expressed concerns about privacy)	106	1	9
Total	3247	26	266	Total	1785	10	136

Table 62: Number of responses by category by the trial sites and the Rest of Australia for baseline and follow up surveys.

Baseline						Follow up					
Category	NQ	NBM	Ballarat	WA	Rest of Australia	Category	NQ	NBM	Ballarat	WA	Rest of Australia
Have easy access to health information for healthcare providers	213	205	196	174	183	To share information between healthcare providers	77	94	107	100	84
Don't know	161	148	183	161	166	Have easy access to health information for healthcare providers	62	66	76	47	83
Have one centralised health record for individuals and healthcare providers	146	149	116	138	154	Have one centralised health record for individuals and healthcare providers	26	23	28	20	19
To share information between healthcare providers	72	59	101	62	76	Don't know	40	33	67	63	82
For individuals to better monitor their own health	37	42	28	57	36	To provide high quality healthcare	7	8	7	17	19
For individuals to have the ability to personalise and control over the access/view of their health information	18	22	33	23	21	To have access to up-to-date and accurate information for individuals and healthcare providers	57	57	54	66	76
To provide high quality healthcare	11	17	18	26	22	To increase Government's access to information about people's health in order to control and monitor them	27	26	10	15	27
To have access to up-to-date and accurate information for individuals and healthcare	27	27	5	15	11	For individuals to better monitor their own health	6	9	10	9	14

Baseline						Follow up					
Category	NQ	NBM	Ballarat	WA	Rest of Australia	Category	NQ	NBM	Ballarat	WA	Rest of Australia
providers											
To increase Government's access to information about people's health in order to control and monitor them	16	16	9	22	17	For individuals to have the ability to personalise and control over the access/view of their health information	16	22	22	17	20
Other	18	16	20	27	19	Other (e.g., no purpose, waste of money, expressed concerns about privacy)	23	23	20	24	26
Total	719	701	709	705	705	Total	341	361	401	378	450

Benefits experienced from having a My Health Record

Only those respondents who had created a My Health Record were asked about the resulting benefits: 420 individuals answered.

Of the 420 respondents, 64% indicated that there was no benefit to them from having a My Health Record or that they were yet to see any benefit from having a My Health Record (n=268), and 6% said that having a My Health Record gave their healthcare provider/s easy access to their health information (n=27). My Health Record also allowed them to have control over access and to personalise their My Health Record (n=24, 7%).

Most categories of responses in the follow up survey were consistent with those at baseline. Most respondents in both the baseline and follow up surveys indicated that they had not seen or were yet to experience any benefits from having a My Health Record. Compared to baseline, no respondent indicated that they did not know the benefits from having a My Health Record (Table 61).

Table 63: Benefits experienced from having a My Health Record expressed by respondents in the baseline and follow up surveys.

Baseline			Follow up		
Category	n	%	Category	n	%
There was no benefit from having a My Health Record	324	64%	There was no benefit from having a My Health Record or none yet	268	64%
To allow easy access to health information for healthcare providers	44	9%	To allow easy access to health information for healthcare providers	27	6%
For individuals to have the ability to personalise and control over the access/view of their health information	40	8%	For individuals to have the ability to personalise and control over the access/view of their health information	24	7%
Have one centralised health record for individuals and healthcare providers	23	5%	To share information between healthcare providers	16	4%
For individuals to better monitor their own health	18	4%	Have one centralised health record for individuals and healthcare	15	4%

Baseline			Follow up		
Category	n	%	Category	n	%
			providers		
Don't know	15	3%	For individuals to better monitor their own health	8	2%
To provide high quality healthcare	7	1%	To provide high quality healthcare	5	1%
To share information between healthcare providers	4	1%	To have access to up-to-date and accurate information for individuals and healthcare providers	5	1%
To have access to up-to-date and accurate information for individuals and healthcare providers	2	0%	Other (e.g., unsure, does not feel its necessary to access the My Health Record, have not accessed it)	52	14%
Other (e.g., confirmation that the record is a good thing, unsure)	31	6%			
Total	508	100%	Total	420	100%

Some quotes from respondents describing the benefits experienced from having a My Health Record:

"None recently but in the past when having to see a Doctor that I'd not visited before, while away on holiday to see my son, having all my details available for them to make judgement on my problem and give me appropriate Scripts/medical treatment."

"Better understanding of my condition/s as all doctors etc. have the same info. available instantly and if all doctors/nurses update the system correctly the information will be available anywhere in Australia for appropriate use."

"Less duplication and better coordinated care and the availability of my medical results and histories is useful and good to have."

"Recent Emergency visit was made easier as the Dr, nurses had access to my health records."

"Being able to remind myself of procedures, and treatments done that I may have forgotten about."

"Knowing about the history of medicines that I have been prescribed and the how often I visit the doctor."

"It's all in one spot and that's the best thing. If I were to have an episode during the night, my husband knows how to get my details and like I said it wouldn't matter where we were, it would be ok."

"Well the fact of going into the hospital, I've been able to go into the hospital and tell them which medications I want to take and I know what I got. But as far as remembering each medication I don't do that. So having it there on record, I can go into the hospital and don't have to worry about remembering it."

"Doctors having quick access to my medical history should I require urgent attention"

"no delay and no misinformation about medicines taken."

"Very convenient and I can access it at any time and its pretty easy to use."

"None yet. Been in and out of hospital multiple times last 18 months, and nothing was added on my account."

Age group: Similar to the findings from the baseline survey, most respondents across age groups also indicated that there was no benefit, or they had not yet experienced any, from having a My Health Record (Table 62)

Table 64: Number of responses per category expressed by age groups from the baseline and follow up surveys.

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
There was no benefit from having a My Health Record	63	88	88	85	There was no benefit from having a My Health Record / or none yet	37	78	85	68
To have easy access to health information for healthcare providers	14	15	10	5	To allow easy access to health information for healthcare providers	7	7	6	7
For individuals to have the capacity to personalise and have control over access/view of the health information	17	11	10	2	For individuals to have the ability to personalise and control over the access/view of the health information	5	7	9	3
Have one centralised health record for individuals and healthcare providers	8	7	7	1	To share information between healthcare providers	2	4	5	5
For individuals to better monitor their own health	8	4	4	2	Have one centralised health record for individuals and healthcare providers	4	5	5	1
Don't know	5	3	2	5	For individuals to better monitor their own health	4	3	1	0
To provide high quality healthcare	3	2	2	0	To provide high quality healthcare	1	0	2	2
To share information between healthcare providers	1	1	1	1	To have access to up-to-date and accurate information for individuals and healthcare providers	1	2	2	0
To have access to up-to-date and accurate information	1	1	0	0	Other (e.g., unsure, does not feel it's necessary to access the My	14	16	13	9

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
for individuals and healthcare providers					Health Record, have not used the My Health Record)				
Other	13	8	7	3					
Total	133	140	131	104	Total	75	122	128	95

Other demographics: There were no observable differences in the responses when asked about the benefits of having a My Health Record between Aboriginal and Torres Strait Islander people, those who spoke a language other than English at home, and those in different sites. The pattern of results for each demographic group was consistent with the overall results from the follow up survey. When compared to the results from the baseline study, the top three benefits reported by respondents in both studies are consistent across the three demographic groups (Table 63 to Table 65).

Table 65: Number of responses per category against respondents' identification as an Aboriginal and/or Torres Strait Islander from the baseline and follow up surveys.

Baseline				Follow up			
Category	No	Prefer not to say	Yes	Category	No	Prefer not to say	Yes
There was no benefit from having a My Health Record	310	7	7	There was no benefit from having a My Health Record/ or none yet	259	1	8
To have easy access to health records for healthcare providers	37	1	5	To allow easy access to health records for healthcare providers	25	0	2
For individuals to have the capacity to personalise and control over the access/view of their health information	36	0	4	For individuals to have the ability to personalise and control over the access/view of their health information	24	0	0
Have one centralised health record for individuals and healthcare providers	23	0	0	To share information between healthcare providers	16	0	0
For individuals to better monitor their own health	15	0	3	Have one centralised health record for individuals and healthcare providers	15	0	0
Don't know	15	0	0	For individuals to better monitor their own health	8	0	0
To provide high quality healthcare	7	0	0	To provide high quality healthcare	5	0	0
To share information between healthcare providers	5	0	0	To have access to up-to-date and accurate information for individuals and healthcare providers	3	0	2

Baseline				Follow up			
Category	No	Prefer not to say	Yes	Category	No	Prefer not to say	Yes
To have access to up-to-date and accurate information for individuals and healthcare providers	1	0	1	Other (e.g., unsure, does not feel its necessary to access the My Health Record, have not used the My Health Record)	49	0	3
Other	24	0	7				
Total	473	8	27	Total	404	1	15

Table 66: Number of responses per category against respondents' identification as to whether they spoke another language apart from English at home from the baseline and follow up surveys.

Baseline				Follow up			
Category	No, I only speak English	Prefer not to say	Yes	Category	No, I only speak English	Prefer not to say	Yes
There was no benefit from having a My Health Record	304	2	18	There was no benefit from having a My Health Record / or none yet	254	1	13
To have easy access to health records for healthcare providers	41	1	2	To allow easy access to health records for healthcare providers	23	0	4
For individuals to have the capacity to personalise and control over the access/view of their health information	37	0	3	For individuals to have the ability to personalise and control over the access/view of their health information	21	0	3
Have one centralised health record for individuals and healthcare providers	20	0	3	To share information between healthcare providers	16	0	0
For individuals to better monitor their own health	18	0	0	Have one centralised health record for individuals and healthcare providers	15	0	0
Don't know	13	0	2	For individuals to better monitor their own health	8	0	0
To provide high quality healthcare	6	0	1	To provide high quality healthcare	4	0	1
To share information between healthcare providers	4	0	0	To have access to up-to-date and accurate information for individuals and healthcare providers	4	0	1
To have access to up-to-date and accurate information for individuals and healthcare providers	2	0	0	Other (e.g., unsure, does not feel it's necessary to access the My Health Record, have not	48	0	4

Baseline				Follow up			
Category	No, I only speak English	Prefer not to say	Yes	Category	No, I only speak English	Prefer not to say	Yes
				used the My Health Record)			
Other	30	0	1				
Total	475	3	30	Total	393	1	26

Table 67: Responses by category against the trial sites and the Rest of Australia from the baseline and follow up surveys.

Baseline						Follow up					
Category	NQ	NBM	Ballarat	WA	Rest of Australia	Category	NQ	NBM	Ballarat	WA	Rest of Australia
There was no benefit from having a My Health Record	77	65	44	66	72	There was no benefit from having a My Health Record / or none yet	62	68	38	49	51
To have easy access to health records for healthcare providers	7	12	8	4	13	To allow easy access to health records for healthcare providers	3	4	2	8	10
For individuals to have the capacity to personalise and control over the access/view of their health information	11	7	7	8	7	For individuals to have the ability to personalise and control over the access/view of their health information	5	8	7	1	3
Have one centralised health record for individuals and healthcare providers	5	6	3	4	5	To share information between healthcare providers	3	6	0	3	4
For individuals to better monitor their own health	4	5	1	6	2	Have one centralised health record for individuals and healthcare providers	4	3	3	3	2
Don't know	4	2	1	4	4	For individuals to better monitor their own health	1	4	1	0	2

Baseline						Follow up					
Category	NQ	NBM	Ballarat	WA	Rest of Australia	Category	NQ	NBM	Ballarat	WA	Rest of Australia
To provide high quality healthcare	1	0	2	1	3	To provide high quality healthcare	0	3	1	1	0
To share information between healthcare providers	1	2	0	1	0	To have access to up-to-date and accurate information for individuals and healthcare providers	1	0	1	0	3
To have access to up-to-date and accurate information for individuals and healthcare providers	1	1	0	0	0	Other (e.g., unsure, does not feel its necessary to access the My Health Record, have not used the My Health Record)	12	12	6	10	12
Other	3	5	7	9	7						
Total	114	105	73	103	113	Total	91	108	59	75	87

Expected benefits from having a My Health Record

A total of 1,421 people who had not created a My Health Record answered the question about the expected benefits of having a My Health Record, and a total of 1,429 meaningful responses were analysed (Table 66). 20% of the respondents indicated that they were unsure of the benefits (n=280). 17% said the My Health Record would allow their health information to be shared amongst healthcare providers who are treating them, and 15% identified no benefits that were expected to come, or none yet, from having a My Health Record.

The categories expressed by respondents in the follow up survey are consistent with those at baseline. The most common categories expressed by respondents in both studies were that they were unsure of the expected benefits from having a My Health Record (Table 66).

Table 68: Expected benefits from having a My Health Record expressed by respondents in baseline and follow up surveys.

Baseline			Follow up		
Category	n	%	Category	n	%
Don't know	829	26%	Don't know	280	20%
To have easy access to health records for healthcare providers	744	23%	To share information between healthcare providers	248	17%
There was no benefit from having a My Health Record	333	10%	There was no benefit from having a My Health Record, or none yet	218	15%
Have one centralised health record for individuals and healthcare providers	300	9%	To have easy access to health records for healthcare providers	154	11%
To share information between healthcare providers	293	9%	Have one centralised health record for individuals and healthcare providers	120	8%
To provide high quality healthcare	252	8%	To provide high quality healthcare	100	7%
For individuals to have the capacity to personalise and control over the access/view of their health information	132	4%	To have access to up-to-date and accurate information for individuals and healthcare providers	99	7%

Baseline			Follow up		
Category	n	%	Category	n	%
For individuals to better monitor their own health	120	4%	For individuals to better monitor their own health	56	4%
To have access to up-to-date and accurate information for individuals and healthcare providers	76	2%	To have access to up-to-date and accurate information for individuals and healthcare providers	39	3%
So Government can have access to information about people's health in order to control and monitor them	11	0%	So Government can have access to information about people's health in order to control and monitor them	9	1%
Other (e.g., do not see the need for a My Health Record, concerns about privacy and security of the My Health Record)	115	4%	Other (cost saving, cheaper cost for health service, makes life easier)	106	7%
Total	3,205	100%	Total	1,429	100%

Some quotes from respondents describing the expected benefits from having a My Health Record:

"Being able to visit medical practitioners and them being able to view full medical history rather than relying on patient memory."

"Less wait time for doctors and specialist to share information/results."

"My health history will be intact even if my doctor moves, or I move."

"Faster and more efficient treatment because doctors can access the records."

"Continuity of medical care so if you travel and used doctors they would be using the safe records and ultimately provide you with the best care."

"It would save having to repeat yourself, remember important details, medications, illnesses and diseases would be available to all health carers. A holistic approach would be far better for all."

"It would reduce the likelihood of the accidental administering of medicines to which patients are allergic, or their accidental over-exposure to x-rays, and also the use of blood from an incompatible blood group."

"I think it probably increases communication between various health bodies rather than having one history here and another there. You would have on history in one place so it's easier for them to look back as sometimes you don't always remember or you don't remember every appointment you had and every scan you've had, and also to decrease the amount of paperwork."

"Different healthcare providers would have access to my records easily and quickly. I suppose... It's just a better treatment regime."

"I have allergies so I expect that it would [be] easier to communicate those with new medical professions and there would be fewer communication breakdowns."

"Not sure, have not heard anything about it apart from one flyer from the Government, have not been told how to access it or where it is kept."

"No need for patients to take records with them when seeing various doctors. Info will all be online for them to access."

"Ease of tracking information between healthcare providers (e.g. referrals)."

"Don't have enough information to make a decision."

"One source for practitioners to use and promote a holistic view of my health."

"That everything is up to date and in one place and not subject to paper loss. Although I'm not feeling confident about the paper system especially as the Census didn't go so well."

“Better informed medical care in emergency health situation where the careers are not familia[r] with my history”.

“[To have] total control of my health from all perspectives.”

“Access to my health records and share with whom needs to see it.”

“Invasion of my privacy if you call that a 'benefit'.”

“Don’t think there would be any benefits because my doctors already share information about me.”

“At this stage – none”

“Unsure if they are any advantages.”

Age group: When the responses were analysed by age groups in the follow up survey, the most common responses from respondents aged 50 to 64 years (n=94) and over 65 years (n=94) was that they were unsure of the benefits, whereas the most common responses from people aged 18 to 34 years (n=47) and 35 to 49 years (n=62) was that the My Health Record would allow information to be shared amongst healthcare providers (Table 37). The pattern of results is consistent with the trend of results found from the baseline survey (Table 37).

Table 69: Number of responses per category per age group from the baseline and follow up surveys.

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
Don't know	150	195	262	222	Don't know	31	60	94	94
To have easy access to health records for healthcare providers	188	211	214	131	To share information between healthcare providers	47	62	81	58
There was no benefit from having a My Health Record	43	80	132	78	There was no benefit from having a My Health Record, or none yet	12	48	84	73
Have one centralised health records for individuals and healthcare providers	71	90	85	54	To have easy access to health records for healthcare providers	34	42	56	22
To share information between healthcare providers	66	72	99	56	Have one centralised health record for individuals and healthcare providers	24	31	39	26
To provide high quality healthcare	47	58	83	64	To provide high quality healthcare	15	20	30	34
For individuals to have the capacity to personalise and control over the access/view of their health information	49	38	31	14	To have access to up-to-date and accurate information for individuals and healthcare providers	10	21	36	32
For individuals to better monitor their own health	47	28	31	14	For individuals to better monitor their own health	8	18	15	15
To have access to up-to-date and accurate information for individuals and healthcare providers	18	19	23	16	To have access to up-to-date and accurate information for individuals and healthcare providers	8	12	15	4
So Government can have access to information about people's health in order to control and monitor them	0	3	6	2	So Government can have access to information about people's health in order to control and monitor them	0	3	3	3

Baseline					Follow up				
Category	18-34	35-49	50-64	65+	Category	18-34	35-49	50-64	65+
Other	35	27	27	26	Other	22	35	23	26
Total	714	821	993	677	Total	211	352	476	387

Note: Some respondents in the follow up survey did not provide their age, therefore, the overall total of responses for the follow up survey would be lower than the overall total of responses for this question.

Other demographic groups: Results from the follow up survey showed that most people in the opt-in trial sites and the rest of Australia (comparison site) were unsure of benefits from having a My Health Record. Most people in the opt-out trial sites (NBM and NQ) indicated that the My Health Record would benefit them by allowing their healthcare providers to share their health information (Table 68). This pattern of results in the follow up survey is consistent with the responses gathered from the baseline survey.

Those respondents who identified as Aboriginal and/or Torres Strait Islander and those who said they spoke a language other than English at home also said that they were unsure or did not know the benefits of having a My Health Record. The next most common benefit was that having a My Health Record would allow their healthcare providers to share their health information, followed by perceptions that there was no benefit, or none yet, from obtaining a My Health Record (Table 39 and Table 40). These findings are consistent with the pattern of findings from the baseline survey for each of these demographic groups.

Table 70: Number of responses per category against the trial sites and the rest of Australia from the baseline and follow up survey

Baseline						Follow up					
Category	NQ	NBM	Ballarat	WA	Rest of Australia	Category	NQ	NBM	Ballarat	WA	Rest of Australia
Don't know	171	148	160	168	182	Don't know	32	40	68	66	73
To have easy access to health records for healthcare providers	139	182	156	139	128	To share information between healthcare providers	43	43	72	41	49
There was no benefit from creating/having a My Health Record	61	60	79	51	82	There was no benefit from having a My Health Record, or none yet	40	45	36	44	52
Have one centralised health record for individuals and healthcare providers	52	52	78	59	59	To have easy access to health records for healthcare providers	27	23	27	34	43
To share information between healthcare providers	48	43	72	54	76	Have one centralised health record for individuals and healthcare providers	20	18	19	25	38

Baseline						Follow up					
Category	NQ	NBM	Ballarat	WA	Rest of Australia	Category	NQ	NBM	Ballarat	WA	Rest of Australia
To provide high quality healthcare	44	46	71	51	40	To provide high quality healthcare	19	10	34	20	16
For individuals to have the capacity to personalise and control over the access/view of their health information	31	36	18	20	27	To have access to up-to-date and accurate information for individuals and healthcare providers	17	19	29	12	22
For individuals to better monitor their own health	25	22	24	29	20	For individuals to better monitor their own health	11	8	11	10	16
To have access to up-to-date and accurate information for individuals and healthcare providers	9	13	21	19	14	To have access to up-to-date and accurate information for individuals and healthcare providers	4	4	13	10	8
So Government can have access to information about people's health in order to control and monitor them	2	3	1	2	3	So Government can have access to information about people's health in order to control and monitor them	0	3	2	1	3
Other	18	13	29	34	21	Other	17	21	22	24	22
Total	600	618	709	626	652	Total	230	234	333	287	342

Note: Not all respondents in the follow up survey provided their location, therefore, the overall total of responses for the follow up survey would be lower than the overall total of responses for this question.

Table 71: Number of responses per category against respondents' identification as an Aboriginal and/or Torres Strait Islander from the baseline and follow up surveys.

Baseline				Follow up			
Category	No	Prefer not to say	Yes	Category	No	Prefer not to say	Yes
Don't know	793	10	26	Don't know	274	1	5
To have easy access to health records for healthcare providers	710	7	27	To share information between healthcare providers	238	3	7

Baseline				Follow up			
Category	No	Prefer not to say	Yes	Category	No	Prefer not to say	Yes
There was no benefit from creating/having a My Health Record	313	9	11	There was no benefit from having a My Health Record, or none yet	206	3	9
Have one centralised health record for individuals and healthcare providers	283	2	15	To have easy access to health records for healthcare providers	146	1	7
To share information between healthcare providers	287	0	6	Have one centralised health record for individuals and healthcare providers	113	0	7
To provide high quality healthcare	239	3	10	To provide high quality healthcare	97	0	3
For individuals to have the capacity to personalise and control over the access/view of their health information	126	0	6	To have access to up-to-date and accurate information for individuals and healthcare providers	98	0	1
For individuals to better monitor their own health	110	1	9	For individuals to better monitor their own health	53	1	2
To have access to up-to-date and accurate information for individuals and healthcare providers	74	0	2	To have access to up-to-date and accurate information for individuals and healthcare providers	37	1	1
So Government can have access to information about people's health in order to control and monitor them	11	0	0	So Government can have access to information about people's health in order to control and monitor them	8	0	1
Other	110	1	4	Other	103	1	2
Total	3,056	33	116	Total	1,373	11	45

Table 72: Number of responses per category against respondents' identification as to whether they spoke another language apart from English at home from the baseline and follow up surveys.

Baseline				Follow up			
Category	No, I only speak English	Prefer not to say	Yes	Category	No, I only speak English	Prefer not to say	Yes
Don't know	763	9	57	Don't know	258	0	22
To have easy access to health records for healthcare providers	693	4	47	To share information between healthcare providers	228	3	17
There was no benefit from creating/having a My Health Record	313	2	18	There was no benefit from having a My Health Record, or none yet	210	1	7
Have one centralised medical records for individuals and healthcare providers	270	2	28	To have easy access to health records for healthcare providers	138	2	14
To share information between healthcare providers	273	2	18	Have one centralised health record for individuals and healthcare providers	112	0	8
To provide high quality healthcare	227	2	23	To provide high quality healthcare	97	0	3

Baseline				Follow up			
Category	No, I only speak English	Prefer not to say	Yes	Category	No, I only speak English	Prefer not to say	Yes
For individuals to have the capacity to personalise and control over the access/view of the My Health Record	107	1	24	To have access to up-to-date and accurate information for individuals and healthcare providers	91	0	8
For individuals to better monitor their own health	109	1	10	For individuals to better monitor their own health	50	2	4
To have access to up-to-date and accurate information for individuals and healthcare providers	67	0	9	To have access to up-to-date and accurate information for individuals and healthcare providers	35	0	4
So Government can have access to information about people's health in order to control and monitor them	10	0	1	So Government can have access to information about people's health in order to control and monitor them	6	1	2
Other	98	0	17	Other	94	0	12
Total	2,930	23	252	Total	1,319	9	101

Summary of findings from the survey of individuals in the general population

Increased awareness and understanding of the My Health Record system amongst users

Approximately one quarter of participants had heard about the My Health Record; however, participants in the opt-out trial areas were more likely to have had exposure to awareness raising information about the My Health Record system during the trial period than the rest of Australia.

Participants in the opt-out trial site were more likely to state that they had a My Health Record than the rest of Australia. The majority of respondents in the opt-out trial site (58%) did not recall receiving a letter about the My Health Record stating that they didn't receive one or didn't know if they received one.

Participants in the opt-in trial areas were more likely to have had exposure to awareness raising information about the My Health Record system during the trial period than the rest of Australia.

Increased participation in, and use of, the My Health Record System by individuals

Participants in the opt-out trial site were more likely to increase their viewing of prescription records than the rest of Australia; however, this is based on few numbers and may be a result of underpowered analysis, rather than a true difference. There were no differences in other indicators of use or participation in the opt-out trial sites compared to the rest of Australia.

There were no differences in any indicators of use or participation in the opt-in trial sites compared to the rest of Australia.

A number of participants felt that the My Health Record had allowed their treating team members to be on the same page about their health.

The majority of respondents with a My Health Record reported that they received no benefit, but some felt that the My Health Record provided an easy way for healthcare providers to access their health information and assist in clinical decision making.

The main reason for not creating a My Health Record was because they were unaware or not sufficiently informed about the My Health Record system or they believed that having a My Health Record was unnecessary.

Increased confidence to use the system amongst users

There were no differences in any indicators of confidence between the opt-out trial sites and the rest of Australia. There were no differences in any indicators of confidence between the opt-in trial sites and the rest of Australia.

Appendix 7 Findings from survey of healthcare providers

Methods

An online survey was conducted at baseline of healthcare providers who agreed to participate. Those who agreed to be followed up were contacted directly by the evaluation team and asked to complete a second survey. Sampling was conducted in each trial location and the rest of Australia with an aim to have 363 participants for each trial arm.

Healthcare providers were sourced through a number of avenues: distribution through the NQ and NBM PHNs' communication channels and via the Health Identifier Service (HIS) operator's database of registered healthcare providers. In the PHNs, a link to the survey was sent to those individuals and organisations listed on the PHN databases. A number of healthcare providers were selected from the HIS database to be sent an email with information about the survey and a link to take part. A random selection of healthcare providers (31,590), from all areas of Australia, was selected for inclusion in the email list. An email was sent to each selected healthcare provider requesting their participation. Another number of healthcare providers from the NQ (8,763), NBM (4,372), Ballarat (2,011) and Western Australia (WA) (37,822) areas were selected and sent an email requesting them to participate. Using sample power of 0.8, an alpha error of 0.05 and a 50% attrition rate the aim of the selection process was to obtain a minimum of 700 respondents to the baseline survey in each of the trial/non-trial sites with emphasis on over selecting for GPs, other doctors and pharmacists. Accounting for attrition, this ensured 350 respondents per trial arm completing the follow up survey. Respondent selection in the trial and non-trial sites was guided by geographic locations relevant to where the trial and non-trial sites were located. Recruitment across both trial and non-trial sites was stratified by healthcare provider type to increase the likelihood of achieving a representative sample from all healthcare provider types.

A description of the sample by avenue of recruitment is provided in Table 1. A total of 2,036 participants responded at both baseline and follow up. Of which, there were 24 responses with duplicate email addresses that were removed from analysis, leaving 2,012 participants in the analysis set. There were a small number of instances where healthcare providers' location had either changed between identification and contact or was incorrectly identified in the first instance.

Table 1. Survey respondents by trial site and source of survey invitation

Invitation source	Trial Sites					Missing location	Total sample
	Northern Qld	NBM	Ballarat	WA	Rest of Australia		
<i>HIS</i>							
<i>Rest of Australia</i>	23	14	8	70	741	9	865
<i>NBM</i>	0	90	0	0	29	1	120
<i>Northern Qld</i>	178	0	0	1	27	3	209
<i>WA</i>	2	0	0	737	12	11	762
<i>Ballarat</i>	0	0	57	0	8	0	65
<i>PHN</i>							
<i>NBM</i>	0	8	0	0	0	0	8
<i>Northern Qld</i>	6	1	0	0	0	0	7
TOTAL	209	113	65	808	817	24	2,036

HIS = Health Identifier Service; NBM = Nepean Blue Mountains; PHN = Primary Health Network; Qld = Queensland; WA = Western Australia

Online surveys

Questions were developed and piloted by the evaluators internally and in consultation with the Department. At the end of the survey, respondents were asked to indicate whether they would be willing to be contacted for follow up by the evaluator.

Approach to quantitative analysis

Routine descriptive methods were used to describe survey responses at the level of each trial site and control group (non-trial). The postcode of a respondent's primary workplace (as provided within the survey by the respondent) was used to assign respondents to either one of the four trial sites (Ballarat, WA, NQ, NBM), or the control site, rest of Australia. Respondents with a missing postcode were excluded from analysis. Respondent characteristics were compared across trial sites to identify potential differences. Measures of awareness, use, influences and benefits from use of the My Health Record were compared across trial sites.

Approach to qualitative analysis

The approach to the analysis of qualitative data generated by the healthcare provider surveys was based on Krueger's Framework Analysis (1994, 2000)^{22,23}. The Framework outlines five key stages: familiarisation, identifying a thematic index, charting, mapping and interpretation. Qualitative data in the healthcare provider surveys was analysed by coding the information provided by the respondents. Codes were used as a means or device for identifying categories and patterns in the data. The analysis of qualitative data was overseen by a lead coder and the process involved:

- segmenting the data
- identifying key categories and patterns in the data (coding)
- discussing emerging categories and patterns across multiple coders
- moderating categories and patterns in line with group discussion
- summarising data according to key categories.

Demographics

The healthcare provider population consisted of 58% females, with an average age of 47.9 years. The majority of respondents were allied health or other providers (31%), followed by nurses (22%). Hospitals were the healthcare provider organisation type most represented in the sample (41%). The majority of respondents (92%) had a computer available for clinical purposes only or for both clinical and administrative purposes. An overview of the baseline characteristics is presented in Table 2.

Table 2. Baseline characteristics of respondents who participated in baseline and follow up survey¹

Characteristic	Opt-out n=322	Opt-in n=873	Rest of Australia n=817	Total sample n=2012
<i>Profession; n (%)</i>				
General Practitioner	53 (16.4)	111 (12.7)	175 (21.4)	339 (16.9)
Specialist & Other Med.	27 (8.4)	82 (9.4)	232 (28.4)	341 (17.0)
Pharmacist	33 (10.3)	88 (10.1)	153 (18.7)	274 (13.6)

²² Krueger RA (1994) Focus Groups: A Practical Guide for Applied Research. Thousand Oaks, CA: Sage Publications.

²³ Krueger RA & Casey MA (2000) Focus Groups: A Practical Guide for Applied Research, 3rd ed. Thousand Oaks, CA: Sage Publications.



<i>Characteristic</i>	Opt-out n=322	Opt-in n=873	Rest of Australia n=817	Total sample n=2012
<i>Nurse</i>	91 (28.3)	252 (28.9)	98 (12.0)	441 (21.9)
<i>Allied health, Other &Unspecified</i>	118 (36.7)	340 (39.0)	159 (19.5)	617 (30.7)
Sex; n (%)				
<i>Male; n (%)</i>	98 (33.7)	238 (29.9)	340 (45.0)	676 (36.7)
<i>Female; n (%)</i>	193 (66.3)	558 (70.1)	416 (55.0)	1617 (63.3)
Age; mean (sd)	48.8 (12.8)	47.8 (12.8)	47.5 (13.4)	47.9 (13.1)
Tenure: mean (sd)	22.2 (13.6)	22.5 (13.4)	22.2 (13.9)	22.3 (13.6)
Clinical Hrs/Wk; mean (sd)	28.9 (13.2)	32.6 (16.5)	31.6 (16.1)	30.9 (15.4)
Country of Graduation				
<i>Graduated in Aust; n (%)</i>	268 (83.5)	674 (77.4)	686 (84.0)	1628 (81.0)
<i>Graduated Other; n (%)</i>	53 (16.1)	197 (22.6)	131 (16.0)	381 (19.0)
Size of Workplace; n (%)				
<i>1-5 FTE</i>	131 (40.8)	325 (37.6)	330 (40.6)	786 (39.36)
<i>6-10 FTE</i>	52 (16.2)	103 (11.9)	104 (12.8)	259 (13.0)
<i>11-20 FTE</i>	23 (7.2)	83 (9.6)	72 (8.9)	178 (8.9)
<i>>20 FTE</i>	115 (35.8)	354 (40.9)	307 (37.8)	776 (38.8)
Computer; n (%)				
<i>None</i>	5 (1.6)	15 (1.7)	7 (0.9)	27 (1.3)
<i>Clinical use only</i>	6 (1.9)	35 (4.0)	30 (3.7)	71 (3.5)
<i>Admin use only</i>	16 (5.0)	73 (8.4)	43 (5.3)	132 (6.6)
<i>Admin and clinical use</i>	295 (91.6)	748 (85.9)	737 (90.2)	1780 (88.6)
Internet; n (%)				
<i>No internet</i>	3 (1.0)	4 (0.5)	5 (0.6)	12 (0.6)
<i>DSL/Cable/Fibre</i>	141 (45.6)	397 (47.5)	433 (54.7)	971 (50.2)
<i>Mobile</i>	27 (8.7)	66 (7.9)	39 (4.9)	132 (6.8)
<i>Satellite/Dial-up</i>	3 (1.0)	8 (1.0)	7 (0.9)	18 (0.9)
<i>Other/Don't Know</i>	135 (43.7)	361 (43.2)	307 (38.8)	803 (41.5)

FTE = full time equivalent workers; Med. = Medical practitioner; sd = standard deviation;

1 Totals exclude missing responses

Increased Awareness and Understanding of the My Health Record system amongst users

Within both the opt-out trial site and the rest of Australia comparator group, 82% of healthcare providers were aware of the My Health Record (or PCEHR) at baseline (Table 3). During the trial period, 39% of respondents in the opt-out trial site²⁴ recalled having seen or heard about the My Health Record which was statistically significantly higher (23%) than in the rest of Australia comparator group (Table 3). Although a greater proportion in both the opt-out and rest of Australia respondents knew if their workplace was registered after the trial period, this increase was more

²⁴ The 'opt-out trial site' or the 'opt-out group' consists of both respondents in NQ and NMB.



pronounced in the opt-out group (11% increase in the opt-out trial site vs 5.9%). However, the difference in this increase (4.8% adjusted) was not statistically significant.

There were statistically fewer respondents in the opt-in trial site²⁵ (63%) compared with the rest of Australia (82%) who were aware of the My Health Record (or PCEHR) at baseline (Table 3). During the trial period, 20% of respondents in the opt-in trial site recalled having seen or heard about the My Health Record system which was not statistically significantly lower than the 23% in the rest of Australia comparator group (Table 3). Although a greater proportion in both the opt-in and rest of Australia respondents knew if their workplace was registered after the trial period, this increase was more pronounced in the opt-in group (9% increase in the opt-in trial site vs 5.9%). However, the difference in this increase (3.4% adjusted) was not statistically significant.

Table 3. Awareness/ Exposure to My Health Record and work place registration. Rest of Australia and Opt-out intervention group¹

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted difference
	Baseline	Follow up		Baseline	Follow up			
Aware of My Health Record at baseline; n (%)	262 (81.9)	N/A	N/A	667 (81.7)	N/A	N/A	0.2²	-
Exposed to My Health Record since baseline at follow up; n (%)	N/A	117 (38.6)	N/A	N/A	180 (23.4)	N/A	15.2^{***2}	-
Knew if workplace is registered; n (%)	144 (44.7)	152 (55.7)	11.0	408 (50.2)	384 (56.1)	5.9	5.1	4.8

1 Totals exclude missing responses 2 chi2 test * 5% statistical significance **1 statistical significance

Table 4. Awareness/ Exposure to My Health Record and work place registration. Rest of Australia and Opt-In intervention group

	Opt-in	Opt-in	Difference (%)	Rest of Australia	Rest of Australia	Difference (%)	Difference of difference	Adjusted difference
	Baseline	Follow up		Baseline	Follow up			
Aware of My Health Record at baseline; n (%)	547 (63.0)	N/A	N/A	667 (81.7)	N/A	N/A	18.7^{**2}	-
Exposure to My Health Record since baseline at follow up; n (%)	N/A	159 (19.5)	N/A	N/A	180 (23.4)	N/A	3.9²	-
Know if workplace is registered; n (%)	366 (42.0)	376 (51.1)	9.1	408 (50.2)	384 (56.1)	5.9	3.2	3.4

Of healthcare providers, general practitioners were more likely to have had exposure to awareness raising information about the My Health Record system than any other healthcare provider type (Figure 1).

²⁵ The 'opt-in trial site' or the 'opt-in group' consists of respondents in WA and Ballarat.

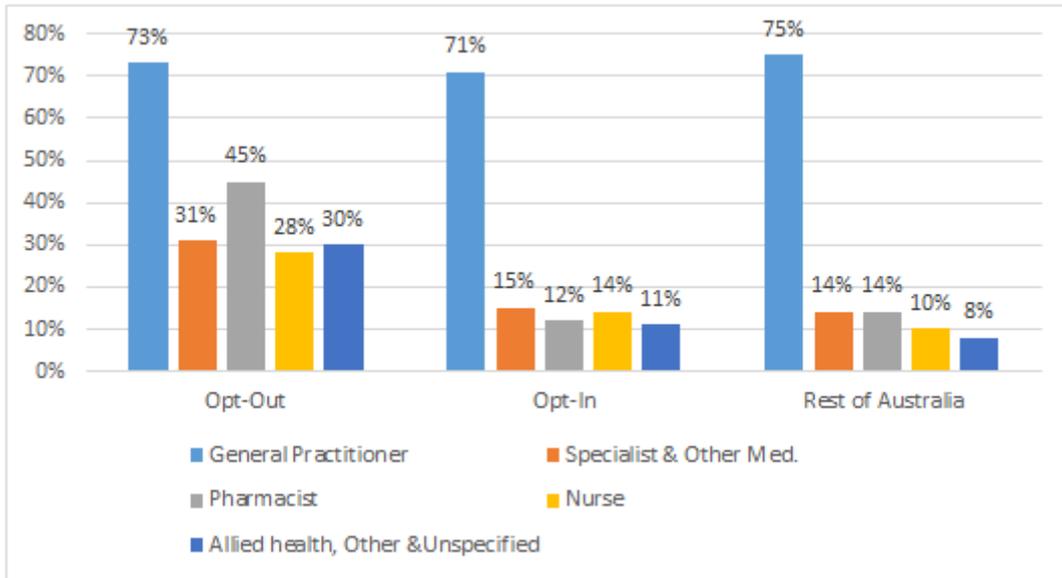


Figure 1. Provider exposure to My Health Record by intervention group and profession at follow up

With regards to exposure to information or other material relating to the My Health Record during the trial period, a greater proportion of respondents in the opt-out trial (15%) relative to the rest of Australia (6%) listed local media as a source (Figure 2).

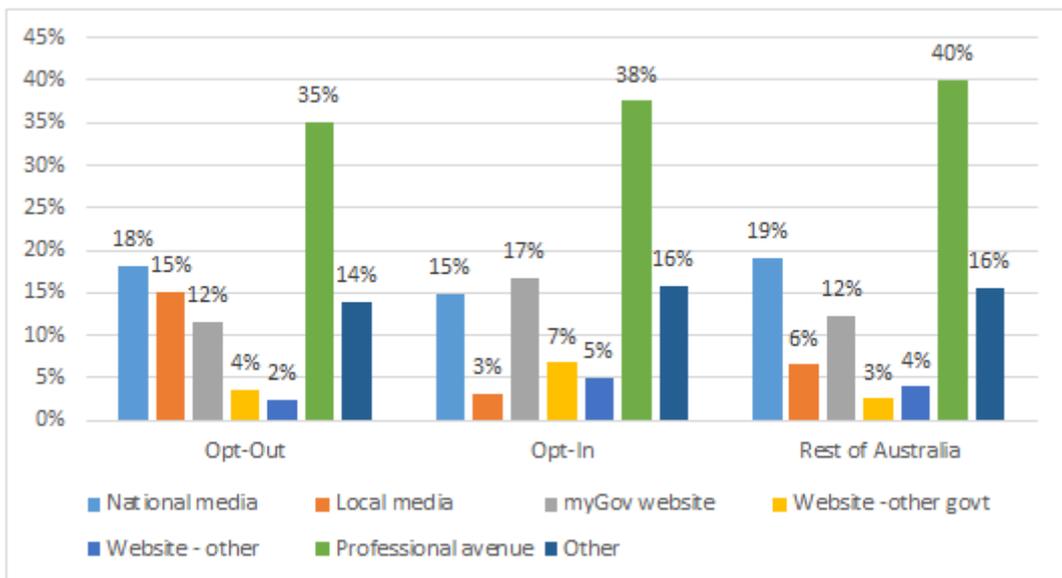


Figure 2. Healthcare provider exposure to My Health Record by intervention group and source of material

Increased confidence to use the My Health Record system amongst users

There were no statistically significant differences in any of the trial sites during the trial period with regards to change in confidence in the Government to ensure confidentiality of the My Health Record system. However, in general, across all trial sites, the confidence in the Government to ensure confidentiality fell over time. At follow up, there were no significant differences between trial sites in healthcare providers' reported: confidence that the My Health Record system is secure from external threats; confidence in the Government to keep patients' personal information in the My Health Record system confidential; or level of trust in the Government and others to keep patient medical information safe and use this information in an appropriate way.

Table 5. Confidentiality of the My Health Record system at baseline and follow up. Rest of Australia and opt-out¹

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Baseline	Follow up			
Confidence in Government capacity to ensure confidentiality; n (%)								
Really confident	26 (8.1)	19 (7.2)	-0.9	68 (8.4)	48 (7.1)	-1.3	0.4	0.4
Confident	101 (31.5)	76 (28.8)	-2.7	283 (34.8)	217 (32.3)	-2.5	-0.2	0.7
Not sure	104 (32.4)	88 (33.3)	0.9	238 (29.2)	192 (28.6)	-0.6	1.5	-0.4
Not confident	53 (16.5)	44 (16.7)	0.2	150 (18.4)	136 (20.2)	1.8	-1.6	-0.5
Really not confident	37 (11.5)	37 (14.0)	2.5	75 (9.2)	79 (11.8)	2.6	-0.1	-0.3

¹ Totals may not add up to sample size or percentages to 100% due to missing responses

Table 6. Confidentiality of the My Health Record system at baseline and follow up. Rest of Australia and Opt-in

	Opt-in	Opt-in	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Follow up	Baseline			
Confidence in Government capacity to ensure confidentiality; n (%)								
Really confident	64 (7.3)	45 (6.3)	-1.0	68 (8.4)	48 (7.1)	-1.3	0.3	0.5
Confident	288 (33.0)	225 (31.7)	-1.3	283 (34.8)	217 (32.3)	-2.5	1.2	-0.2
Not sure	302 (34.6)	218 (30.7)	-3.9	238 (29.2)	192 (28.6)	-0.6	-3.3	-0.2
Not confident	140 (16.1)	147 (20.7)	4.6	150 (18.4)	136 (20.2)	1.8	2.8	0.1
Really not confident	78 (8.9)	76 (10.7)	1.8	75 (9.2)	79 (11.8)	2.6	-0.8	0.2

Table 7. Confidentiality of the My Health Record system at baseline and follow up. Rest of Australia and Opt-in

	Opt-out	Opt-in	Rest of Australia
	Follow up	Follow up	Follow up
Confidence that My Health Record is secure from external threat; n (%)			
Really confident	14 (5.4)	42 (6.0)	36 (5.4)
Confident	65 (24.9)	194 (27.6)	202 (30.4)
Not sure	93 (35.6)	220 (31.3)	188 (28.3)
Not confident	50 (19.2)	163 (23.2)	153 (23.0)
Really not confident	39 (14.9)	83 (11.8)	85 (12.8)
Confidence in Government to keep patients' personal info in My Health Record confidential; n (%)			
Really confident	14 (5.5)	42 (6.0)	36 (5.4)
Confident	65 (24.9)	194 (27.6)	202 (30.4)
Not sure	93 (35.6)	220 (31.3)	188 (28.3)
Not confident	50 (19.2)	163 (23.2)	153 (23.0)
Really not confident	39 (14.9)	83(11.8)	85(12.8)
Level of trust in Government and others to keep patient medical information safe and use appropriately; n (%)			
To a great extent	23 (8.7)	54 (7.6)	70 (10.4)
Very much	61 (23.1)	185 (26.0)	186 (27.7)
Somewhat	118 (44.7)	345 (48.5)	271 (40.3)
Very little	36 (13.6)	78 (10.9)	98 (14.6)
Not at all	26 (9.9)	50(7.0)	47 (7.0)

Across all three groups, there was an increase in the proportion of respondents who had received training on the My Health Record system (10.4%, 3.1% and 3.7% in the opt-out, opt-in and rest of

Australia groups respectively). The difference in the increased proportion between the opt-out and rest of Australia groups who had received training was statistically significant (6.2% adjusted). However, the proportion of participants in the opt-out group who had received training remained relatively low (less than 15%). The majority of training was provided face to face across all three groups (72.2%; 76.6%; 75.9% in opt-out, opt-in and rest of Australia respectively). In general, there was an increase in the perceived effectiveness of the training between baseline and follow up across all three groups with no statistically significant difference in the change of training effectiveness between the groups.

Table 8. My Health Record Training. Rest of Australia and Opt-out.

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Baseline	Follow up			
Received training; n (%)								
Yes	12 (3.8)	37 (14.2)	10.4	38 (4.7)	56 (8.4)	3.7	6.7	6.2**
No	308 (96.3)	223 (85.8)	-10.5	778 (95.3)	611 (91.6)	-3.7	-6.8	
Training format; n (%)								
Online training	0 (0.0)	3 (8.3)	8.3	6 (15.8)	3(5.6)	-10.2	18.5	16.2
Face to face training	10 (83.3)	26 (72.2)	-11.1	25 (65.8)	41(75.9)	10.1	-21.2	-19.8
Online + face to face	2 (16.7)	6(16.7)	0	5 (13.2)	7(13.0)	-0.2	0.2	1.6
Other	0 (0.0)	3(5.6)	5.6	2 (5.3)	3(5.6)	0.3	5.3	2.1
Effectiveness of training when applied in workplace; n (%)								
Extremely effective	1 (8.3)	0(0.0)	-8.3	1(2.7)	5(9.1)	6.4	-14.7	-5.9
Very effective	1(8.3)	8(22.2)	13.9	7(18.9)	16(29.1)	10.2	3.7	-16.0
Moderately effective	8(66.7)	16(44.4)	-22.3	12(32.4)	18(32.7)	0.3	-22.6	-03.8
Slightly effective	0(0.0)	6(16.7)	16.7	5(13.5)	10(18.2)	4.7	12	8.8
Not effective at all	2(16.7)	6(16.7)	0.0	12(32.4)	6(10.9)	-21.5	21.5	16.8

Table 9. My Health Record Training. Rest of Australia and Opt-in.

	Opt-in	Opt-in	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Follow up	Baseline			
Received training; n (%)								
Yes	31 (3.6)	47 (6.7)	3.1	38 (4.7)	56 (8.4)	3.7	-0.6	-0.3
No	842 (96.5)	658 (93.3)	-3.2	778 (95.3)	611 (91.6)	-3.7	0.5	
Training format; n (%)								
Online training	4 (12.9)	4 (8.5)	-4.4	6 (15.8)	3(5.6)	-10.2	5.8	4.6
Face to face training	21 (67.7)	36 (76.6)	8.9	25 (65.8)	41(75.9)	10.1	-1.2	-3.9
Online + face to face	3 (9.7)	6 (12.8)	3.1	5 (13.2)	7(13.0)	-0.2	3.3	7.1
Other	3 (9.7)	1 (2.1)	-7.6	2 (5.3)	3(5.6)	0.3	-7.9	-7.8
Effectiveness of training when applied in workplace; n (%)								
Extremely effective	2 (6.5)	5(10.6)	4.1	1(2.7)	5(9.1)	6.4	-2.3	0.2
Very effective	5(16.1)	14(29.8)	13.7	7(18.9)	16(29.1)	10.2	3.5	-0.6
Moderately effective	11(35.5)	15(31.9)	-3.6	12(32.4)	18(32.7)	0.3	-3.9	-2.2
Slightly effective	5(16.1)	10(21.3)	5.2	5(13.5)	10(18.2)	4.7	0.5	0.2
Not effective at all	8(25.8)	3(6.4)	-19.4	12(32.4)	6(10.9)	-21.5	2.1	2.4

Increased participation in, and use of, the My Health Record system by users

Participation

Across all three groups, there was an increase in the number of respondents who reported their workplace as being registered on the My Health Record system. The increase during the trial was greater in the opt-out trial site (9.8%) relative to the rest of Australia (4.6%) although the difference (4.3% adjusted) was not statistically significant. There was no substantive or significant difference between the increase in registered workplaces within the opt-in site (5.9%) and the rest of Australia (4.6%).

Table 10. Work place registration and access to My Health Record. Rest of Australia and Opt-out intervention group¹

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted difference
	Baseline	Follow up		Baseline	Follow up			
Workplace registered; n (%)	52 (16.2)	71 (26.0)	9.8	153 (18.8)	163 (23.8)	4.6	5.2	4.3
Ever accessed My Health Record; n (%)	30 (9.3)	57 (20.9)	11.6	90 (11.1)	118 (17.3)	6.1	5.5	5.2

¹ Totals exclude missing responses ² chi2 test * 5% statistical significance **1 statistical significance

Table 11. Work place registration and access to My Health Record. Rest of Australia and Opt-in intervention group

	Opt-in	Opt-in	Difference (%)	Rest of Australia	Rest of Australia	Difference (%)	Difference of difference	Adjusted difference
	Baseline	Follow up		Baseline	Follow up			
Workplace registered; n (%)	94 (10.8)	123 (16.7)	5.9	153 (18.8)	163 (23.8)	4.6	1.3	1.2
Ever accessed My Health Record; n (%)	64 (7.4)	103 (14.0)	6.7	90 (11.1)	118 (17.3)	6.1	0.6	0.9

Contribution



Although there was an increase over the trial period in the proportion of healthcare providers uploading documents to the My Health Record system, this increase was across all three groups. The increase was more pronounced in the opt-out trial site relative to the rest of Australia, although the difference was not statistically significant.

Table 12. Document Upload to the My Health Record system, for those who have ever accessed the My Health Record system. Rest of Australia and Opt-out intervention group

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Baseline	Follow up			
<i>How many documents have you uploaded in the last 4 wks; n (%)</i>								
None	20 (66.7)	27 (50.0)	-16.7	62 (69.7)	66 (57.4)	-12.3	-4.4	-9.0
< 5	7 (23.3)	12 (22.2)	-1.1	20 (22.5)	24 (20.9)	-1.6	0.5	3.5
6 - 10	2 (6.7)	3 (5.6)	-1.1	3 (3.4)	11 (9.6)	6.2	-7.3	1.8
11 or more	1 (3.3)	12 (22.2)	18.9	4 (4.5)	14 (12.2)	7.7	11.2	3.7

Table 13. Document Upload to the My Health Record system, for those who have ever accessed the My Health Record system. Rest of Australia and Opt-in intervention group

	Opt-in	Opt-in	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Baseline	Follow up			
<i>How many documents have you uploaded in the last 4 wks; n (%)</i>								
None	34 (54.8)	46 (46.0)	-8.8	62 (69.7)	66 (57.4)	-12.3	3.5	-0.2
< 5	20 (32.3)	26 (26.0)	-6.3	20 (22.5)	24 (20.9)	-1.6	-4.7	-0.8
6 - 10	3 (4.8)	11 (11.0)	6.2	3 (3.4)	11 (9.6)	6.2	0	0.1
11 or more	5 (8.1)	17 (17.0)	8.9	4 (4.5)	14 (12.2)	7.7	1.2	0.9

Use

There was no statistically significant difference between baseline and follow up in the proportion of healthcare providers uploading documents to the My Health Record system in either of the groups. The change over time in self-reported document uploads was also not statistically significantly different across the three groups.

Table 14. Use of My Health Record system, for those who have ever accessed the My Health Record system. Rest of Australia and Opt-out intervention group¹

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Baseline	Follow up			
<i>How many documents have you viewed in the last 4 wks; n (%)</i>								
None	12 (40.0)	24 (42.1)	2.1	41 (46.1)	49 (41.5)	-4.6	6.7	4.6
< 5	14 (46.7)	24 (42.1)	-4.6	42 (47.2)	51 (43.2)	-4	-0.6	-2.5
6 - 10	2 (6.7)	3 (5.3)	-1.4	3 (3.4)	11 (9.3)	5.9	-7	-0.9
11 or more	2 (6.7)	6 (10.5)	3.8	3 (3.4)	7 (5.9)	2.5	1.3	-1.2

¹ Totals exclude missing responses

Table 15. Use of My Health Record system, for those who have ever accessed the My Health Record system. Rest of Australia and Opt-in intervention group

	Opt-in	Opt-in	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Baseline	Follow up			
How many documents have you viewed in the last 4 wks; n (%)								
None	28 (43.8)	37 (35.9)	-7.9	41 (46.1)	49 (41.5)	-4.6	-3.3	-4.5
< 5	28 (43.8)	50 (48.5)	4.7	42 (47.2)	51 (43.2)	-4	8.7	2.2
6 - 10	3 (4.7)	6 (5.8)	1.1	3 (3.4)	11 (9.3)	5.9	-4.8	1.0
11 or more	5 (7.8)	10 (9.7)	1.9	3 (3.4)	7 (5.9)	2.5	-0.6	1.4

There was no statistically significant difference between the opt-out and rest of Australia groups in the change over time for a number of a-priori identified potential determinants of use to the My Health Record system. This was also the case for the comparisons between the opt-in and rest of Australia groups.

Table 16. Determinants of use of the My Health Record' Rest of Australia and Opt-out intervention group¹

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Baseline	Follow up			
Current access to all information; n (%)								
Always	79 (24.7)	36 (11.9)	-12.8	201 (24.6)	96 (12.5)	-12.1	-0.7	-2.9
Mostly	124 (38.8)	111 (36.6)	-2.2	285 (34.9)	290 (37.7)	3.1	7.5	-2.2
Half the time	20 (6.3)	26 (8.6)	2.3	77 (9.4)	91 (11.8)	2.4	-0.1	0.2
Some of the time	45 (14.1)	72 (23.7)	9.6	137 (16.8)	169 (22.0)	5.2	4.4	1.7
Never	52 (16.3)	58 (19.1)	2.8	116 (14.2)	123 (16.0)	1.8	1.0	3.1
Influence of patients' desire; n (%)								
Extremely likely	93 (29.0)	89 (33.7)	4.7	247 (30.4)	227 (33.8)	3.4	1.3	0.3
Somewhat likely	136 (42.4)	105 (39.8)	-2.6	343 (42.2)	286 (42.6)	0.4	-3.0	< -0.1
Neither	65 (20.3)	54 (20.5)	0.2	160 (19.7)	106 (15.8)	-3.9	4.1	-0.2
Somewhat unlikely	10 (3.1)	9 (3.4)	0.3	32 (3.9)	27 (4.0)	0.1	0.2	0.1
Extremely unlikely	17 (5.3)	7 (2.7)	-2.6	31 (3.8)	25 (3.7)	-0.1	-2.5	-0.1
Believe that My Health Record will improve access to information; n (%)								
Strongly disagree	24 (7.5)	44 (16.3)	8.8	62 (7.6)	117 (17.3)	9.7	-0.9	1.1
Disagree	13 (4.1)	34 (12.6)	8.5	34 (4.2)	60 (8.9)	4.7	3.8	0.2
Neither	66 (20.6)	104 (38.5)	17.9	146 (18.0)	274 (40.4)	22.4	-4.5	-1.4
Agree	119 (37.1)	55 (20.4)	-16.7	307 (37.8)	138 (20.4)	-17.4	0.7	-1.5
Strongly agree	99 (30.8)	33 (12.2)	-18.6	263 (32.4)	89 (13.1)	-19.3	0.7	1.5
Believe that My Health Record will save you time; n (%)								
Strongly disagree	27 (8.5)	54 (20.2)	11.7	85 (10.6)	124(18.5)	7.9	3.8	3.4
Disagree	36 (11.4)	40 (14.9)	3.5	73 (9.1)	76(11.3)	2.2	1.3	1.0
Neither	81 (25.6)	111 (41.4)	15.8	200 (24.8)	288(42.9)	18.1	-2.3	-2.0
Agree	98 (30.9)	43(16.0)	-14.9	245 (30.4)	117(17.4)	-13	-1.9	-2.3
Strongly agree	75 (23.7)	20 (7.5)	-16.2	203 (25.2)	66(9.8)	-15.4	-0.8	-0.1

¹ Totals may not add up to sample size or percentages to 100% due to missing responses

Table 17. Determinants of use of the My Health Record. Rest of Australia and Opt-out intervention group

	Opt-in	Opt-in	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted Difference of difference
	Baseline	Follow up		Follow up	Baseline			
Current access to all information; n (%)								
Always	215 (24.7)	113 (13.8)	-10.9	201 (24.6)	96 (12.5)	-12.1	1.2	0.1
Mostly	286 (32.8)	280 (34.1)	1.3	285 (34.9)	290 (37.7)	3.1	-1.8	0.1
Half the time	77 (8.8)	105 (12.8)	4	77 (9.4)	91 (11.8)	2.4	1.6	<-0.1
Some of the time	156 (17.9)	184 (22.4)	4.5	137 (16.8)	169 (22.0)	5.2	-0.7	-0.1
Never	137 (15.7)	139 (16.9)	1.2	116 (14.2)	123 (16.0)	1.8	-0.6	-0.1
Influence of patients' desire; n (%)								
Extremely likely	234 (26.9)	213 (30.2)	3.3	247 (30.4)	227 (33.8)	3.4	-0.1	-0.4
Somewhat likely	350 (40.3)	287 (40.7)	0.4	343 (42.2)	286 (42.6)	0.4	0	0.4
Neither	192 (22.1)	154 (21.8)	-0.3	160 (19.7)	106 (15.8)	-3.9	3.6	0.1
Somewhat unlikely	44 (5.1)	24 (3.4)	-1.7	32 (3.9)	27 (4.0)	0.1	-1.8	<-0.1
Extremely unlikely	49 (5.6)	27 (3.8)	-1.8	31 (3.8)	25 (3.7)	-0.1	-1.7	<-0.1
Believe that My Health Record will improve access to information; n (%)								
Strongly disagree	55 (6.3)	78 (10.9)	4.6	62 (7.6)	117 (17.3)	9.7	-5.1	-2.8
Disagree	55 (6.3)	45 (6.3)	0	34 (4.2)	60 (8.9)	4.7	-4.7	-1.1
Neither	157 (18.1)	332 (46.3)	28.2	146 (18.0)	274 (40.4)	22.4	5.8	-2.2
Agree	332 (38.3)	170 (23.7)	-14.6	307 (37.8)	138 (20.4)	-17.4	2.8	1.6
Strongly agree	269 (31.0)	92 (12.8)	-18.2	263 (32.4)	89 (13.1)	-19.3	1.1	4.0
Believe that My Health Record will save you time; n (%)								
Strongly disagree	72 (8.3)	92(13.0)	4.7	85 (10.6)	124(18.5)	7.9	-3.2	-1.8
Disagree	75 (8.7)	55(7.8)	-0.9	73 (9.1)	76(11.3)	2.2	-3.1	-1.0
Neither	232 (26.9)	344(48.7)	21.8	200 (24.8)	288(42.9)	18.1	3.7	-1.0
Agree	261 (30.2)	138(19.6)	-10.6	245 (30.4)	117(17.4)	-13	2.4	1.4
Strongly agree	223 (25.8)	77(10.9)	-14.9	203 (25.2)	66(9.8)	-15.4	0.5	2.3

At follow up, there were no significant differences between the three groups with regards to healthcare provider beliefs about the following attributes of the My Health Record system: access to information about patient health; ability to apply best practice care; informs medication management choices; saves time sourcing patient information; spend less time communicating to other healthcare providers; enables patients to better manage healthcare; adds time to upload data.

Table 18. Determinants of use of the My Health Record. Rest of Australia, Opt-out and Opt-in at follow up

	Opt-out	Opt-in	Rest of Australia
	Follow up	Follow up	Follow up
Improves access to information about my patient's health; n (%)			
Strongly disagree	42 (15.6)	73 (10.3)	111 (16.5)
Somewhat disagree	36 (13.4)	50 (7.1)	65 (9.7)
Neither	103 (38.3)	309 (43.8)	269 (40.1)
Somewhat agree	53 (19.7)	181 (25.6)	130 (19.4)
Strongly agree	35 (13.0)	93 (13.2)	96 (14.3)

	Opt-out	Opt-in	Rest of Australia
	Follow up	Follow up	Follow up
<i>Improves ability to apply best practice care; n (%)</i>			
Strongly disagree	43 (16.2)	80 (11.4)	111 (16.5)
Somewhat disagree	33 (12.4)	41 (5.9)	70 (10.4)
Neither	114 (42.9)	329 (47.0)	285 (42.4)
Somewhat agree	50 (18.8)	164 (23.4)	121 (18.0)
Strongly agree	26 (9.8)	86 (12.3)	86 (12.8)
<i>Helps inform medication management choices potentially avoiding adverse drug events; n (%)</i>			
Strongly disagree	48 (18.0)	75 (10.6)	109 (16.2)
Somewhat disagree	30 (11.2)	38 (5.4)	71 (10.6)
Neither	122 (45.7)	351 (49.8)	296 (44.1)
Somewhat agree	40 (15.0)	145 (20.6)	110 (16.4)
Strongly agree	27 (10.1)	96 (13.6)	85 (12.7)
<i>Saves time sourcing patient information; n (%)</i>			
Strongly disagree	45 (16.8)	82 (11.7)	127 (18.9)
Somewhat disagree	41 (15.3)	49 (7.0)	77 (11.5)
Neither	104 (38.8)	319 (45.4)	267 (39.73)
Somewhat agree	45 (16.8)	147 (20.9)	121 (18.0)
Strongly agree	33 (12.3)	105 (15.0)	80 (11.9)
<i>Helps spend less time communicating information to other healthcare providers; n (%)</i>			
Strongly disagree	46 (17.1)	86 (12.2)	133 (19.9)
Somewhat disagree	37 (13.75)	64 (9.1)	71 (10.6)
Neither	114 (42.4)	335 (47.5)	284 (42.5)
Somewhat agree	50 (18.6)	129 (18.3)	109 (16.3)
Strongly agree	22 (8.2)	91 (12.9)	72 (10.8)
<i>Enables patients to better manage healthcare.; n (%)</i>			
Strongly disagree	42 (15.6)	73 (10.4)	104 (15.5)
Somewhat disagree	30 (11.1)	41 (5.8)	62 (9.3)
Neither	128 (47.4)	364 (51.7)	312 (46.6)
Somewhat agree	48 (17.8)	151 (21.5)	129 (19.3)
Strongly agree	22 (8.15)	75 (10.65)	63 (9.40)
<i>Adds time to upload data.; n (%)</i>			
Strongly disagree	30 (11.2)	58 (8.2)	61 (9.09)
Somewhat disagree	18 (6.7)	37 (5.2)	46 (6.8)
Neither	124 (46.1)	390 (55.2)	341 (50.8)
Somewhat agree	62 (23.1)	146 (20.7)	134 (20.0)
Really not confident	39 (14.9)	83 (11.8)	85 (12.8)

Intentions to view and upload documents to the My Health Record system

Although not statistically significantly different, the opt-out group compared with the other groups has more intention over the next four months to view and upload to the My Health Record system.

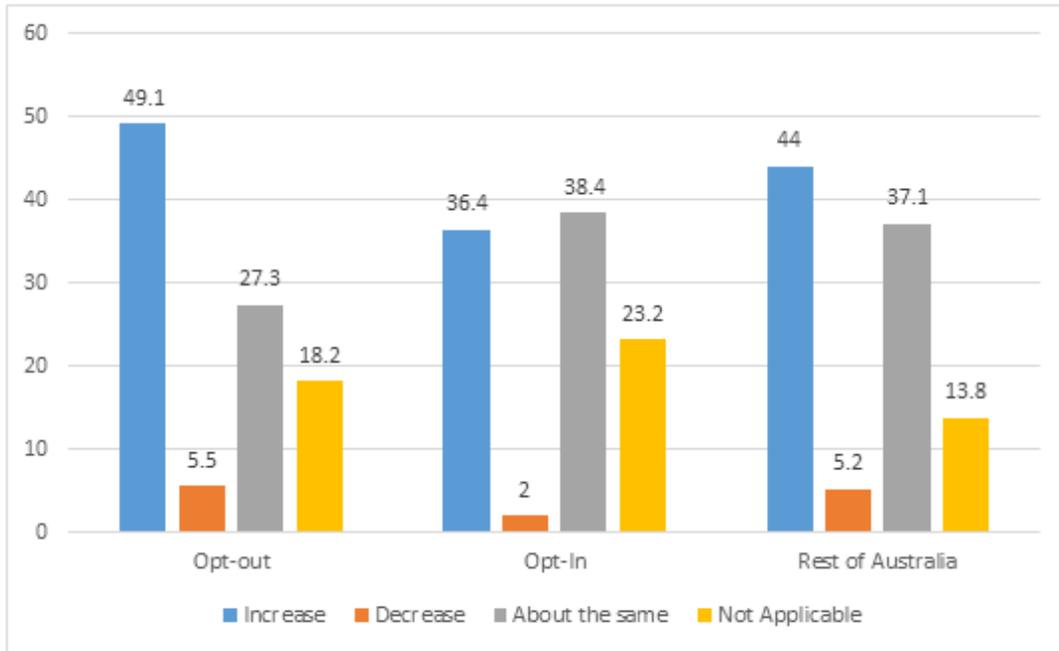


Figure 3. Healthcare providers' intention to view My Health Records in the next four months %, by intervention group

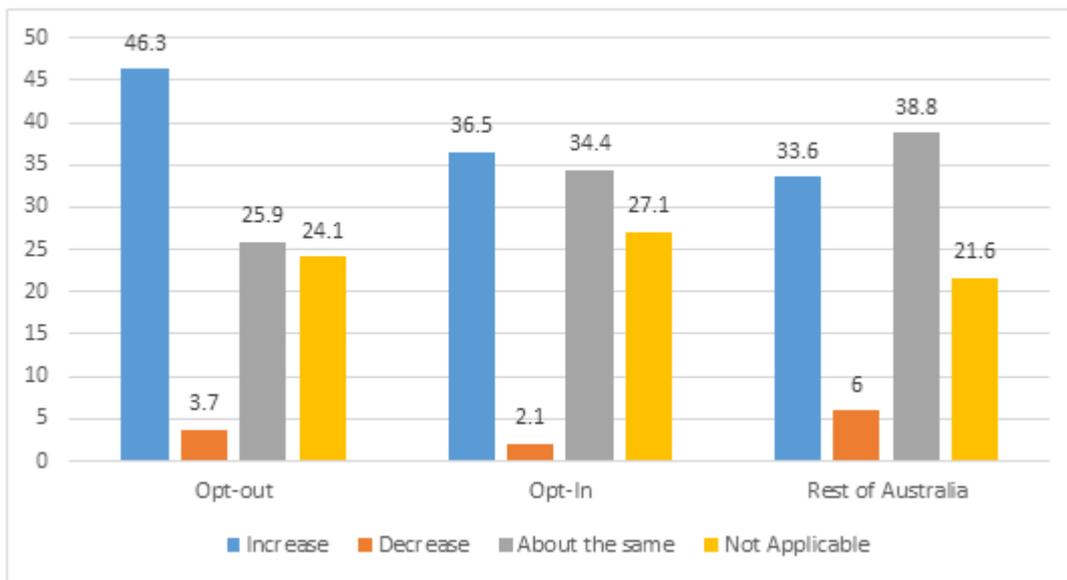


Figure 4. healthcare providers' intention to upload to the My Health Record system in the next four months %, by intervention group

Potential Benefits from Use of My Health Record System

Among healthcare providers who had accessed the My Health Record system, there were no statistically significant differences between trial sites in the proportion of healthcare providers who reported: My Health Records providing information otherwise unknown; providing confidence in a clinical decision; or leading to a change in clinical treatment.

Table 19. Impact of My Health Records on respondents' clinical practice and decision making, Rest of Australia and Opt-out intervention group¹

	Opt-out	Opt-out	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted difference of difference
	Baseline	Follow up		Baseline	Follow up			
<i>My Health Record has provided information otherwise unknown; n(%)</i>								
Yes	3 (10.0)	7 (12.3)	2.3	7 (8.0)	17 (14.3)	6.3	-4.1	-3.7
No	27 (90.0)	50 (87.7)		81 (92.1)	102 (85.7)			
<i>My Health Record has provided confidence in clinical decision; n(%)</i>								
Yes	3 (10.0)	2 (3.5)	-6.5	5 (5.7)	11 (9.2)	3.5	-10.0	-7.9
No	27 (90.0)	57 (96.5)		83 (94.3)	119 (91.8)			
<i>My Health Record has led to a change in clinical treatment; n(%)</i>								
Yes	1 (3.3)	1 (1.8)	-1.5	2 (2.3)	5 (4.2)	1.9	-3.4	-3.0
No	29 (96.7)	57 (98.2)		86 (97.7)	114 (95.8)			

¹ Totals may not add up to sample size or percentages to 100% due to missing responses

Table 20. Impact of the My Health Record system on respondents' clinical practice and decision making, Rest of Australia and Opt-in intervention group

	Opt-in	Opt-in	Difference	Rest of Australia	Rest of Australia	Difference	Difference of difference	Adjusted difference of difference
	Baseline	Follow up		Baseline	Follow up			
<i>My Health Record has provided information otherwise unknown; n(%)</i>								
Yes	12 (19.1)	9 (8.8)	-10.3	7 (8.0)	17 (14.3)	6.3	-16.7	-15.1
No	51 (81.0)	93 (91.2)		81 (92.1)	102 (85.7)			
<i>My Health Record has provided confidence in clinical decision; n(%)</i>								
Yes	12 (19.1)	12 (11.9)	-7.2	5 (5.7)	11 (9.2)	3.5	-10.7	-6.1
No	51 (81.0)	101 (88.1)		83 (94.3)	119 (91.8)			
<i>My Health Record has led to a change in clinical treatment; n(%)</i>								
Yes	9 (14.3)	5 (5.0)	-9.3	2 (2.3)	5 (4.2)	1.9	-11.2	-8.6
No	54 (85.7)	101 (95.0)		86 (97.7)	114 (95.8)			

At follow up, there was no statistically significant difference between groups with regards to healthcare providers identifying an instance in the past four weeks where the My Health Record had led to improved capacity for multidisciplinary team care.

Table 21. Outcomes from use of the My Health Record system at Follow up

	Opt-out	Opt-in	Rest of Australia
	Follow up	Follow up	Follow up
<i>Has My Health Record led to improved capacity for multidisciplinary team care; n(%)</i>			
Yes	20 (7.7)	34 (5.0)	43 (6.6)
No	240 (92.3)	653 (95.1)	613 (93.5)

Results of Qualitative Analysis

The baseline survey of the evaluation did not ask all the questions asked in the follow up survey. Questions were added to gather more information about results from the baseline survey.

We first describe the general findings for each qualitative question from the follow up survey. Where possible, we then compare the results from the follow up study with the baseline study. However, the frequency and proportions reported in the tables below for the follow up study cannot be directly compared with those reported in the baseline, as the proportions calculated from the baseline included people who did not respond in the follow up study.

The findings for each question in the follow up study were analysed by demographic groups - their health profession, and their location. The pattern of results by different demographic groups were then compared with the overall pattern of results. They were also compared with those findings from the baseline study that were also analysed by different demographic groups.

Note: When responses to the qualitative questions (i.e. open-ended questions) could be classified under two different categories, they were then coded in those two categories. Therefore, the total number of responses described in the following section does not reflect the total number of respondents who answered the question. Rather, it represents the total number of concepts or categories respondents provided to answer a question. It should also be noted that the percentages reported within each question can only be interpreted for that question as they account for the percentage of total number of categories expressed in response to a question, rather than the total number of people who responded to the question. Responses that did not directly address the questions asked or were not able to be interpreted were categorised as “Other”.

Results for each open-ended question in the healthcare provider survey are described as a whole, highlighting the key categories and responses provided. The findings are then broken down and presented in demographic groups to identify any observable differences or key findings within: health profession; and location.

Reasons for not accessing any My Health Records

Healthcare providers who said they had never accessed any My Health Records were asked their reasons for not doing so. 1,202 respondents offered meaningful responses in the follow up survey, and a total of 1,247 concepts were analysed.

Healthcare providers in the follow up study mentioned lack of awareness or information about the My Health Record system as their reason for not accessing any My Health Records (n=360, 29%). Next, healthcare providers said they did not have access to the My Health Record system (n=350, 28%). The third most frequent reason was that there was no need to use the My Health Record system, as they were currently using other methods to compile patients’ information (n=170, 14%). In addition, lack of training and lack of patient uptake and use of the My Health Record system also discouraged healthcare providers from accessing the My Health Record system (n=170, 14%).

Table 22 shows the frequency and proportion of responses by the reasons respondents gave for not accessing any My Health Records.

The response categories from respondents in the follow up survey were consistent with those in the baseline study. The trends that emerged in the follow up study were consistent with the results from the baseline study - that is, the top five common reasons for not accessing a My Health Record were similar across the two surveys.

Table 22. Reasons for not accessing any My Health Records by categories from respondents in the baseline and follow up surveys

Baseline survey			Follow up survey		
Category	n	%	Category	n	%
Lack of awareness/information relating to My Health Record	1,614	25	Lack of awareness/information relating to My Health Record	360	29%
No access to My Health Record system	1,161	18	No access to My Health Record system	350	28%
Do not see a need for My Health Record (use other methods to compile patient information)	1,136	18	Do not see a need for My Health Record (use other methods to compile patient information)	170	14%
Lack of training	740	12	Lack of training	51	4%

Baseline survey			Follow up survey		
Category	n	%	Category	n	%
Lack of uptake and use of the My Health Record by patients	291	5	Lack of uptake and use of the My Health Record by patients	41	3%
Unaware of the My Health Record system altogether	288	4	Too time consuming	41	3%
Perceptions about the effectiveness and efficiency of the My Health Records in providing good health	187	3	Perceptions about the effectiveness and efficiency of the My Health Records in providing good health	25	2%
Too time consuming	147	2	Complications when registering for My Health Record or issues with usability of My Health Record System	21	2%
Complications when registering for My Health Record or issues with usability of My Health Record system	135	2	Incompatible Clinical Information System (CIS) software	18	1%
Incompatible Clinical Information System (CIS) software	112	2	Privacy and security concerns	12	1%
Privacy and security concerns	103	2	In the process of implementing use of the My Health Record system with practice	10	1%
Not interested in participating in the My Health Record	54	1	Cost for setting up My Health Record system in the organisation	8	1%
Concerns about individual control of records	53	1	Concerns about individual control of records	5	0%
Cost for setting up My Health Record system in the organisation	31	0	Not interested in participating in the My Health Record	5	0%
In the process of implementing use of the My Health Record system with practice	13	0	Unaware of the My Health Record system altogether	4	0%
Others (e.g., current role do not have patient contact; not currently practising)	355	6	Others (e.g., current role do not have patient contact; not currently practising)	126	10%
Total	6,420	100	Total	1,247	100%

Some quotes from respondents who provided reasons for not accessing any My Health Records:

"We use paper notes. Do not know how to upload documents to My Health Record."

"I am a psychologist and it doesn't apply to my profession."

"I am not registered & have never received any information or offers to join. I would like to. I am not interested in the PIP component."

"We haven't been sent any information to our practice about My Health Records as far as I know."

"Haven't been encouraged or shown how to make use of it."

"We need some training and encouragement."

"There has been no official instruction from my hospital to do so."

"Haven't been exposed or trained with it."

"Have had no introduction or formal training/teaching, to say it is at our work place."

"Not set up with access in workplace yet."

"Access is not available in my work place."

"No available in my workplace to my knowledge."

"Think the potential risks of misuse of confidential information outweigh the benefits for all except the very elderly and infirm, or mentally disabled."

"Confidentiality concerns especially as I am a psychotherapist."

"I cannot rely on information which can be amended by the patient."

"Did not need it."

"Tried to access information for one patient but they did not have anything in their My Health Record file. Have not had the need to access information for any other patients."

"It is not 'on our radar'. No patient has ever mentioned it, and we don't routinely ask."

"No patient coming to my practice has such a record to my knowledge. In addition, I would have to purchase a new computer system and spend more time on data entry to enter data into My Health Record."

"Have not had any patients with My Health Records uploaded by other doctors."

"We are not yet registered as our computer software is not ready for this."

"I have tried. I don't know the proper way to do so. Also the registration process is complicated especially for newly migrated health professionals. Sensing some information to newly migrated health professionals in this regard would be helpful."

"Unable to connect, tried on multiple occasions and spent significant amount of time."

"Untrusted information. Security issues. Often no internet access at work."

"Waste of time and money."

"Inefficient and no evidence of uptake elsewhere."

"I refuse to be involved unless I'm paid for my time. I also don't like the system that allows patients to change the record."

Profession of respondents

Of the 1,202 respondents to this question in the follow up survey, three did not indicate their health profession and were excluded from the analysis. The professions of 1,199 respondents were analysed against their reasons for not accessing a My Health Record. The number in each profession is shown in Table 23. 24% were medical specialists (n=295), followed by nurses/midwives (19%), GPs (12%) and pharmacists (12%).

Pharmacists, podiatrists, optometrists, dentists, other professions, psychologists and specialists said that lack of awareness of the My Health Record was their most prominent reason. Nurses/midwives, physiotherapists, and occupational therapists said the key reason for not accessing the My Health Record system was that it was not available to them in their workplaces. GPs mainly felt that there was no need for the My Health Record system as they already use appropriate methods to collect patient information. Table 24 presents the frequency of the responses by category expressed by respondents who provided reasons for not accessing a My Health Record by their health professions in the follow up survey. The pattern of results found from the follow up survey was consistent to those revealed in the baseline survey.

Table 23. Number of responses per category against healthcare provider types who provided reasons for not accessing a My Health Record in the follow up study.¹

Health profession type	Category																Total	%
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16		
General Practitioner	19	14	34	8	13	15	13	2	3	4	2	2	3	0	1	11	144	12
Nurse/midwife	44	102	36	9	4	5	0	0	1	0	2	0	0	0	0	35	238	19
Physiotherapist	35	39	11	5	1	3	0	0	2	0	0	1	0	1	1	9	108	9
Pharmacist	47	46	5	12	3	4	2	3	4	0	1	1	0	0	1	15	144	12
Podiatrist	5	2	0	1	2	0	0	1	0	0	1	0	0	0	0	0	12	1
Optometrist	13	2	3	0	1	0	0	1	2	0	0	0	0	0	0	0	22	2
Dentist	15	10	1	0	1	2	1	1	0	1	1	1	0	1	0	1	36	3
A&TSI healthcare provider	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	2	0
Other	32	27	23	3	0	4	0	7	2	2	0	1	0	1	1	10	113	9
Psychologist	28	16	19	1	1	3	1	1	1	1	0	2	0	0	0	8	82	7
Occupational therapist	13	18	4	1	1	1	0	0	0	0	1	0	0	0	0	9	48	4
Medical Practitioner - other specialist	107	72	33	10	14	4	8	5	4	5	1	0	2	2	0	28	295	24

1. Description of codes for the categories are listed in the table below.

Table 24. Description of codes used in Table 23 and Table 25.

Code	Category	Code	Category
1	Lack of awareness/information relating to My Health Record system	9	Incompatible Clinical Information System (CIS) software
2	No access to My Health Record system	10	Privacy and security concerns
3	Do not see a need for My Health Record system (use other methods to compile patient information)	11	In the process of implementing use of the My Health Record system with practice

Code	Category	Code	Category
4	Lack of training	12	Cost for setting up My Health Record system in the organisation
5	Lack of uptake and use of the My Health Record system by patients	13	Concerns about individual control of records
6	Too time consuming	14	Not interested in participating in the My Health Record
7	Perceptions about the effectiveness and efficiency of the My Health Record system in providing good health	15	Unaware of the My Health Record system altogether
8	Complications when registering for My Health Record or issues with usability of My Health Record system	16	Other

Table 25. Number of responses per category against healthcare provider types who provided reasons for not accessing a My Health Record in the baseline survey ¹.

Health profession type	Number of responses by category																Total	%
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16		
Medical Practitioner - general practitioner	111	53	122	105	87	50	60	38	22	39	9	13	25	12	21	18	785	13
Nurse or midwife	284	309	240	97	21	23	13	20	11	3	3	3	3	10	82	86	1208	19
Physiotherapist	143	82	79	50	11	6	2	4	7	4	0	1	0	4	15	19	427	7
Pharmacist	209	152	99	141	37	13	15	18	11	5	1	4	3	5	29	34	776	13
Podiatrist	16	5	11	11	2	3	2	3	1	2	0	1	1	0	1	3	62	1
Optometrist	29	10	11	14	0	1	0	2	2	4	0	1	0	1	3	1	79	1
Dentist	72	33	38	5	2	1	1	1	2	1	0	1	2	0	7	7	173	3
A&TSI healthcare provider	4	5	4	2	0	1	0	0	0	0	0	0	0	1	2	0	19	0
Other (e.g., Dental Hygienist; Chiropractor; Radiologist)	154	95	109	39	13	5	7	7	12	5	0	0	0	6	24	61	537	9
Psychologist	139	98	114	35	3	8	6	11	14	17	0	4	2	2	15	49	517	8
Occupational therapist	90	76	64	31	7	2	5	2	3	1	0	0	1	1	18	32	333	5
Medical Practitioner - other specialist	160	241	243	210	107	34	76	29	27	21	0	3	16	12	71	44	1294	21

1. Description of codes for categories are listed in Table

All healthcare providers who gave reasons for not accessing a My Health Record identified the location of their primary workplace in the follow up survey.

In the follow up survey, respondents in Northern Queensland and in the rest of Australia reported the same top three reasons for not accessing the My Health Record system: lack of awareness; not seeing a need for the My Health Record system; and the My Health Record system not being available in their workplace. The exception was the pattern of results for the NBM, Ballarat and Western Australia trial sites.

Equal numbers of responses from NBM indicated that respondents were unaware of the My Health Record system or they had no access to the My Health Record system (n=14). The top three reasons for not accessing the My Health Record system in Ballarat were: the My Health Record system not being available in their workplace; lack of awareness of the My Health Record system; and they did not see a need to use the My Health Record system, as they already had other methods in place to get patient's information. The top three responses from Western Australia were: the My Health Record system not being available in their workplace; lack of awareness; and people did not see the need for the My Health Record system.

These results were consistent with the pattern of results from the baseline study describes responses across the trial and non-trial sites in the baseline and follow up surveys.

Table 26. Frequency and proportion of responses in the baseline and follow up about why respondents had not accessed the My Health Record system.

Baseline						Follow up					
Category	NQ	NB M	Ballarat	WA	Rest of Australia	Category	NQ	NB M	Ballarat	WA	Rest of Australia
Lack of awareness/information relating to My Health Record	234	92	59	687	542	Lack of awareness/information relating to My Health Record	33	14	9	137	167
No access to My Health Record system	152	74	42	566	327	No access to My Health Record system	29	14	15	158	134
Do not see a need for My Health Record system (use other methods to compile patient information)	205	102	26	407	396	Do not see a need for My Health Record system (use other methods to compile patient information)	23	8	8	59	72
Lack of training	76	48	30	264	322	Lack of training	4	3	2	23	19
Lack of uptake and use of the My Health Record system by patients	41	13	7	77	153	Lack of uptake and use of the My Health Record system by patients	3	1	1	12	24
Unaware of the My Health Record system all together	58	18	6	94	112	Too time consuming	8	2	3	15	13
Perceptions about the effectiveness and efficiency of the My Health Records in providing good health	11	6	5	60	105	Perceptions about the effectiveness and efficiency of the My Health Record system in providing good health	0	2	1	6	16
Too time consuming	27	13	2	42	63	Complications when registering for My Health Record or issues with usability of My Health Record System	1	3	1	7	9
Complications when registering for My Health Record system or issues with usability of My Health Record System	14	5	6	49	61	Incompatible Clinical Information System (CIS) software	3	1	0	7	7
Incompatible Clinical Information System (CIS) software	20	8	3	35	45	Privacy and security concerns	1	1	0	2	7

Baseline						Follow up					
Category	NQ	NB M	Balla rat	WA	Rest of Austr alia	Category	NQ	NB M	Balla rat	WA	Rest of Austr alia
Privacy and security concerns	14	8	4	29	48	In the process of implementing use of the My Health Record system with practice	0	0	1	5	3
Not interested in participating in the My Health Record system	7	2	1	24	20	Cost for setting up My Health Record system in the organisation	1	2	0	2	3
Concerns about individual control of records	3	2	0	29	19	Concerns about individual control of records	1	1	0	1	4
Cost for setting up My Health Record system in the organisation	1	3	0	19	8	Not interested in participating in the My Health Record	0	2	0	0	3
In the process of implementing use of the My Health Record system with practice	3	1	2	7	0	Unaware of the My Health Record system all together	0	0	0	3	1
Others (e.g., current role do not have patient contact; not currently practising)	1	6	12	233	103	Others	17	7	4	49	49
Total	867	401	205	2623	2324	Total	124	61	45	486	531

Would you access the My Health Record system if it were simpler to use?

Healthcare providers who had not accessed any My Health Records were asked if they would access the My Health Record system if it were simpler to use, and a total of 1,416 responses were analysed. 36% responded 'Yes' and only 4% said 'No'. Another 59% said 'Don't know'. The pattern of results in the follow up survey were different from the baseline where most respondents indicated that they would use the My Health Record system if it were simpler to use (Table 27.).

Table 27. Frequency and proportion of responses in the baseline and follow up about whether respondents would access the My Health Record system if it were simpler to use.

Baseline			Follow up		
Category	n	%	Category	n	%
Yes	2,674	50%	Don't know	839	59%
Possibly /Maybe /Perhaps	753	14%	Yes	515	36%
Unsure	558	10%	No	62	4%
Probably yes/likely to	418	8%			
No	371	7%			
Would like more education/information/training first	165	3%			
Probably no/ likely not to (Not necessarily)	161	3%			
Other responses (e.g., providing suggestions for functionality and useability, questioning the relevance to their area of expertise and providing more detailed reasoning for not accessing the My Health Record system)	284	5%			
Total	5,384	100%	Total	1,416	100%

Some quotes from respondents who provided other responses about accessing the My Health Record system if it were simpler to use.

Some quotes from respondents who provided other responses about accessing the My Health Record system if it were simpler to use.

“Usability is essential for a useful system although I do not think patient confidentiality should suffer in any way to achieve it.”

“Maybe. If it adds to my workload, I won't use it. If it is only used by a small number of people then I won't use it.”

“I am not convinced that it will give me all the specific information I might need e.g. detailed immunisation history or detailed pathology findings”

“As far as I am aware, radiology is not covered as yet. The pathology records may be useless, as would surgical documents. But accessing digitised images from other sites would be a significant benefit.”

“Definitely. If there an icon easily to press a button which is saved as an attachment with the patient's most updated record, that will be very useful”

“If our IT department allowed and facilitated it, I would”

Profession of respondents

In the follow up survey 1,411 healthcare providers answered whether they would access the My Health Record system if it were made simpler. The numbers in each profession are listed in Table 28: 23% were medical specialists, 22% were nurses/midwives and 12% were pharmacists. Apart from GPs, most responses from these professions said they were unsure whether they would access the My Health Record system if it were simpler to use. GPs indicated that they would use it if it was simpler to use. Findings from the follow up survey were inconsistent with the results from the baseline survey. Respondents across professions in the baseline survey indicated they would use the system if it were easier to use (7).

Table 28. Proportion and number of responses by profession of healthcare providers' accessing the My Health Record system if it were made simpler to use in the baseline and follow up surveys.

Profession	Baseline								Follow up			
	Category							Total	Category			Total
	Yes	Maybe, perhaps possibly	Unsure	Likely	No	Want more education /training first	Not likely		Don't know	Yes	No	
General practitioner	288	101	52	71	74	11	26	623	58	66	10	134
Nurse or midwife	571	133	100	47	45	42	25	963	196	104	11	311
Physiotherapist	185	43	53	22	7	18	6	334	87	34	3	124
Pharmacist	455	49	43	44	21	19	5	636	89	77	3	169
Podiatrist	22	16	5	3	3	0	2	51	8	4	0	12
Optometrist	34	16	8	1	5	3	1	68	13	9	2	24
Dentist	86	29	13	5	9	8	6	156	20	17	3	40
A&TSI healthcare provider	5	2	6	1	1	1	0	16	1	1	0	2
Psychologist	145	82	69	31	43	20	25	415	83	39	5	127
Occupational therapist	115	31	38	20	21	8	10	243	70	16	7	93
Medical Practitioner - other specialist	558	186	116	145	102	25	44	1176	39	12	2	53
Other	206	65	55	26	39	10	11	412	174	132	16	322

In the follow up survey, 42% (n=571) of the responses to the question whether healthcare providers would access the My Health Record system if it were simpler to use were from the rest of Australia location. The NQ trial site collected 10% (n=137) of the responses. The NBM trial site collected 5% (n=65). 40% of the responses were collected from the Western Australia trial site (n=571) and 4% were from the Ballarat trial site (n=51).

Contrary to the results at baseline, in the follow up survey most respondents in all sites responded that they do not know whether they would access the My Health Record system if it were simpler to use (8).

Table 29. Frequency of responses by categories against location.

Location	Baseline								Follow up				
	Category								Total	Category			Total
	Yes	Maybe, /Possibly /Perhaps	Unsure	Likely to	No	Others	Want more education training first	Not likely		Don't know	Yes	No	
NQ	308	117	63	17	48	0	15	21	600	80	49	8	137
NBM	161	40	23	40	23	2	9	7	311	40	23	2	65
Ballarat	83	40	10	10	4	23	8	7	188	30	19	2	51
WA	1,111	367	240	86	148	188	76	79	2338	363	189	19	571
Rest of Australia	1,011	189	222	265	148	71	57	47	2047	326	235	31	592

The following questions asked in the follow up survey were additional questions that were not asked to participants in the baseline survey.

How did the My Health Record system provide patient information which was previously unknown?

The 32 respondents who indicated that the My Health Record system gave them previously unknown patient information described how it did so. 12 said the My Health Record system gave them information about patients' admissions or visits to hospital, including Discharge Summaries. 11 said the My Health Record system showed them previous medical history, diagnosis and test results of patients to inform their clinical care, and 5 said it provided information about changes to their medication or whether they got their prescription filled (9).

Table 30. Frequency and proportion of responses by category expressed by respondents about how the My Health Record system provided patient information previously unknown to them.

Category	n	%
Information about admissions/visits to hospitals, including discharge summaries	12	38%
Previous medical history / diagnoses / test results	11	34%
Information about medication changes/prescriptions filled	5	16%
Other responses	2	6%
Previous referral sources	1	3%
Medicare card numbers / patient details	1	3%
Total	32	100%

Some quotes from respondents who described how the My Health Record system provides patient information previously unknown to them:

"One patient had hospital discharge records on their My Health Record which I was unable to obtain from the hospital in a timely manner."

"Information about admissions to other facilities that I didn't know about and medication changes that I was unclear on."

"I saw dispense records I had not previously seen."

"The prescription data was able to show me what prescriptions and doses were previously dispensed."

"I was able to access a medically complicated patient's records while she was visiting."

How did the My Health Record system modify your approach to diagnosis or treatment of a patient?

Most of the 11 respondents who indicated that the My Health Record system modified their approach to diagnosis or treatment of their patient said it provided information about past medical history or additional information not disclosed by the patient. Some also indicated the My Health Record system gave them information about their patients' hospital admissions and prescriptions that led them to do further assessments, and the My Health Record system allowed them to update a My Health Record to reduce confusion about a patient's condition (Table 31).

Table 31. Categories expressed by respondents about how the My Health Record system modified their approach to diagnosis and treatment of a patient.

Category	n
Provided information about past medical history / additional information not disclosed by patient	6
Provided information regarding hospital admissions	1
Influenced prescription of certain medications	1
Provided information to do assessments	1

Category	n
Allowed doctor to update patient's My Health Record to reduce confusion about a patient's condition	1
Others	1
Total	11

Some quotes from respondents who described how the My Health Record system modified their approach to diagnosis or treatment of a patient:

"Found out past medical history which I was not aware of."

"I have been able to follow through with the appropriate approach to management of symptoms for toys patient when I knew the underlying aetiology of the problem."

"In one occasion a confusing information triggered me to contact a colleague".

How did the My Health Record system provide you with more confidence in clinical decisions made for a patient?

People who responded 'Yes' when asked whether the My Health Record system provided them with more confidence in their clinical decision, were asked to elaborate on their response. 19 people provided responses. 10 said that the My Health Record system reassured them that they were not missing any important information by showing them their patient's previous medical history, diagnosis, medication and previous treatments from GPs/medical specialists. Others reported that the My Health Record system enabled them to make an informed decision regarding their patient's medication or future management; provided information that was not previously known/understood by patients themselves; and gave patients additional control over their health.

Table 32. Categories expressed by respondents about how the My Health Record system provide them with more confidence in clinical decisions made for their patients.

Category	n
Reassured clinicians that they were not missing important information	10
Enabled informed decision making regarding patient medication	3
Provided information about the patient that the patient was not aware of or did not understand	2
Gave patients additional control over their health	2
Others	2
Total	16

Some quotes from respondents who described how the My Health Record system provided them with more confidence in clinical decisions made for a patient

"I could see previous information tests undertaken."

"Confirmed inpatient doses and changes to medication."

"... it is about the patient not having a clear idea of what has happened to them therefore making plans for the future needs more information. It is much easier to access the My Health Record for a discharge summary than contact the hospital for that, and quicker."

"People have control with all areas of their health which we feel is so important."

How the My Health Record system led to improved capacity for multidisciplinary team care

Respondents who indicated that the My Health Record system had led to improved capacity for multidisciplinary team care were asked to elaborate the events/reasons to justify their decision. A total of 66 people responded. 36 felt that the My Health Record system had improved information sharing between healthcare providers which improved continuity of care for their patients. 8 reported that they felt it has not led to improving the capacity for multidisciplinary team care but could see how it would be in the future. Another 6 felt that it had improved communication and coordination of care between those involved in a patient's care (Table 33).

Table 33: How the My Health Record system led to improved capacity for multidisciplinary team care

Categories	n
Improved information sharing	36
It had not improved multidisciplinary team care but it could in the future.	8
Improved communication between those involved in patient care / improved coordination of care	6
Others	16
Total	66

Some quotes from respondents who described how the My Health Record system led to improved capacity for multidisciplinary team care

"I haven't used this system but I understand how it works and it would greatly improve the flow of correct information for a Multidisciplinary team."

"I chose YES because I believe it can, but I haven't actually demonstrated that as yet."

I can see what decision that other people have made and can view visits in hospital that the patient has had. This informs me about what MDT [the multidisciplinary team] members may be useful for a patient."

"Allow outpatient notes to be reviewed during clinic review with easier access."

"People have control with all areas of their health which we feel is so important."

"I haven't accessed it recently but it allows access to almost all the information I need from all the disciplines involved in the patient's care. It allows any information I enter to be visible to all the other disciplines that require it."

"Increased communication between providers."

Did training influence healthcare providers' decision to use the My Health Record system and why?

121 respondents had received formal training in the use of the My Health Record system, and described how the training influenced their decision to use the My Health Record system. 31 said the training improved confidence to use the My Health Record system by showing how easy it was to use, and highlighted the My Health Record system's security and its benefit. 15 said their use was driven by the ePIP incentive. 25 said 'No' and 8 said 'Yes' without describing their reasons why. 11 said that they were interested in using it, but were experiencing some technical barriers to using the system. 8 felt the training was poorly delivered, and they would like to receive more information before using the My Health Record system.

Table 34. Whether training influence healthcare providers' decision to use the My Health Record system and why?

Category	n	%
Yes, it improved my confidence to use system	31	26%

Category	n	%
No	25	21%
Using system for ePIP incentive	15	12%
Interested to use but experienced technical barrier to use the system	11	9%
No, it was badly explained or received inadequate training	8	7%
Yes	8	7%
No, haven't needed to use it yet	7	6%
No, was already planning on using it or were using it	7	6%
Others	5	4%
No, had concerns about privacy and security and patient's ability to control access	4	3%
Total	121	100%

Some quotes from respondents who described whether training influenced their decision to use the My Health Record and reasons why:

"No. Very straight forward to use but time consuming."

"Training inadequate I do not feel confident to use."

"No. I still want to do it even though it was badly explained."

"The training was very good however as yet our pharmacies have not been successful at linking up."

"The training was very good and explained how to use it. Training was provided by dispense vendor. Unfortunately using the system is the issue. It's often slow and always incomplete records."

"Yes, prior to training I was apprehensive about the internet security now I feel more confident. Also, the usability of the health record was explained, so I feel more confident in the capabilities of My Health Record to improve care coordination and service integration."

"Yes, better understanding on how to access and use the system. Previously didn't know how to access records."

"I am very committed to electronics record systems for health to improve patient care, patient empowerment and health knowledge and subsequent self-management. I see My Health Record as a first step towards good electronic records. Specialists and GPs and allied health and hospital staff need much more intensive training and awareness of My Health Record before any of your previous questions about benefits will be realised. The results of this survey may intimate there is little benefit but there needs to be adequate time for this to be taken up by the health profession i.e. "several years". Don't give up on this! Basically, it's too early to assess effectiveness. The My Health Record in the opt-out trial areas will already be invaluable in a disaster where people are evacuated and can't remember their mess. The already existing ability to access pubs [public] data will be invaluable- and this is available even if a health summary hasn't been uploaded."

"Would be more likely to use cautiously if easier to use. Would be much more likely to utilise if it was possible for a patient to comment on rather than delete files or if there was a way of logging for health care providers what files have been deleted."

"No - Threat of loss of E Health practice payment made majority vote to use it."

"No. I had planned to use it, but needed the training to facilitate my ability to use it."

Additional comments about the impact of the ePIP incentive payment

Healthcare providers who had indicated that their organisation qualified to receive the ePIP incentive were asked in the follow up study whether they had additional comments about the impact of ePIP on their use of the My Health Record system. 256 responses were received. 142 of

the respondents were GPs and 114 were specialists. Almost half respondents were from the rest of Australia comparison site. A third were from Western Australia, and 28 from Northern Queensland.

85 said they were unsure how the ePIP incentive would affect their use of the My Health Record system, either because they had not received any information about the ePIP incentive, or were unaware of the ePIP program overall. 25 said the ePIP incentive encouraged their use of the My Health Record system, and another 20 felt the ePIP incentive payment did not influence their use of the My Health Record system. 4 said the My Health Record system needed to be improved for it to be used, regardless of the ePIP incentive, and another 4 felt the ePIP incentive payment should be higher or extended to other staff to encourage use of the My Health Record system.

Table 35. Impact of ePIP incentive of the My Health Record system use

Category	n	%
Unsure how it would impact them	85	33%
ePIP encouraged their use of the My Health Record system	25	10%
Does not affect healthcare providers' use	20	8%
The My Health Record system needs to be improved before it is used regardless of ePIP	4	2%
Payment should be higher / should to other staff to encourage use	4	2%
Did not receive any incentive	3	1%
Others (e.g., no)	115	45%
Total	256	100%

Some quotes from respondents provided additional comments about the impact of ePIP on their My Health Record system use:

"I was not aware of any incentives offered. I work for a private health organisation. I would love to have access to patient records to facilitate improvements in care offered."

"Might upload info because of the financial incentive, but suspect from what I am hearing from colleagues that what is being uploaded with the new incentive is both inaccurate and poor, as most GPs feel unable to spare the time to make 2 sets of comprehensive records under current financial restrictions."

"The practice incentive payment is not an incentive for myself as I do not receive any of this payment. If I received a direct payment to myself I would be uploading a significant amount of data on a very regular basis."

"I have only uploaded enough to meet requirement for payment. I have had to encourage those patients to enrol and a number of them declined. No one asked. I had to introduce the subject and educate them then discuss and wait while they decide."

"Great use of my time."

"We will continue to ensure we upload the minimum number of shared health summaries to maintain our PIP payments each quarter. As the uptake improves (if it does) we will re-evaluate our use of the system. Currently our Doctors have no interest in the system."

"I hope that the ePIP encourages other providers to participate. I have uploaded many health summaries for my regular patients but only rarely have found summaries uploaded elsewhere"

"It is helpful & gives some reward for effort. However, I would try to keep using My Health Record for my patient's benefit."

"Personally I would rather forgo the incentive payment than encourage use of an unwieldy system than doesn't help my care of my patients. However, the practice is actively encouraging patients to start with a shared

health summary in order to access the PIP. I think we may fall short this quarter. I am not actively encouraging patients to sign up, and only act if a patient requests it specifically.”

“I really don't know much about it, have no idea how to use the system - it's up to me to chase this up. If a patient asked me then I would look into it but lack of time during consults and at the end of the day means that I just haven't bothered to look at the system at all.”

Other additional comments

372 respondents took the opportunity to add further comments at the end of the follow up healthcare provider survey. 144 expressed concerns about the usefulness of the My Health Record system or its effective implementation. 62 said they were unaware of the My Health Record system.

20 were positive about the My Health Record concept, and said it would be good idea to pursue the rollout, or they believed it to be beneficial to healthcare providers and individuals. 14 respondents reinforced their concerns about confidentiality, privacy and system security. 4 expressed concern that the My Health Record system, in its current form, lacked the functionality and technical aspects they believed would be beneficial to the health system as a whole.

Other common categories identified included requests for training, funding and incentives for healthcare provider use and participation and general negative sentiment towards the Government and big data collection.

Table 36 below presents the number of the common categories identified from respondents who chose to add further comments.

Table 36. Number of common categories identified from respondents who chose to add further comment.

Category	n	%
Concern for My Health Record being useful or effective	144	39%
Unaware of My Health Record's use and functionality	62	17%
Negative perceptions of the Government generally or of the potential of the Government monitoring the data	48	13%
Funding and ePIP issues	24	6%
My Health Record is a good idea or it will be useful	20	5%
More training required	18	5%
Concerns for confidentiality, privacy and system security	14	4%
Wasteful of Government time and money	11	3%
Concern for accuracy and completeness of My Health Record data	10	3%
Praise for a centralised system	7	2%
Praise for accessible and accurate records and positive impact for complex cases	6	2%
Concern for lack of individuals and practitioners using My Health Record	4	1%
My Health Record system needs better functionality, more technical advancements and enabling of uploading images	4	1%
Total	372	100%

Summary of findings from the survey of healthcare providers

Increased awareness and understanding of the system amongst users

Awareness among healthcare providers in the rest of Australia was high (82%); however, only 56% of respondents knew if their workplace was registered for the My Health Record system at the end of the trial period. Respondents in the rest of Australia were most likely to have had exposure to awareness raising information about the My Health Record from professional networks (i.e. other colleagues, PHN, professional bodies).

Participants in the opt-out trial areas were more likely to have had exposure to awareness raising information about the My Health Record system during the trial period than the rest of Australia.

Participants in the opt-in trial areas were not statistically significantly more likely to have had exposure to awareness raising information about the My Health Record system during the trial period than the rest of Australia.

Increased participation in, and use of, the My Health Record System by users

Across all three groups, there was an increase in the number of respondents who reported their workplace as being registered on the My Health Record system. The increase during the trial was greater in the opt-out trial site relative to the rest of Australia although the difference was not statistically significant.

Although there was an increase over the trial period in the proportion of healthcare providers uploading documents on to the My Health Record system, this increase was across all three groups.

There was no statistically significant difference between baseline and follow up in the proportion of healthcare providers uploading documents on to the My Health Record system in either of the groups.

The change over time in self-reported document uploads was also not statistically significantly different across the three groups.

At follow up, there were no significant differences between the three groups with regards to healthcare provider beliefs about the following attributes of the My Health Record system: access to information about patient health; ability to apply best practice care; informs medication management choices; saves time sourcing patient information; spend less time communicating to other healthcare providers; enables patients to better manage healthcare; adds time to upload data.

There was no statistical difference in respondents' intention to use the My Health Record system over the next four months between the trial sites.

Increased confidence to use the system amongst users

There were no differences in any indicators of confidence to use the My Health Record system between the opt-out trial sites and the rest of Australia.

There were no differences in any indicators of confidence to use the My Health Record system between the opt-in trial sites and the rest of Australia.

Across all three groups, there was an increase in the proportion of respondents who had received training on the My Health Record system. The difference in the increased proportion between the opt-out trials and the rest of Australia who had received training was statistically significant but not between opt-in and the rest of Australia. Indeed, the proportion of participants who had received

training remained relatively low. The majority of training was provided face to face across all three groups.

There was no statistically significant difference observed in the reported effectiveness of the training received on the My Health Record. Overall, over 80% of respondents who had received training considered the training to be at least slightly effective or better.

In the rest of Australia, confidence in the Government's capacity to ensure confidentiality of patients' records fell over the trial period.

Appendix 8 Summary reflections from National, State and Health Service stakeholders

This section describes the reflections of Departmental officers, representatives from State Health Departments who had direct line of sight in the opt-out trials and local hospitals, and health service officers who were involved in the opt-out trials. They were asked to reflect on the improvements to the My Health Record system, approaches to implement the My Health Record activities, and lessons learned from the opt-in and opt-out trials.

Opt-in versus Opt-out approach to participant engagement?

All the stakeholders interviewed were very supportive of the opt-out participation arrangement model, based on their observations and experience. State Health Departments that were involved in the opt-out trials supported a national roll out. Commonwealth officers who had observed both the opt-out and opt-in trial sites also concluded that the opt-out approach had achieved better outcomes.

Timing of the trials and the length of the evaluation measurement period

All stakeholders acknowledged that the timeframe for the trials was too short to allow all the planned activities in the trial sites to be fully implemented, and therefore for all the potential lessons to be observed.

Advice for future communication

Communication was universally regarded as the key area where lessons had been learned. All the stakeholders saw the need for a national marketing campaign, supplemented by locally tailored communication materials, to ensure people were aware of the My Health Record system and could make an informed decision to opt-out or opt-in. Public awareness of the My Health Record was low to non-existent at the start of the trial period, and this negatively affected the trials. Low individual awareness persisted even after the first round of planned communication with members of the public in the opt-out sites, and after assisted registration was provided in the opt-in trial sites.

Those interviewed felt that communication about the My Health Record in the two opt-out trial sites needed to occur earlier, to improve awareness of the My Health Record before individuals received their letters and brochures. A few felt that individuals also needed to be followed up after receiving the letter. Some suggested that follow up letters should include referring them to the PHNs or the My Health Record website, or invitations to attend community forums explaining the My Health Record system. Better ways to communicate and educate individual members of the public were required to make them aware of the benefits of My Health Record, and to help them make an informed decision about opting-out or opting-in. For example, more ways needed to be developed to answer people's questions than merely referring them to the My Health Record website. Other suggested improvements were: messaging individuals about how they could access the My Health Record and set up their privacy settings, and making the process for healthcare providers to register with the My Health Record system simpler and easier to understand. They felt that simple messages about the My Health Record system and its benefits were not disseminated well across the population in the opt-out trial sites.

All those interviewed learned from the trials that most individuals and many healthcare providers were unaware of the My Health Record and its benefits. Those who had conducted forums in the trial sites found that healthcare providers were largely unaware or had little knowledge of the My Health Record, its features and its benefits. Those with direct contact with hospitals in the trial sites



(other than Ballarat) said they had observed interest and uptake in My Health Record once the healthcare providers were exposed to it.

Some respondents reflected on problems with the mailing lists for the letters (such as letters sent to deceased individuals, or problems arising from the overlapping trial boundaries between the Nepean Blue Mountains Primary Health Network (NBM PHN) and Western New South Wales Primary Health Network (WNSW PHN)). They indicated that more preparatory work to ensure data quality should occur before issuing letters to the public. Some were opposed to using letters in future. One said the mailout process in opt-out sites had been a failure and a waste of money; others did not rule out using letters again so long as they were not the only source of communication, and data issues were resolved.

Other respondents felt that national advertising and communication should include a roadmap detailing the functionality of My Health Record, the plans to upgrade its functionality, and when upgrades would be released. They expected that a roadmap that was regularly updated and well distributed would increase the credibility of the My Health Record system with individuals and healthcare providers, who may expect more from the My Health Record system than it can currently deliver, but would be happy to reserve judgement knowing what was to come. This type of roadmap would encourage healthcare providers and individuals to continue to view and use the My Health Record system even if they had previously found little or no information.

In the case of communications to healthcare providers, interviewees suggested that a comprehensive engagement strategy for all healthcare provider types was essential. Specific communications for hospital settings was also suggested.

Some common healthcare provider-related concerns emerged that should be addressed: some interviewees noted that several complex issues had been raised with them in the course of implementing the trial and should be resolved. Suggestions made to address policy issues and to be incorporated in training materials for healthcare providers in the future included:

- Providing advice to healthcare providers on their duty of care related to checking My Health Records.
- Developing scenarios that could be used in training, and other advisory documents that could be available to healthcare providers on the My Health Record website.
- Mechanisms to protect the My Health Records of vulnerable populations and to ensure the credibility of the My Health Record system.
- Advice for vulnerable populations such as children and young people, those with alcohol and drug disorders, domestic violence victims, those under child protection, and other vulnerable people should be communicated to healthcare providers and individuals, saying clearly how the My Health Record system would be managed and who could access it.
- Advice for healthcare providers on how and when the My Health Record might be used in court proceedings.
- Clear guidance that it was a “myth” that a healthcare provider had to obtain consent from patients every time he or she uploaded information about them to My Health Record. There was a belief (and there were some reports) that the training and education provided by PHN staff during the trials incorrectly reinforced that this was the case.

Two stakeholders noted that hospital staff and other healthcare staff had raised concerns with them about the confidentiality of the medical workforce’s My Health Records in practices and hospitals. These were situations where people both worked and were seen clinically, and where sensitive information, such as sexual health, HIV, hepatitis C, mental health and alcohol and other drugs



treatment might be accessible to colleagues. Materials and policies specifically targeting these healthcare provider-related concerns should be developed.

Other suggestions made by stakeholders about future communications regarding the My Health Record system included:

- how or whether people could transfer their health information from overseas into their My Health Record
- strategies to reach specific populations, such as patients who lack capacity due to dementia or more transient states of cognitive impairment and others with carers acting as legal guardians (e.g. people with a disability, the elderly, CALD populations)
- assurances that information in the My Health Record system is stored in Australia.

Capacity of Government's infrastructure to manage inquiries

If the Government decides to implement a national opt-out participation model, one stakeholder felt that it should be rolled out in a staged manner, geographically based on the IT readiness of different Jurisdictions or of different regions within Jurisdictions. This was viewed as impractical by others consulted, especially where geographic boundaries were blurred, and patients were mobile across boundaries, and individuals in neighbouring suburbs could have different My Health Record options. They saw potential for confusion. Most importantly, it would mean the loss of the beneficial impact of a national marketing campaign, which in their view was clearly necessary. This alternative view was that sufficient lead time and a careful planning model in close consultation with States and Territories should be able to address most concerns about capacity.

Stakeholders also emphasised the need to ensure that the helplines for both individuals and healthcare providers were equipped and capable to handle the volume and nature of inquiries. They noted that the Department needed to ensure that the people working on the helplines were adequately trained to answer detailed questions about the My Health Record system. From the trials in the NQ and NBM PHNs, the opt-out data revealed that about 1,600 people opted out on the first date they could, 4 April 2016. 1,584 cases opted out in a face to face contact at the Department of Human Services (DHS), which managed the opt-out process in the opt-out trial sites. DHS feedback indicated there was a need to investigate whether Medicare offices would be able to manage the large quantity of people opting out through a face to face contact, if the model is used nationally.

Other stakeholders also raised outsourcing the face to face method of opting out: Australia Post and pharmacies were viewed as suitable parties to provide face to face information and assistance if people decided to opt out from having a My Health Record. However, any approach to remuneration to assist people to opt out would need to be carefully designed, so that there was not an incentive to encourage people to opt-out.

Some stakeholders raised concerns about the capability and capacity of the national IT support infrastructure to cope with and resolve a large number of technical errors and barriers in a timely manner, especially if a national opt-out participation model is rolled out. It was also suggested that the Department should consider implementing processes to handle complaints about privacy and security when the My Health Record system was more embedded into clinical workflows. The Department could create a 'knowledge bank' or 'repository' of policies for people to access when they would like to clarify the security and privacy aspects of My Health Record.



Improving education and training

Stakeholders strongly encouraged efforts to work with medical colleges, professional associations and peak bodies of healthcare providers in Australia to attach Continuous Professional Development (CPD) points to the My Health Record training activities. Some also suggested that digital health components (such as telehealth, and the My Health Record system) should be embedded into learning modules or competency assessment tools for healthcare providers at undergraduate and postgraduate levels, as well as in professional education programs. In the trial site hospitals, linchpin roles such as Clinical Nurse Educators had been identified as important conduits for training.

Collaboration with medical colleges and relevant professional bodies should also extend to developing standards and criteria for the quality of information being uploaded to the My Health Record system.

Improving access to My Health Record system

Owing to the difficulties in registering for and accessing the myGov account before logging in or registering for a My Health Record, a few stakeholders felt that this issue needed to be resolved as quickly as possible, especially if a national opt-out approach is implemented. One suggested that the Department could create a video explaining how people can register for a myGov account. Another suggested that creating a third-party application to access the My Health Record could gain better traction with individuals to register and use the My Health Record system.

All stakeholders believed that individuals' demand for the My Health Record system would drive its adoption by healthcare providers.

The registration process for healthcare providers was also regarded as difficult, challenging and a barrier to their uptake of the My Health Record system. It was highlighted that the registration process and the online authentication process for healthcare providers needs to be improved. Additionally, it was also suggested that there is a need to improve access to the My Health Record system for all pharmacies through connected pharmacy software.

Solutions also need to be developed for people to access the My Health Record in rural and remote regions where there is no reliable internet or it is too expensive to access. It was suggested that the Department could possibly create a shared community access point for those living in areas that have limited Internet connection.

Some concerns were raised about people with low computer literacy and their capacity to access the My Health Record. It was acknowledged that some older people are not interested in viewing their My Health Record themselves, but see the benefits of having one used by their healthcare providers. The conclusion was that, for people who wish to learn the basics of accessing their My Health Record, there may be some existing community-based computer training/computer support programs that could be leveraged to include modules on how to use the My Health Record, at relatively low cost.

Supporting vulnerable groups to opt out

It was highlighted that approaches to some populations and vulnerable groups needed to be designed appropriately to ensure they received the education and assistance to opt out from having a My Health Record, if they chose to do so.

Carers of patients lacking capacity

Concerns were raised about ways to communicate with carers of patients lacking capacity (e.g. dementia patients and people with a cognitive disability) who were unable to make an informed



decision to opt-out from having My Health Record, if a national opt-out participation arrangement was rolled out. Potential solutions included communicating to carers through States' and Territories' Offices of the Public Guardian, National Disability Insurance Scheme agencies, and professional peak bodies of Residential Aged Care providers. It was also suggested that the Department would need to work with Jurisdictions to develop strategies to best communicate about the My Health Record system with carers in their region.

Culturally linguistically and diverse populations (CALD)

Similarly, Departmental officers were also concerned about the best way to communicate to CALD populations about the My Health Record system. It was suggested that the Department could map out national, state and local migrant settlement support groups, or equivalent groups that engage CALD populations to disseminate information and educate CALD populations about the My Health Record.

Prisoners and young people in detention

The opt-out trials also informed the Departmental officers of approaches to engage and inform prisoners and young people in detention. Given that this population group has limited or no internet and phone access, special dedicated arrangements need to be made to ensure that they make an informed decision about having a My Health Record or not. The Department has worked alongside the Jurisdictions involved in the trials to communicate and assist people in correction or detention to opt-out from having a My Health Record. Further work with each Jurisdiction would be required if a national roll out of opt-out arrangements occur.

Approach to reward healthcare providers for using the My Health Record

Some stakeholders suggested that the incentives for using the My Health Record system should be linked to good clinical practice. For example, embedding the reward for use of the My Health Record system into other more clinically relevant incentives such as those that might be planned for future initiatives like the Health Care Homes initiative. GPs using the My Health Record system could also be rewarded through existing incentive plans (e.g. care plans and mental health plans). Suggestions to include a requirement in any commissioning/tender/funding process by the PHNs to require commissioned services to demonstrate that they are My Health Record enabled were also mentioned.

National capacity to support implementation of My Health Record activities at the local level

Departmental officers interviewed emphasised that support from the national level, especially from the Australian Digital Health Agency (the Agency), will need to continue to be provided to the PHNs after the trials conclude. Some also felt that having a representative from the national level to attend local events to communicate to people about the My Health Record system would increase the credibility of the messages, and encourage adoption. Consistent messaging, branding guidelines and templates should be provided to local delivery partners. These communication materials also should be designed to allow modification to suit local contexts.

PHNs' capacity to roll out national participation arrangements

It was emphasised that there was a need to understand and get advice from the PHNs (before rolling out activities) about the level of staffing and resources they required to implement any participation model. Consultations with the PHNs would inform how support at the national level could be tailored to local needs. All stakeholders felt that the PHNs involved in both opt-in and opt-out trials had done a very good job in the limited timeframe to implement the My Health Record activities in their regions.



Having a comprehensive engagement strategy for all healthcare provider types was thought to be essential. In the future, when the My Health Record system is more developed, the Department should consider making the use of My Health Record compulsory for all healthcare providers. Interviewees who had direct contact with hospital and health services found it difficult to convince healthcare providers about the benefits of the My Health Record system when healthcare providers outside their facilities were not contributing but were merely viewing documents. Some also suggested that the Agency needed to work better with software providers to enable automatic uploading of documents to the My Health Record system through the practice's/hospital's clinical information software (unless indicated otherwise by patients). Further engagement with software providers was required to ensure better integration of clinical information software with the My Health Record system.

Support from Jurisdictions to roll out My Health Record activities

It was agreed by all interviewees that State and Territory Health Departments and their health services would need to allocate resources to ensure the roll out of the My Health Record in those services. Jurisdictions would need to work with the Department to design and implement My Health Record activities in public hospitals and health services, especially if a national opt-out participation arrangement model is rolled out. They felt that involving the Jurisdictions would fast track implementation as they would have a better understanding of the public health system in their Jurisdiction and more experience and expertise in digital health related change management than the PHNs. Additionally, resources and staffing should be provided to the Jurisdictions, to be placed in public hospitals and health services.

Stakeholders in Jurisdictions reported that additional staff and resources would be required for any state-wide implementation of an opt-out model. They also felt that there was a need to have visible engagement from the Jurisdiction and that the digital health group in a Jurisdiction could play a key role in advocacy, collaboration with other levels of government and agencies and oversight to achieve consistency in implementation in HHSs (or equivalent). Just as with the national project team, they emphasised that any staff recruited at the Jurisdictional level to work in HHSs (or equivalent) must have the right skill sets and content knowledge (health system and health records); and that adequate time for recruitment is crucial to achieve this. NSW Health concluded that a model whereby two lead change agents were placed in LHDs (and guided by a central entity) was an appropriate model for implementation of the opt-out model, based on their experience and lessons learned. They noted the work they have done to present the MBS and PBS in a way that makes it easier for healthcare providers to use it in a meaningful way has proven to be very successful with healthcare providers and may be a useful thing to consider for national roll out in consultation with the other States and Territories.

Timing of the evaluation of the My Health Record system

It was noted that the evaluation framework should have been commissioned at an earlier stage, particularly during the design of the trials. While the evaluability phase of the evaluation did contribute to refinements in the design of the trials, it could have done so much earlier. The relatively short reporting period for the evaluation was also noted.

Including more clinically useful information to the My Health Record system

Stakeholders identified there was a need to include Pathology and Diagnostic Imaging Reports in the My Health Record system before pushing for a significantly increased participation of the My Health Record system. It was also suggested that the My Health Record system should also include a summary view of medications taken by individuals.



There were some differences about what should come first in preparation for any national roll out of the opt-out model. Some health service based stakeholders suggested that a strong push should be made to get all hospitals uploading Discharge Summaries so when the full opt-out model was launched GPs would see useful material immediately. Others felt that a strong push should continue nationally to get GPs to upload Shared Health Summaries and Event Summaries so that if an opt-out was launched nationally hospital based healthcare providers would see useful information immediately. Others said both needed to happen at once.

Concept of the My Health Record system

Stakeholders in State Health Departments and local hospitals and health services who had direct line of sight to the trial in NQ PHN and NBM PHN were very supportive of the My Health Record system. Some stakeholders in the local hospitals and health services viewed the My Health Record system as a 'free highway' between primary care to other parts of the healthcare system. They felt that the My Health Record system could be embedded into programs that they were currently developing or are being implemented to connect healthcare providers in the hospitals to other healthcare providers outside of the facilities to bring together key information along the patient pathway. Examples of these programs or enhancements were provided in NQ and NSW.



Appendix 9 Northern Queensland Primary Health Network (NQ PHN) opt-out Trial Site

Based on the key elements of the National Change and Adoption Strategy, the design and implementation of this trial included providing support on the ground for:

- widespread population registration through the automatic creation of My Health Records
- generating more clinically useful content in the My Health Record system
- extensive adoption by healthcare providers across sectors
- education, training and communication

These activities were hoped to contribute to the following outcomes:

- increased awareness and understanding of the My Health Record system amongst users
- increased confidence to use the My Health Record system amongst users
- increased participation in, and use of, the My Health Record system by users
- increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system

The planning phase for the Northern Queensland (NQ) trial began in December 2015. The NQ PHN worked closely with the National Trials Team of the Department of Health to scope and plan how activities at the national and local level could work best together with both top-down and bottom-up approaches. The official launch of the NQ trial by the Federal Member for Leichhardt, the Hon Warren Entsch MP was on 4 March 2016.

The PHN worked closely with the National Evaluators from January 2016 to assist with the design of the national evaluation framework, its templates and tools, and participated continually across the life of the trial in contributing data both to the National Trials Team for accountability purposes and to the trial evaluator for monitoring and evaluation purposes. The tools for the evaluation were designed so that participating PHNs could use the data generated to track activities as well as reflections and lessons learned. A final reflection workshop between the PHN and the evaluation team drew together reflections and lessons learned across the total period covered by the evaluation (February to September 2016).

It was agreed in the implementation plan that the focus of trial activities would be, in the first instance, general practices/general practitioners, pharmacies and the general population. The timeframe for the national evaluation from February to September 2016 means that some of the outcomes data presented below do not include the impact of activities in the trial site. Some activities, such as work with public and private hospitals, the residential aged care sector, other medical specialists, allied healthcare providers and social media campaigns targeting the general population, were just beginning towards the end of the data collection period for the evaluation.

All the stakeholders interviewed were very supportive of the opt-out participation arrangement.

Non-program factors in the NQ PHN trial

The trial in the NQ PHN ran in the context of the following significant factors outside the control of the PHN and the National Trials Team and which may have had an impact on the implementation and effect of trial activities. These were:

- digitisation of the medical records in public hospitals and health services across the NQ PHN during the time of the trial, which delayed the work of staff appointed to conduct education and training in those hospitals
- the broader workforce availability issues in regional, rural and remote areas in general affected the capacity of the PHN to recruit staff in a timely way to support the implementation of the trial. This recruitment period extended to over four months of the six-month trial period
- a number of system usability issues (e.g. difficulties accessing and registering for a myGov account for individuals, and difficulties registering and accessing the My Health Record system for healthcare providers). These have been progressively improved at the national level and are now planned to be addressed based, on the experience in the trials

The demographic and geographic context of the NQ PHN opt-out trial

Some key demographic and geographic characteristics of the NQ PHN are presented below so that the reader of this case study can make a judgement about the relevance and generalisability of the experience to their own setting.

The footprint of the NQ PHN covers the far north of Queensland, ranging from north of Rockhampton to the Torres Strait. It spans a total area of over 510,000km², and has a population of approximately 696,600 people in 2014²⁶. Figure 1 shows the areas in NQ that were covered in the opt-out trial. The NQ PHN contains three regional centres - Cairns, Townsville and Mackay.²⁷

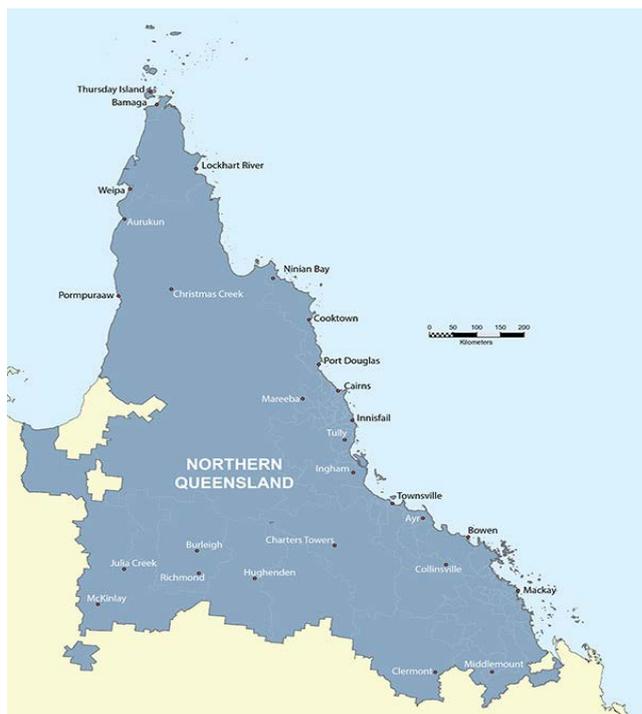


Figure 20 NQ PHN opt-out trial area²⁸

²⁶ Data based on Department of Health PHN profiles December 2015 as described in NQ PHN Health Needs Assessment Report in June 2016. <http://professionals.primaryhealth.com.au/wp-content/uploads/2016/06/NQPHN-Health-Needs-Assessment-June-2016.pdf>

²⁷ Data sourced from <http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator>

²⁸ Data based on Department of Health PHN profiles December 2015 as described in NQ PHN Health Needs Assessment Report in June 2016. <http://professionals.primaryhealth.com.au/wp-content/uploads/2016/06/NQPHN-Health-Needs-Assessment-June-2016.pdf>



Age and gender distribution

Figure 2 shows that NQ PHN has more people in the younger and middle age groups (under 50 years of age). In total, NQ PHN has 50.92% (n=354,786) males and 49.08% (n=341,898) females in the region²⁹.

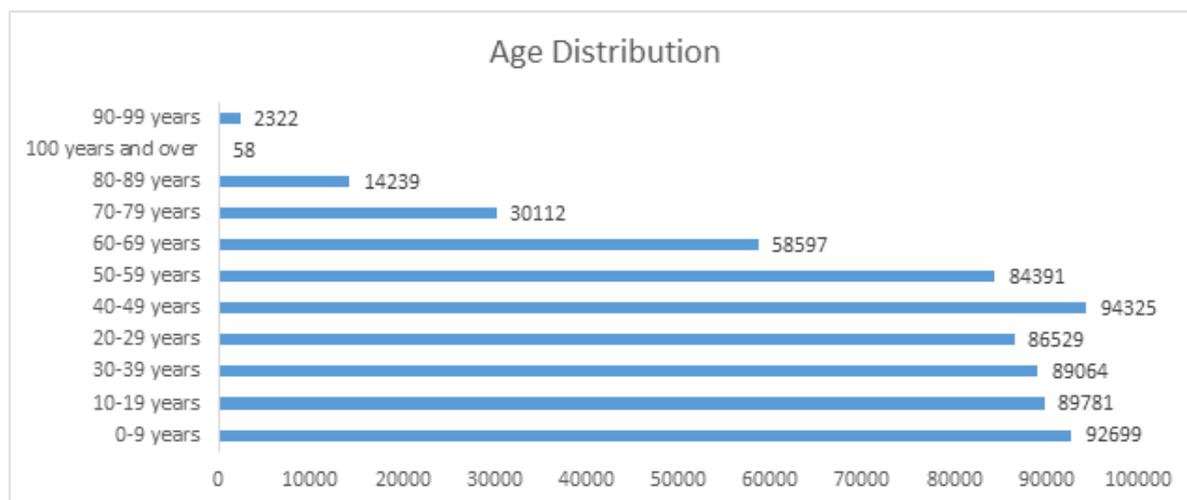


Figure 21: Age distribution in NQ PHN

Aboriginal and Torres Strait Islander population

Of note, within the NQ PHN footprint, 11% of the total population are Aboriginal and Torres Strait Islander people.³⁰ Table 1 presents the proportion of Aboriginal and Torres Strait Islander peoples against the total population in each Hospital and Health Service (HSS) region.

Table 1 Indigenous population of NQ PHN by HHS region in 2014³¹

Hospital and Health Service region	Total Indigenous Australian Population	Total Population	Indigenous Population (%)
Torres and Cape	17,200	25,200	68
Cairns and Hinterland	32,800	250,000	13
Townsville	20,300	239,300	8
Mackay	9,100	182,000	5

Non-English Speaking

Approximately 4.4% (30,552 people) of the population in NQ PHN spoke a language other than English at home³². 1.2% of the population in NQ PHN reported that they do not speak English well or at all.

²⁹ Australian Government Department of Health. (2016). PHN Northern Queensland.

[http://www.health.gov.au/internet/main/publishing.nsf/Content/4004C25B9DD213D2CA257F150004140E/\\$File/PHN%20Infographic%20-%20Northern%20Queensland.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/4004C25B9DD213D2CA257F150004140E/$File/PHN%20Infographic%20-%20Northern%20Queensland.pdf)

³⁰ Northern Queensland Primary Health Network. (2016). Health Needs Assessment June 2016: Description of Health Service Use, Workforce and Consumer need for Northern Queensland Primary Health Network. <http://professionals.primaryhealth.com.au/wp-content/uploads/2016/06/NQPHN-Health-Needs-Assessment-June-2016.pdf>

³¹ Information was based on 2011 Census Population and Housing data



Internet Connectivity

Given that there is limited information available about internet connectivity by the PHN footprint or the Local Government Areas within the PHN, the Statistical Area Level 4 (SA4) is considered to be a better source of data to reflect the internet connectivity in areas covered by the PHN. As such, the proportion of the population shown in Figure 3 may overestimate the true percentage of people in the region who have access to the internet in 2011.

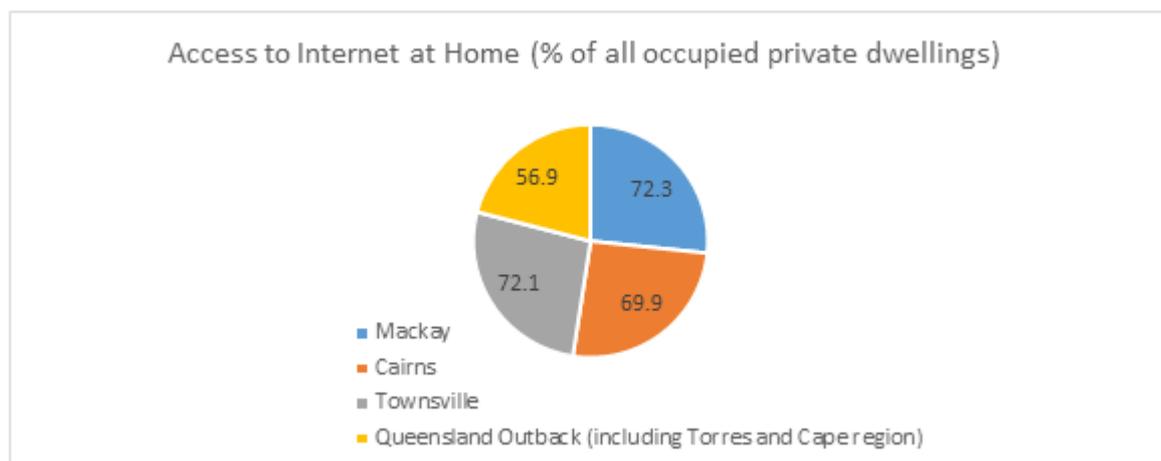


Figure 3 Proportion of all occupied private dwellings who have access to the internet at home by Main Statistical Area Structure Classification 4³³

Other notable characteristics of the population of the NQ PHN

The PHN contains a significantly higher number of people who are more likely than the rest of the general population to change locations and, consequently, to move between healthcare providers both within the PHN footprint and in other parts of Australia. For example, the members of the Defence Force based in Townsville and the workforce of the mining industry, including fly-in fly-out workers.³⁴

Differences in demographics between NQ PHN and Australia as a whole

The NQ PHN had a higher proportion of Aboriginal and Torres Strait Islander people in the region (11%) compared to Queensland (4%) as a whole and Australia (3%)³⁵ in 2011. Fewer people in NQ PHN spoke a language other than English (4.4%) when compared to Australia (19.3%) and Queensland (9.3%). The trend was similar for those who spoke English 'not well' or 'not well at all' in NQ PHN (1.2%) when compared to Australia (2.7%). They, however, were on par with the proportion reported in Queensland (1.1%) in 2011.³⁶ The data about internet connectivity in NQ PHN also

³² Northern Queensland Primary Health Network. (2016). Health Needs Assessment June 2016: Description of Health Service Use, Workforce and Consumer need for Northern Queensland Primary Health Network. <http://professionals.primaryhealth.com.au/wp-content/uploads/2016/06/NQPHN-Health-Needs-Assessment-June-2016.pdf>

³³ Based on Australian Bureau of Statistics 2011 Census of Population and Housing dataset.

³⁴ Department of Health. (2016). My Health Record Opt-Out Participation Trial Implementation Plan Northern Queensland version 0.12.

³⁵ Australian Bureau of Statistics. (2011). Estimates of Aboriginal and Torres Strait Islander Australians <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3238.0.55.001>

³⁶ Australian Bureau of Statistics. (2011). Estimates of Aboriginal and Torres Strait Islander Australians <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3238.0.55.001>



suggests that fewer people have access to the internet at home (67.8%) than in Queensland as a whole (75%) and in Australia as a whole (73.9%)³⁷.

My Health Record Activities in NQ PHN Opt-Out Trial Site

Contracting and Design of the Trial

The design of the trial began in December 2015 in preparation for costing and contracting. This work was undertaken by the PHN within its existing resources led by their Chief Operating Officer. A total of \$2,390,449.60 (GST included) was agreed between the PHN and the Department to deliver the activities in the trial site. The PHN received initial seed funding of \$275,000 (GST included) so that they could commence recruitment to agreed positions.

The Governance of the Trial Locally

The NQ PHN established a *My Health Record Implementation Committee* to provide advice to and oversight of the implementation of the trial. The Implementation Committee included members of all major stakeholder organisations within the PHN footprint: the Department of Health, including the National Trials Team; the Independent Evaluator; representatives from Queensland Health, Allied Health Professions Australia (AHPA), the Pharmacy Guild, Leading Age Services Australia, the Australian College of Rural and Remote Medicine (ACRRM); key software providers (Fred NXT); senior executives of major public hospitals and health services across the PHN, and Apunipima Cape York Council.

The responsibilities of the Implementation Committee included:

- developing, reviewing and implementing strategies to promote the uptake and use of My Health Record system by healthcare providers and individuals
- critically evaluating the trial's performance against the implementation plan, agreed milestones and evaluation framework.
 - reviewing weekly data reports provided by the Department of Health
 - developing, reviewing and implementing strategies to address areas of non-performance, as identified in the weekly data reports
- contributing to the formal evaluation of the trial, and making recommendations to the Department of Health regarding potential national rollout of the participation model

The NQ PHN Implementation Committee met fortnightly from December 2015 to March 2016, and from April 2016 onwards it met monthly.

In practice, and due to the pace of the trial's implementation, this Committee, whilst considered useful by stakeholders involved, did not ultimately realise its problem solving or high level strategic aims. Rather it was felt to provide a very useful information exchange and update function about progress and the impact of factors outside the control of the PHN (e.g. the digitalisation of the electronic records in the major hospitals within the PHN footprint) which in turn allowed the PHN to reallocate resources or reorder activities.

What sort of workforce structure supported the implementation of the trial in NQ PHN?

Table 2 below outlines the key roles, responsibilities and distribution of workforce across the PHN footprint. These positions were progressively recruited from 15 February to late July 2016. The model of recruitment was largely an open recruitment process to market. The impact of the availability locally of appropriately skilled and knowledgeable staff meant that some key positions

³⁷ Data sourced from <http://stat.abs.gov.au/itt/r.jsp?databyregion#/>



were not filled for some months (for example, the Director of Digital Health in NQ PHN in May 2016) and others were delayed until the last 2 months of the evaluation period (for example, in Cape and Torres Strait HHS).

Local workforce availability issues affecting all health systems in regional, rural, remote and very remote areas applied equally to the PHN's attempts to recruit appropriately qualified and knowledgeable staff for the trial.

Table 2 Roles and Responsibilities of the My Health Record team in NQ PHN

Roles	Summary of responsibility	Positions n=
Director of Digital Health	Lead NQ PHN roll out of the My Health Record Participation Trial Implementation Plan; coordinate and monitor all program activity; oversee financial and program reporting; and management of all My Health Record program staff	1
Regional My Health Record Coordinator	Coordinators were based at Cairns, Cape and Torres Strait, Townsville and Mackay to lead local planning, coordination and delivery of regional activity and regional digital health program staff. Part of their work included providing face to face and group training, advertising 'Good News Stories' and identifying practices that used My Health Record successfully	3
HHS My Health Record Integration Officer	Officers were based within each HHS to coordinate activity from within the HHS to improve My Health Record viewing and uploading. Activities include supporting Nurse Navigators to incorporate the My Health Record system into their care processes and practice, as appropriate	4
My Health Record Program Officer	Work under the direction of the regional and Indigenous Digital Health Program Coordinators to deliver My Health Record events, training and activities	9
Indigenous My Health Record Coordinator	Support Aboriginal and Torres Strait Islander Communities, Aboriginal Medical Services, and Aboriginal Community Controlled Health Organisations (ACCHOs) to increase use of the My Health Record system through training and engagement	1
My Health Record Administrative Support – phone and events booking	Assist in the coordination of Digital Health Team activities, support registration of participants and coordination of events	2
My Health Record Administrative Support- Healthcare provider readiness mapping	Conduct agreed primary healthcare provider mapping to ascertain the current levels of healthcare provider's computerisation, internet connectivity, practice software type, healthcare provider and organisation registration for My Health Record participation (IHPO, IHPI, NASH)	2
Total positions		22

Source: NQ PHN My Health Record Opt-Out Participation Trial Implementation Draft v12; NQ PHN My Health Record Implementation Resource Plan and Budget

What activities were implemented during the trial period to support the achievement of identified outcomes?

The work of the PHN locally was supported by several national activities undertaken by the Department or the Australian Digital Health Agency³⁸ (the Agency). These included:

- conducting software mapping for pharmacy, allied healthcare providers and other sectors as agreed with the PHN
- developing baseline participation and use data
- updating the National Health Services Directory by identifying the healthcare provider organisations who are registered with My Health Record
- mapping the registration process to understand the critical failure points and work to streamline/simplify from a healthcare provider's perspective
- understanding the critical failure points, work to simplify/streamline from a healthcare provider perspective and establish specific work flows for the trial sites
- mapping the national support line to understand the critical failure points, streamline/simplify from a healthcare provider perspective and establish specific workflows from the trial sites
- the official trial launch
- providing national support line to troubleshoot problems, and to provide support including advice regarding organisations/healthcare providers' registration, software connection, embedding the My Health Record system into workflow and viewing and uploading documentation
- engaging with the software vendors to understand the trajectory of development for upgrades and 'nudge' the market to resolve technical issues where necessary within the trial period
- delivering train-the-trainer sessions to the PHN staff
- disseminating the My Health Record creation notification letters to individuals and information about how to opt-out
- creating and implementing an online opt-out portal
- disseminating letters of confirmation to individuals who chose to opt-out of having a My Health Record created for them
- the Department working with key Departments at the national and state level who are responsible for veterans and members of the Defence Force and potentially hard to reach groups such as those in custodial settings, juvenile justice settings, child protection, forensic mental health settings, and those under the care of public guardians
- developing communication materials specifically for the trials and appropriately for different target segments
- engaging third parties to distribute: brochures nationally; play My Health Record promotional videos in practice waiting rooms; distribute, count and reconcile numbers of brochures; promote material in interactions with the practice managers

The activities planned by the PHN were:

- conduct a digital health mapping exercise of the My Health Record system connectivity and clinical information systems for all healthcare providers
- inform and assist healthcare providers/organisations with the registration process for the My Health Record system based on the digital health mapping exercise

³⁸ The Australian Digital Health Agency was established on 1 July 2016 with staff transferred from the Department of Health and the National eHealth Transition Authority (NeHTA).



- work with local HHS and Queensland Health, engage with public hospitals, including emergency departments.
- raise awareness for clinicians and staff accessing Queensland Health facilities of the My Health Record system, and targeting Public Emergency Departments (with conformant software) to increase views of My Health Record
- identify and document challenges of the My Health Record system in relation to both its operation in the Queensland Health setting and more broadly (for the purposes of improvements both during trial period and into the future)
- support primary healthcare centres with compatible software to access My Health Record, and identify and explore other opportunities to interact with My Health Record. Support Nurse Navigators to incorporate the My Health Record system into their care processes and practice as appropriate and where these roles are commencing as part of the trial
- promote the availability of the online training modules
- arrange, coordinate and deliver face to face training as required
- provide targeted training for Aboriginal healthcare providers
- disseminate local communications and media campaigns to individuals and healthcare providers
- engage with key groups by engaging and providing communications materials to appropriately target local key consumer groups including, but not limited to, Indigenous populations, people with mental health conditions, parents of newborns, elderly people, people with chronic disease conditions, people with a disability, homeless and the general public
- conduct education sessions to educate key priority groups about My Health Record and the option to opt-out
- engage with individuals at point of care including brochures and posters
- conduct stakeholder engagement forums across the region for key stakeholder groups including, but not limited to general practices, Aboriginal medical services, allied healthcare providers, Indigenous populations, hospitals, other medical specialists, aged care facilities and other key healthcare provider groups
- distribute information materials/resources to healthcare providers
- distribute visual awareness collateral to registered healthcare providers
- identify practices using My Health Record and seek to share case studies or 'Good News Stories' demonstrating the benefits for patients and healthcare providers of My Health Record.

What was achieved in the five-month timeframe available to the trial is as follows:

Mapping of digital health capacity

The mapping of the digital health capacity of healthcare providers in the trial site was conducted and has been continually updated throughout the trial period. The mapping exercises covered general practitioners/practices, pharmacies, allied healthcare providers, other medical specialists and residential aged care facilities. Different types of issues arose across healthcare provider groups, such as:

- the types of clinical information software used
- validated My Health Record system registration
- the currency of their digital certificate (NASH PKI) ³⁹

³⁹ NASH certificates let healthcare providers and supporting organisations to securely communicate and exchange health information electronically. It provides access to providers to the My Health Record system.

- their use of the My Health Record system
- different types of benefits from use of the My Health Record system for different healthcare provider groups
- how the My Health Record can be integrated as part of the workflow in their business operations

The results of the mapping were used to inform the strategy and approach for engagement activities with healthcare providers, to help with healthcare provider or practice registration, training and education activities and/or additional support where required (e.g. providing technical support).

At the end of the evaluation period, the PHN had engaged with a total of 164 general practices, Aboriginal medical services and after-hours services (out of 200 known), 160 pharmacies (out of 171 known), 333 allied health, dental and mental health services (out of 721 known), 63 residential aged care facilities (out of 112 known), and 76 other medical specialists (out of 127 known). The PHN had identified that, of the known practices across their footprint, 154 general practices, Aboriginal medical services and after-hours services and 19 pharmacies had a NASH certificate. Fewer than seven allied health, dental and mental health, residential aged care facilities and other medical specialists had a NASH certificate. Of the 200 known general practices, Aboriginal medical services and after-hours services, 142 had location/site certificates. 51 known pharmacies, 100 allied health, dental and mental health services, two residential aged care facilities and eight medical specialists had location/site certificates.⁴⁰

Education and Training

The delivery of face to face education and training to healthcare providers (general practitioners/general practices, pharmacies, allied healthcare providers, other medical specialists, residential aged care facilities and private and public hospitals) was the major focus of effort by NQ PHN. This included using training materials provided from the national team, the development of resources locally to fill gaps as required and the development and distribution of resource guides from some software vendors. There are various software issues for different products used in particular healthcare provider segments, and differences among the willingness or capacity of software vendors to collaborate with PHN staff in supporting training. NQ PHN has had to adapt its activities accordingly. The training provided in NQ PHN also demonstrated how to use the My Health Record system via the Provider Portal to those healthcare providers without conformant software. Efforts in the later part of the trial also included approaches seeking to link the training delivered to Continuous Professional Development (CPD) points for healthcare providers.

A total of 203 training sessions about how to use the My Health Record system (including clinical software training) were conducted in NQ, and 1,242 healthcare providers were trained across May to September. Of the 203 training sessions, 173 were delivered in the community setting and 30 in local HHSs across Cairns, Mackay and Townsville. Note that training activities in the Cape and Torres area were delivered by project officers in Cairns, as the officer responsible for activities in the Cape and Torres Strait area was only recruited in late July 2016. Most training sessions were delivered to general practices (n=84), followed by pharmacies (n=42); Aboriginal medical services (n=18); nurses (n=15); and public hospitals and health services (n=12). Fewer than 10 training sessions were delivered to residential aged care facilities, allied healthcare providers, other medical specialists, and service providers. Seven training sessions were delivered to mixed audiences of healthcare providers

⁴⁰ Location and site certificates refer to Medicare Public Key Infrastructure (PKI) certificates that allow providers access to online services through the Department of Human Services.



and another two to mixed public and healthcare provider groups. Three were delivered directly to general practitioners.

The provision of online training was more of a challenge, partly due to a lack of promotion of their availability at the national level and partly due to less interest in online training from healthcare providers. A total of 96 healthcare providers in NQ PHN registered to participate in the online training from April to September 2016, representing 0.2% of the healthcare providers in the PHN footprint.

[Providing assistance to register with the My Health Record system for healthcare providers/organisations](#)

Efforts by NQ PHN to engage and help healthcare providers to register with the My Health Record system predominantly focused on GPs/general practices and pharmacies. Their support also included resolving technical problems experienced by practices/healthcare providers to access and use the My Health Record system. Complex and difficult technical issues which were not resolved were then referred to the Agency.

Work with other medical specialists, allied healthcare providers and residential aged care facilities only commenced in the last few months of the trial evaluation period. Efforts to engage healthcare providers in the private hospitals also began in the last three months of the evaluation period as they were waiting for the hospitals to be connected to the My Health Record system.

Owing to the digitalisation of the electronic medical records in major public hospitals and health services across NQ, the State Health Department central office and HHS personnel requested that training of hospital staff about the My Health Record system within the facilities be delayed until their training and information processes to support the digitalisation of the electronic medical records was completed. This meant that the PHN's engagement with public hospitals only began in August 2016.

[Dissemination of local communications and media campaigns](#)

In addition to the communication messages developed at the national level, the PHN worked with the National Engagement and Communication Team to develop and ensure consistent messaging in their local communication messages. Following the Ministerial Launch on 4 March, the My Health Record was regularly featured in the PHN's scheduled circulars to approximately 2,400 healthcare providers in their distribution list. The PHN increased their frequency of communication messages during key points of the trial, such as when individuals and healthcare providers could access newly created My Health Records (on 15 June for individuals and 15 July for healthcare providers). Local communication messages developed by the PHN also targeted key priority groups in the population (elderly, parents with newborns, Aboriginal and Torres Strait Islander peoples).

Across February to July 2016, the PHN disseminated a total of 124 communication messages. Of the 124 messages, 77 were directed at individuals and 28 to healthcare providers. Channels of communication included: press advertisement, press interview, advertising messages about the My Health Record through NQ PHN's Facebook page, radio advertisement, online newsletter, and radio interview. Most communication messages directed at individual members of the public were through the PHN's Facebook page and press advertisements, and most healthcare providers were communicated through online newsletters and NQ PHN's Facebook page. Of the communication messages directed at healthcare providers, most were developed to address all healthcare

providers. Five were targeted specifically to GPs, one to allied healthcare providers and another to pharmacists.

Engagement with individual members of the public

Efforts to increase awareness in the general population by engaging consumer groups and other non-health service providers in their region (e.g. playgroups, childcare, associations, libraries, local community centres) were conducted in NQ. Engagement with individual members of the public also included the PHN's participation in various country road shows/exhibitions and/or events held by other business portfolios within the PHN across NQ. For example, NAIDOC day, Refugee Week, Diabetes Week, Cairns Show, Relay for Life Event, Mabo Day, Malachi Cup, Deadly Family Fun Day, Seniors Lifestyle Expo, Thursday Island Colour Run, R U OK? Esplanade Walk (QLD Health/ATODS) and the Italian Festival. During the trial period, the PHN also engaged key priority populations such as Aboriginal and Torres Strait Islander peoples, people with a chronic disease or complex condition, elderly people, homeless people, people with a mental health condition, parents of newborns, and people living with disabilities. Resources were distributed such as Indigenous materials, general brochures, posters, flyers and factsheets, targeted materials to specific populations (e.g. an aged care factsheet and carer factsheet), PowerPoint slides, and PHN staff business cards were distributed in most of the engagement activities with individuals.

Across February to March 2016, a total of 126 engagement activities were held, and approximately 1,014 people were engaged across Cairns, Townsville, Innisfail, Atherton, Ayr, Mackay, Sarina, Bowen and Injinoo by existing PHN staff.

Between April and September 2016, a total of 194 engagement activities were conducted with members of the general public and a total of 6,443 people were reached overall. Additionally, 37 activities were also conducted with mixed groups of individuals and healthcare providers, with a total of 2,024 people engaged overall. The PHN's activity with individuals increased from May to August 2016. Of the 231 activities, 198 activities were held in community settings and 33 in hospitals and health services. Engagement with individual members of the public in the HHS and community settings was evident in Mackay, Cairns and Townsville, while little or no engagement with individuals was recorded in the HHSs and community settings in the Cape and Torres Strait region. This was due to the late recruitment of staff as noted above. In addition to engaging people in country road shows/exhibitions, the PHN also engaged individuals through briefings, consultations, presentations, forums, meetings, workshops and training. The PHN also engaged individuals at Medicare service centres. Most engagement activities by NQ PHN in April to September 2016 were held through country road shows/exhibitions (n=56 activities). Across April to September 2016, most activities were conducted to increase awareness and understanding of the My Health Record (n=195). Another 27 were conducted to distribute resources and materials to the public and nine delivered education and support.

Patient engagement at point of care

The PHN noted that going into practices to engage patients was successful in only some settings with long waiting periods. The PHN therefore reassessed their approach whereby they delivered information/resources to healthcare providers during engagement, and trained receptionists and practice managers, to equip them to engage individuals at the point of care. Additionally, as part of their engagement activities with healthcare providers, the PHN distributed resources/materials to healthcare providers that are targeted to both healthcare providers and their patients. To ensure materials about the My Health Record system are disseminated to the very remote parts of the



region, the State Health Department central office published materials on their intranet so their clinicians in that area would be able to use them when visiting the communities.

Distribution of healthcare provider information pack and “visual awareness collateral”

In the beginning of the trial, the PHN disseminated letters prepared by the National Trials Team about the trial and brochures to 1,660 healthcare providers across their footprint. Information about the My Health Record system was also included in fortnightly PHN newsletters and monthly bulletins. During the trial period, the PHN distributed resources/materials and visual awareness materials to healthcare providers during their engagement with healthcare providers. An estimated total of 6,030 healthcare providers were provided with resources and visual collateral in 1,148 engagement activities. The various resources and materials provided to healthcare providers, included:

- Indigenous, generic and targeted brochures (e.g. for carers and the elderly population), flyers, posters, factsheets (for individuals and healthcare providers) and Frequently Asked Questions, handouts (e.g. Queensland Health handouts)
- Registration information pack for pharmacists, allied healthcare providers and residential aged care facilities
- Digital bulletin
- NQ PHN’s staff business cards
- Powerpoint Slides
- Content pack for receptionists, pharmacists, allied healthcare providers and general practices
- Letters to healthcare providers from NQ PHN CEO
- Link to online resources such as training/ support/demonstrations
- Adhesive stickers & visual awareness collateral (e.g., TENT style resources for desk or table tops).
- Support guides such as NeHTA software guide, Fred IT software guide, allied health registration process, provider portal guides, ePIP checklist, AHPA software guide, and NeHTA registration checklist

Examples of materials provided to GPs as part of the content/healthcare provider packs included:

- Digital bulletin
- generic and Indigenous brochures
- generic & Indigenous posters
- public factsheets
- letters to healthcare providers
- My Health Record support tier
- registration process summary
- ePIP guide
- Provider portal factsheets
- software guide (specific to the practice)
- Frequently asked questions

The evaluation team notes that the content of packs for other healthcare provider groups was adapted as necessary and appropriate to suit their differing needs.



Identification of champions, super users, and “Good News Stories”

In collaboration with other parties involved in the trial, the PHN sought out clinical “champions” and “Good News Stories” throughout the trial period. In addition, they made efforts to develop case studies that demonstrate how multiple healthcare providers from different groups can work together to care for various patient cohorts in August 2016. Due to the short timeframe for the trial, “Good News Stories” that illustrate immediate and long term benefits of the My Health Record to individuals and the health system and local clinical champions for the My Health Record system were only just beginning to emerge at the time of reporting for the evaluation.

Stakeholder engagements with healthcare providers

A three-day series of stakeholder engagements was conducted in January 2016 in NQ. The sessions were attended by healthcare providers from allied Health, HHSs, mental health, general practitioners, remote medical services, pharmacies and Aboriginal medical services. The engagement sessions provided an overview of the My Health Record system, the proposed timeframe for the rollout of the My Health Record Opt-out Trial in NQ and addressed any concerns and barriers.

From February to March 2016, a total of 111 engagement activities were held with healthcare providers, and a total of 842 healthcare providers were engaged overall. Healthcare providers were engaged through education events/workshops, network meetings, reference group meetings, forums and practice visits across NQ. Audiences included various combinations of: principal care providers, nurses, general practitioners, allied healthcare providers, practice managers, pharmacists, dentists, community based aged care providers, HHSs, non-government organisations and community members. Additionally, 54 general practitioners across Townsville and Mackay were engaged from February to March 2016. Two Indigenous specific events were also conducted between February and March in Mackay, which were attended by 27 healthcare providers and community members.

Across April to September 2016, a total of 1,147 engagement activities were conducted with healthcare providers or targeted to healthcare providers, with an estimated total of 15,117 healthcare providers engaged overall. The PHN increased their efforts to engage healthcare providers from May onwards. Of the 1,147 engagement activities, 988 were conducted in community settings and 159 were held in local hospitals and health services. Most engagement activities with healthcare providers were held in the three regional centres of NQ. A small number of engagement activities with healthcare providers were held in the Cape and Torres Strait area. Over the period from April to September, the PHN staff also joined existing activities that were conducted for other portfolios in the PHN, such as practice support, mental health, Indigenous health, health action and aged care. Of the 31 country shows and exhibitions targeting healthcare providers, 15 were healthcare provider-targeted events held by the PHN such as allied health training and pharmacy training (in collaboration with Fred IT). Other engagement methods used by the PHN to engage healthcare providers included: workshops, network meetings, forum, presentations, consultations, training and briefings.

From April to September 2016, the PHN also engaged healthcare providers who care for key priority populations. They included Aboriginal and Torres Strait Islander peoples, people with a chronic disease or complex condition, elderly people, homeless people, people with a mental health condition, parents of newborns and people living with a disability. Of the 1,147 activities held from April to September, 60% were conducted to increase awareness and understanding of the My Health Record system (n=686), 20% provided education, training and support (n=233), and 13% aimed to

provide resources/communication materials (n=154). The rest aimed to follow up with healthcare providers (either after delivering training or approaching them to determine their level of need).

Lessons learned from the opt-out trial in NQ PHN

Timing and duration

All stakeholders involved in the opt-out trial in NQ PHN felt that, while the opt-out nature of the trial (the automatic creation of My Health Records) clearly demonstrates the effectiveness of this method of widespread population registration and therefore increased participation in the My Health Record system, the length of the trial was too short to observe and document the full impact of efforts to change individuals' and healthcare providers' use of the My Health Record. The very large geographic distances covered by the NQ PHN, the significant parts of the PHN that are remote and very remote and the highly variable internet connectivity across the PHN footprint taken together with the short timeframe available for the trial means that it is likely that a longer period of effort and measurement may have demonstrated greater achievements.

There were also lessons learned:

- The timing and sequencing of activities showed the need for a significantly longer lead time at both the national and a local level. In particular, time available to alert and prepare healthcare providers about communication efforts targeting individuals caused some concern at the PHN and healthcare provider levels.
- The same workforce issues that face health systems in the attraction and recruitment of suitably qualified and experienced staff in all regional, remote and rural settings are faced in the context of implementing trials such as this. The model of full recruitment in the open market was a barrier to implementation. Seeking to second from local health services and provide funds to them for backfilling may have been more appropriate in PHNs like NQ, where workforce issues are more pronounced than in PHNs that cover largely metropolitan or outer metropolitan areas.
- A realistic timeframe of the trial to observe the full impact of the efforts conducted in public hospitals and health services is required. Representatives from the HHSs felt at least a full six-month concentrated effort in hospitals and health service settings would be needed to see any change in clinician use of the My Health Record system.

PHN scope and capacity

The trial activities necessitated the PHN working outside its normal scope, for example, working with the secondary care sector (other medical specialists) and the tertiary care sector (private and public hospitals and residential aged care facilities). While most PHNs have experience of working collaboratively with these other sectors to ensure a more joined up health system, other interactions and interventions in those sectors have not previously been part of the PHN brief. The PHN therefore had to build this capacity and the type of relationships, contacts, networks and content knowledge to support it in a very short time.

A longer trial period would have allowed for adequate preparatory work to enable them to understand these groups. They suggest that with this lead time, the PHNs would be able to develop a more targeted effort for these healthcare provider groups and for the public.

This PHN was in the very early stages of its development when the planning for the trial commenced. PHNs were formally established by the Federal Government in July 2015 and planning for the trial began while PHNs were still developing their broader needs analyses and service



commissioning processes. In the future, the rollout of activities to support an opt-out model by PHNs will benefit from having some distance from this intense start-up period.

Trial management and internal communication

There were key lessons learned from the opt-out trials about the importance of a balance between top-down input from the national level and bottom-up input from the trial site level in the direction, design and implementation of trial activities. These include: acknowledging local level expertise and knowledge about local circumstances and their potential impact on the implementation of the trial or local relationships with stakeholders; ensuring that high levels of content knowledge about the My Health Record, local health systems and the culture of health services and healthcare providers are available. The support provided to PHNs needs to be relevant and build collegially on local knowledge.

Working with healthcare providers

The trial in NQ suggests that understanding the workflow of different types of healthcare providers and the key benefit to each healthcare provider group is critical to overcoming their resistance to My Health Record use.

Face to face engagement, training and education activities have been important in increasing awareness and understanding of the My Health Record in healthcare providers. Those healthcare providers who were trained and educated about the My Health Record system were more confident to use it and explain it to others. Future education and training efforts should also consider equipping healthcare providers to answer questions or clarifying any misunderstandings expressed by their patients. Additionally, more engagement, training and education activities should be provided to other healthcare providers, apart from those in general practices.

Additionally, lessons about how the training to healthcare providers should be delivered suggest that training is best delivered when practices are registered with the My Health Record system and have conformant software. This means that the digital health mapping exercise of healthcare providers/practices across the PHN footprint should be completed prior to any engagement with healthcare providers in order to tailor the engagement activity to address the practice's needs.

The trial in NQ PHN suggests that future efforts should focus on improving the registration process and the online authentication process for healthcare providers/organisations to access the My Health Record system. Support from the PHN in assisting practices/organisations in registering, connecting and using the My Health Record system has been crucial in motivating healthcare providers to use the My Health Record system, and should continue.

There were also key lessons learned in the delivery of engagement activities or training from the trial in NQ. Group information sessions with healthcare providers were viewed to be effective in determining how the My Health Record system could be integrated into the clinical workflow. Additionally, delivering training in a small group can be done in 30 minutes, should time be the limiting factor in delivering training effectively. Resources/materials drop off is also a good way to start a conversation with healthcare providers/practices about the My Health Record.

Detailed below are the specific lessons learned and advice for consideration:

Aboriginal and Torres Strait Islander medical services: Future efforts should consider including the 'Closing the Gap' medical information in the My Health Record and communicating when the My Health Record system can provide this functionality to healthcare providers in Aboriginal medical



services. Lack of or limited internet connectivity especially for those in rural and remote region remains a barrier to uptake and use of the My Health Record.

Allied healthcare providers: Once informed about the My Health Record system, its benefits and its accessibility, most allied healthcare providers (including those without conformant software) were interested in using the My Health Record system (including the Provider Portal). The trial in NQ also suggests the need for a better understanding and knowledge about how the My Health Record system could be utilised and embedded into the workflow of allied healthcare providers. This would better target this healthcare provider group to participate and use the My Health Record system.

Improvements to the My Health Record system could also consider providing more access points for healthcare providers who do not have conformant software apart from using the Provider Portal, and getting more software providers on board to ensure their IT system is compatible with the My Health Record system.

The cost of getting conformant software remains a barrier for allied healthcare providers to adopt the My Health Record system. Additionally, communication efforts to healthcare providers, particularly allied healthcare providers should also include clear messages about how their patient's information would be stored and used in the My Health Record system.

General practices: Barriers and issues for practices not yet using the My Health Record system were identified. For example, GPs' reliance on practice staff to upload Shared Health Summaries, and these practice staff are not able to upload documents to the My Health Record system; some have not had time to discuss the My Health Record with their patients and the practices opted out of ePIP payment. Engagement with general practices/general practitioners should extend to practice managers. They are seen as a conduit in preparing the practice for the My Health Record system and the appropriate use of it. The trial in NQ demonstrates that many GPs/general practices participated and used the My Health Record system to receive ePIP. Consequently, many wanted ePIP reassurance and registration training. A few healthcare providers also expressed concerns through the PHN about the pathology results potentially being available to patients in the My Health Record after seven days.

Other medical specialists: Even though most medical specialists were interested in using the My Health Record system, most of them do not have conformant software. Those who had conformant software were happy to use the My Health Record system in their practice.

Pharmacy: Concerns about the usability of the My Health Record system in the pharmacy work setting were raised by pharmacists through the PHN. Some raised the issue that FRED Dispense and the My Health Record system were not configured to allow pharmacy technicians to upload dispensing information to the My Health Record via FRED as they do not have HPI-Is. They were advised that the only way to resolve this issue was to load their initials in FRED for every dispense, and this solution was not seen as practical. Incentivising pharmacies to use the My Health Record system was also suggested. Pharmacies could also be an alternative venue to provide assisted registration to people new in town. This means that it would reduce the administrative burden of general practices. Future efforts to assist healthcare providers to use the My Health Record system should ensure that the national helplines for healthcare providers are equipped and competent to address any questions.

Public hospital: The digitisation of the electronic medical record in the HHSs during the trial period was noted as a non-program factor that has impacted on capacity to make 'inroads' in the hospital



sector within the trial period. Owing to the roll out of the electronic medical record in the facilities, Queensland Health decided to delay the engagement and training activities with healthcare providers to avoid misunderstanding and confusion between the two systems. The digitalisation was viewed to have distracted HHSs from focusing on implementing activities for the My Health Record system. However, one stakeholder said that the roll out of the electronic medical record in the facility might have prepared clinicians for the My Health Record system. Additionally, lessons learned from the trial in public hospitals and health services also suggest that contribution by healthcare providers outside of the hospital facilities is likely to persuade clinicians in hospitals to use the My Health Record system.

Residential aged care facilities: One facility indicated that they would like their healthcare providers to be able to view documents in the My Health Record system via a portable tablet as they make their rounds to the residents in the future.

Public awareness and barriers

The trial in NQ suggests that more awareness raising activities at the national and local level should target members of the public to increase awareness of the My Health Record and its benefits to individuals, the My Health Record system and the society, address misconceptions and concerns about the My Health Record and how people (including healthcare providers) are able to access and use it. Additionally, education and awareness raising activities would address individuals' concerns about how their data would be treated, managed and what it would contain.

All stakeholders believed that individuals would be a key driving force for healthcare providers to use the My Health Record. Improvements in the accessibility and usability of the My Health Record for individuals would also see an increase in their participation and use of the My Health Record.

There were also lessons learned about how best to target key priority populations in NQ. Engagement with people (clinical and non-clinical) within organisations/practices would ensure people in the organisation/practice understand the purpose and benefits of the My Health Record, and share them (including the resources/brochures) with their clients. Certain population groups such as younger people and carers should also be educated about the My Health Record. In particular, carers should be informed about how they can be an authorised representative to manage the My Health Record of another. Messages targeting culturally and linguistically diverse populations should also be simple and clear.

The PHN's efforts to target individuals to date have been somewhat 'opportunistic' where they engaged and distributed materials to members of the public through 'piggy backing' on existing community activities such as country shows, exhibitions and other activities held by another business portfolio of the PHN. They felt that measuring the penetration and reach of these activities was difficult.

Importantly, improving the accessibility of the My Health Record through an individual's myGov account was viewed to be crucial in encouraging people to access their My Health Record. The complexity and the required information to set up a myGov account and then link the My Health Record to an individual's myGov account discouraged individuals from proceeding further.

Advice for future communication efforts

All stakeholders felt that if mass up-take of the My Health Record is to be achieved there will need to be a mixture of mass mediated communication at a national and the local level. Social marketing can

also be an appropriate communication channel, where national level expertise would be most useful with approaches that can then be adapted and localised to specific regions in the PHN and/or to target specific community segments. Communication channels and approaches at the local level need to be tailored for all segments of the community (e.g., elderly, parents, Aboriginal and Torres Strait Islanders and those living in rural and remote settings) to highlight the key messages, features and benefits of the My Health Record. More efforts could be put in place when developing and designing the content of the letter to individuals to ensure messages about the My Health Record and how people would be able to opt out are clearer than they previously were, and are simple to understand.

There were also lessons learned about developing a clear and direct local communication strategy and approach prior the implementation of the activities. This would ensure the communication efforts to target key groups in a wide geographic area are consistent across the region.

The trial also demonstrates that consistent branding, messaging, templates and materials provided from the national level to the local delivery partners is crucial. Lessons learned from the trial highlight the importance of allowing materials and templates provided from the national level to be altered and localised to the specific region or targeted community segment. The trial also suggests that future campaigns could also focus on promoting interpersonal communication about the My Health Record with messages such as 'let your relatives know about the record' and 'help your relatives access their record'.

Training healthcare providers

The trial in NQ suggests that significant efforts and investment are required to resource a national rollout of any participation and use model. Additional staffing resources and materials are required to assist in the education and training as well as raising awareness of the My Health Record in healthcare providers. The trial activities in NQ also indicate that at least one or two visits to a practice is necessary in setting up the organisation to understand and use the My Health Record system in a sustainable way.

Efforts to link CPD points in the training for the My Health Record system were progressively made throughout the trial period. This is viewed to be crucial in persuading healthcare providers to participate in training, including the online training modules. One emerging lesson is that, for many professional groups, such work is more appropriate at the national level, since local activity would be duplicative and resource intensive.

Achievements of the NQ trial

At the time of writing this case study, the following can be claimed as achievements of the opt-out trial in this location. Because the design of the evaluation did not include a comparison between relative effectiveness of the two opt-out trial sites and the results of the variables of interest were very similar across the two opt-out trial sites, the results of the surveys (individuals and healthcare providers), focus groups and interviews, and the analysis of the de-identified data from the National Infrastructure Operator (NIO) about upload, participation and use are reported together.

The findings of the evaluation should be read and understood within the context of the length of the trial and the timing of the measurement period for the evaluation as outlined earlier.

Training evaluation in NQ

The PHN disseminated an online questionnaire to participants who attended their training in order to evaluate the training delivered. A total of 84 participants provided feedback on the training conducted by NQ PHN about the My Health Record system. Of the 84 responses, 44 were allied healthcare providers, 35 were from general practices (i.e., medical receptionist, practice support staff), and three were from pharmacies. Most healthcare providers indicated that the training 'entirely met' or 'partially met' their needs about the My Health Record system, how healthcare providers can access it and upload documents (if applicable), its conformant software, and how to register and assist their patients to use their My Health Record. All except one felt that the training had improved their knowledge about the My Health Record system and was relevant to their practice/profession. One, however, indicated that the training was not relevant to them. Most healthcare providers indicated that they would either register with the My Health Record system, discuss using the My Health Record system with their management, consider using the My Health Record system in their practice or train their colleagues because of the training.

Opt-out rate in NQ

Across both opt-out trial sites in Northern Queensland and Nepean Blue Mountains, 1.9% of the population opted-out of having a My Health Record automatically created for them. Table 3 below lists the reasons given for opting out from most to least frequent. The top four reasons are related to a person's level of understanding of the My Health Record's purpose, benefits and features (e.g. the benefits of having a My Health Record for them and the system and the personally controlled nature of the My Health Record with the capacity to set privacy settings). It is important to note that people were given the option of opting out over a fixed period (between 4 April and 27 May) and that local trial activities to support individuals in their awareness and understanding of the My Health Record were only properly underway from May 2016. This opt-out rate may have been less if there had been a longer lead time and more intense communication efforts at the national and local level to address these concerns.

Table 3. Reasons for opting out in NQ PHN and NBM PHN regions

Reasons for opting out ¹	Frequency
I have no use for a digital health record	24,242
I prefer to manage my medical records on my own	9,495
I prefer that my doctor manages my medical records	6,664
I am concerned about others having access to my private medical information	3,961
I am concerned about the security of my medical information stored online	2,286
I do not trust what the Government or others will do with my medical information	1,354

¹People could choose more than one reason for opting out.

Individual exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system

A stratified representative sample of the general population in the footprints of the PHN participated in an online survey at baseline (February 2016) and at follow up (September 2016). People were asked to indicate whether they had heard about the My Health Record and how, and rate understanding, confidence, participation and use of the My Health Record system. In addition, 106 individuals participated in 12 focus groups across the footprint of the PHN during the follow up

period, including one focus group for recently arrived migrants (with assistance of interpreters) and two Aboriginal and Torres Strait Islander specific focus groups in remote settings.

The online survey of individuals in the opt-out trial sites found that approximately one quarter of participants had heard about the My Health Record; however, participants in the opt-out trial areas were more likely to have heard about the My Health Record system during the trial period than the rest of Australia comparison site. Participants in the opt-out trial site were more likely to state that they had a My Health Record than the rest of Australia comparison site. 58% of the respondents in the opt-out trial site did not recall receiving a letter about the My Health Record, stating that they didn't receive one or didn't know if they received one.

Participants in the opt-out trial sites were more likely to increase their viewing of Prescription Records than the rest of Australia. However, this is based on low numbers and may be a result of underpowered analysis, rather than a true difference. There were no differences in other indicators of use, participation or confidence to use the My Health Record in the opt-out trial sites compared to the rest of Australia. There were no differences in any indicators of confidence to use the My Health Record between the opt-out trial sites and the rest of Australia.

Qualitative responses to the survey included: the My Health Record system had allowed their treating team members to be 'on the same page' with them about their health; while they could not report any benefits from having a My Health Record at the time, they felt that the My Health Record provided an easy way for healthcare providers to access their health record and assist in clinical decision making. The main reasons provided by respondents who were not aware that they had a My Health Record created for them and said that they did not have a My Health Record were: they were unaware or not sufficiently informed about the My Health Record system, or they believed that having a My Health Record was unnecessary.

The focus groups allowed for both unprompted and prompted questioning of participants in relation to the same variables covered by the online survey. The focus group methodology allowed for more in depth discussion with individuals and to observe discussions between individuals about these issues. The focus groups in the opt-out trial sites suggested a very low level of awareness of the My Health Record system and its benefits. There was also very poor recall and recognition of any letters and other print, television or radio information about the My Health Record system. However, once focus group members had the My Health Record (its purposes and its benefits to individuals, the healthcare system and their families) explained to them: (i) there was a high level of support for the My Health Record and its purpose; and (ii) there was negligible concern about privacy/confidentiality and the capacity of the My Health Record system to be secure from external threats. Very few participants in the focus groups within the opt-out trial sites had used their My Health Record.

Those who had used it found it to be user friendly and functional. Many participants were surprised that they had to prompt their healthcare provider to use the My Health Record system, expecting this to be part of standard practice. Most participants in the focus groups expressed the view that use of the My Health Record by healthcare providers should be compulsory.

[Healthcare provider exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system](#)

A stratified representative sample of the healthcare providers in the footprint of the PHN participated in an online survey at baseline (in February 2016) and at follow up (in September 2016). Healthcare providers were asked to indicate whether they had heard about the My Health Record



and how, and rate their understanding, confidence, participation and use of the My Health Record system. In addition, 27 healthcare providers participated in interviews, including GPs, nurses, pharmacists, practice managers and clinical practice managers.

The online survey of healthcare providers in opt-out trial sites found that healthcare providers in the opt-out trial areas were more likely to have heard about the My Health Record system during the trial period than the rest of Australia. There was an increase in the number of respondents who reported their workplace as being registered on the My Health Record system in the opt-out trial sites and the rest of Australia. The increase during the trial was greater in the opt-out trial site relative to the rest of Australia although the difference was not statistically significant.

At follow up, there were no significant differences between the opt-out trial sites and the rest of Australia with regard to healthcare provider beliefs about the following attributes of the My Health Record system: access to information about patient health; ability to apply best practice care; inform medication management choices; save time sourcing patient information; spend less time communicating to other healthcare providers; enable patients to better manage healthcare; add time to upload data.

There was no statistical difference in respondents' intention to use the My Health Record system over the next four months between the opt-out trial sites and the rest of Australia. There were no differences in any indicators of confidence to use the My Health Record system between the opt-out trial sites and the rest of Australia.

Across both the opt-out trial sites and the rest of Australia, there was an increase in the proportion of respondents who had received training in the My Health Record system. The difference in the increased proportion between the opt-out trial sites and rest of Australia was statistically significant. However, the proportion of participants who had received training remained relatively low. The majority of training provided face to face across the two groups. Overall, over 80% of respondents in both opt-out trial sites and the rest of Australia who had received training considered the training to be at least slightly effective or better. There was also an increase in the perceived effectiveness of the training between baseline and follow up across the opt-out trial sites and the rest of Australia with no statistically significant difference in the change of training effectiveness between the opt-out trial sites and the rest of Australia.

The interviews with healthcare providers allowed for both unprompted and prompted questioning in relation to the same variables covered by the online survey. The interview methodology also allows for more in-depth discussion with healthcare providers. The interviews with healthcare providers in opt-out trial sites demonstrate that all interviewees were aware of the My Health Record and understood its purpose, with some having used it prior to the commencement of the trial. Nearly all had participated in the trial activities delivered by the PHNs. Most healthcare providers interviewed could list benefits of using the My Health Record, including: reduces 'Doctor Shopping'; informs clinical decision making; improves multidisciplinary team care; facilitates medical information sharing amongst healthcare providers; becomes a place where important health information is easily accessible; and is useful when patients are travelling or when they present to the Emergency Department.

There were negligible concerns by healthcare providers about privacy and the capacity of the My Health Record system to maintain the confidentiality of the patients and the security to external threat once they understood the My Health Record. Healthcare providers believed that the benefits far outweighed any small risks to confidentiality and security. Those who said they were not



confident said it was because: they were not computer literate; were mindful of the problems with the Census; or they had concerns about the use of the data in the My Health Record and that information would be available to patients they would not otherwise have (such as doctors' notes about a patient, or information in referral letters to or from specialists). Most healthcare providers interviewed stated they were using the My Health Record system to view and/or upload information. Those who had not used the My Health Record system felt it was underdeveloped and that there was little demand from patients to use it. Overall, all healthcare providers interviewed felt a combination of both public demand for the use of the My Health Record and the availability of more clinically useful information would encourage other healthcare providers to use it.

Healthcare providers noted that the ePIP eligibility criteria changed their use of the My Health Record system a little, but not to any great extent.

My Health Record System Operator data

Individuals:

As a result of the automatic creation of My Health Records under the opt-out model, the opt-out trial sites had significant increases both in numbers and proportionally over the rest of Australia. Individuals, in general, were unlikely to restrict access to their My Health Record either by restricting documents or healthcare providers, with less than one percent doing so. Very few actively changed their MBS or PBS item uploading restrictions and this led to a large volume of MBS attendance items being uploaded to their My Health Record. These increases were proportionally higher in opt-out trial sites compared to the rest of Australia. Individuals also viewed documents in their My Health Record. Increases in documents viewed from baseline included: Consumer Entered Health Summary, Audit View, Diagnostic Imaging Report, Health Record Overview, Medicare Overview, Prescription Record View, and Prescription Dispensed View. Overall the level of viewing of these documents between baseline and follow up increased more in the opt-out trial sites and the rest of Australia, though these differences were low.

Healthcare providers:

There were additional healthcare provider organisations registered in the opt-out trial sites and in the rest of Australia. These increases in registrations were consistent throughout the trial period, with only a few sudden increases due to bulk registrations of HPI-Os. The majority of registered healthcare provider organisations in the My Health Record system were general practices, with pharmacies being the next most common. General practices were the healthcare provider organisations that had the most extra HPI-O registrations during the trial period. The opt-out trial sites had a proportional gain in healthcare provider registrations greater than the rest of Australia. There were a number of document types that significantly increased in volume between baseline and follow up and increased significantly more in the opt-out trial sites compared to the rest of Australia. These included: Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Records. The increase in Shared Health Summary uploads is closely linked with the deadline of the ePIP, though the increases were greater in the opt-out trial sites than the rest of Australia comparison site and maintained a higher proportion following on from the first ePIP quarter. The availability of My Health Records may have led to this prolonged increase and this may continue, though a longer follow up is needed to monitor for temporal/seasonal changes. The number of MBS uploads associated with attendances examined in the evaluation increased from baseline to follow up. The proportional increases were greater in the opt-out trial sites compared to the rest of Australia. Of note, there were only minimal differences between opt-out and the rest of



Australia in the percentage of MBS attendance items with a Shared Health Summary upload. The level of accesses of documents increased dramatically during the trial evaluation period with accesses increasing significantly more in the opt-out trial sites than in the rest of Australia. Also of note there was an increase in the number of My Health Records accessed that had no clinical documents in them, with healthcare providers in opt-out trial sites more likely to access My Health Records and upload the first clinical document than those in the rest of Australia.

Appendix 10 Nepean Blue Mountains Primary Health Network (NBM PHN) Opt-out Trial Site

Based on the key elements of the National Change and Adoption Strategy, the design and implementation of this trial included providing support on the ground for:

- widespread population registration through the automatic creation of My Health Records
- generating more clinically useful content in the My Health Record system
- extensive adoption by healthcare providers across sectors
- education, training and communication.

These activities were hoped to contribute to the following outcomes:

- increased awareness and understanding of the My Health Record system amongst users
- increased confidence to use the My Health Record system amongst users
- increased participation in, and use of, the My Health Record system by users
- increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system.

The planning phase for the Nepean Blue Mountains (NBM) trial began in December 2015. The NBM PHN worked closely with the National Trials Team of the Department of Health to scope and plan how activities at the national and local level could work best together in both top-down and bottom-up approaches. The official launch of the trial by the Minister for Health was on 4 March 2016.

The PHN worked closely with the National Evaluator from January 2016 to assist with the design of the national evaluation framework, its template and tools, and participated continually across the full life of the trial in contributing data both to the National Trials Team for accountability purposes and to the trial evaluator for monitoring and evaluation purposes. The tools for the evaluation were designed so that participating PHNs could use the data generated to track activities as well as reflections and lesson learned along the way. A final reflection workshop between the PHN and the evaluation team drew together reflections and lessons learned across the total period covered by the evaluation (February to September 2016).

It was agreed in the implementation plan that the focus of trial activities would be in the first instance, general practices/general practitioners, pharmacies and the general population. The timeframe for the national evaluation from February to September 2016 means that some of the outcome data presented below does not include the impact of activities in the trial site such as work with local public hospitals, the residential aged care sector, other medical specialists, allied healthcare providers and social media campaigns targeting the general population. These activities were just beginning towards the end of the data collection period for the evaluation. Additionally, due to the style of reporting by the NBM PHN, there is less quantitative data in the description of their activities than in the case of the NQ PHN.

Non-program factors in the NBM PHN trial

The trial in NBM PHN ran in the context of the following significant factors that were outside the control of the PHN and the National Trials Team, and which have had an impact on the implementation and effect of trial activities:

- There were a number of system usability issues (e.g., difficulties accessing and registering for a myGov account for individuals, and difficulties registering and accessing the My Health

Record system for healthcare providers). These have been progressively improved at the national level and are now planned to be addressed based on the experience in the trials.

- The broader workforce availability issues in general affected the capacity of the PHN to recruit staff in a timely way to support the implementation of the trial. It was challenging to recruit expertise to advise on specific professional groups and the fixed contract nature of the positions meant that retention was starting to become an issue as the end of the trial period approached.
- A number of technical upgrades that occurred during the trial period for the NBM Local Health District (LHD) would affect the use of the My Health Record in LHDs. For example, there were upgrades to clinical information systems in some LHDs across the PHN footprint during the trial period. Consequently, the limited number of Discharge Summaries that could be uploaded to the My Health Record system during the trial period had an impact on clinicians' contribution to and use of the My Health Record system.

The demographic and geographic context of NBM PHN

Some key demographic and geographic characteristics of the NBM PHN are set out below so that the reader of this case study can judge how relevant and generalisable the experience in this trial site is to their own setting.

The footprint of the NBM PHN covers the north-west regions of New South Wales (NSW), and has a population of approximately 361,012 people across four local Government areas (LGAs): Blue Mountains, Hawkesbury, Lithgow, and Penrith.⁴¹ The NBM PHN covers over 9, 063 km². Most areas in the NBM region are regional centres with a few classified as major cities (Richmond, Windsor, Penrith, Katoomba). Figure 1 shows the areas covered by the trial in NBM.

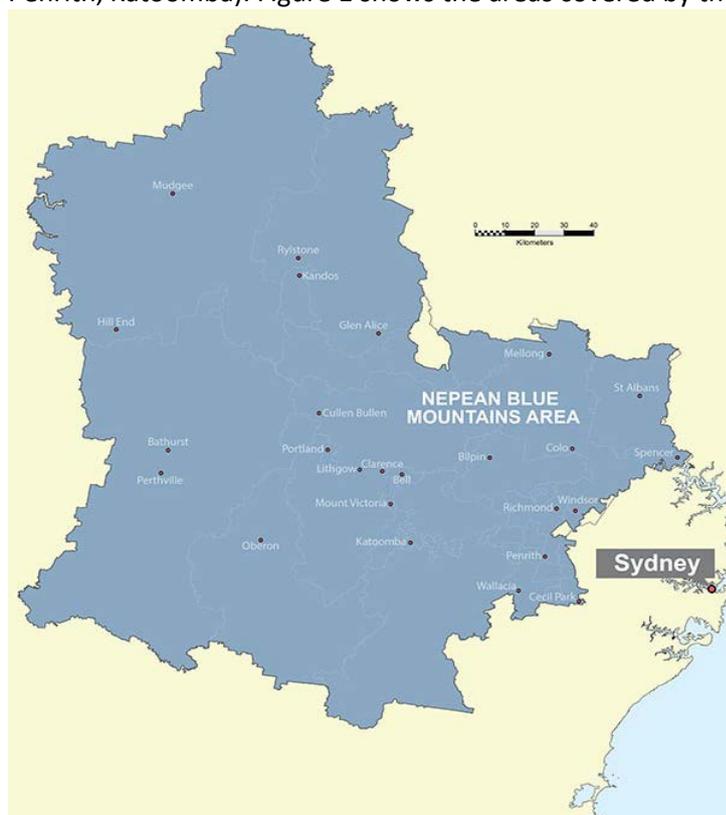


Figure 22 NBM PHN opt-out trial site.

⁴¹ PHN Nepean Blue Mountains Snapshot

[http://www.health.gov.au/internet/main/publishing.nsf/Content/00059FEEA62CAAEDCA257F1500041418/\\$File/PHN%20Infographic%20-%20Nepean%20Blue%20Mountains.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/00059FEEA62CAAEDCA257F1500041418/$File/PHN%20Infographic%20-%20Nepean%20Blue%20Mountains.pdf)

Demographic

Age and gender distribution

The population in the PHN consists of 49.67% males (n=179,315) and 50.33% females (n=181,696). Figure 2 below shows the age distribution in the PHN⁴².

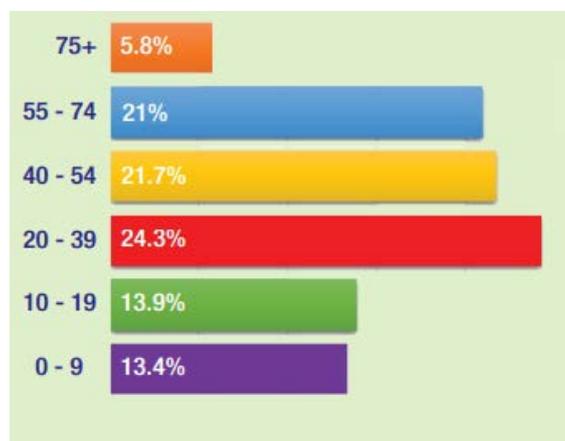


Figure 23 Age distribution in NBM PHN region.

Source: Health Profile Nepean Blue Mountains Region

Aboriginal and Torres Strait Islander population, non-English Speaking and Internet Connectivity

Table 1 demonstrates the demographic information for each of the four LGAs within the NBM PHN region. Based on 2011 Census data, approximately 2.5% of the total population in the PHN identified as being Aboriginal and/or Torres Strait Islander (n=9,212). Penrith LGA has the largest population of people who speak a language other than English at home (14.6%). Approximately 1.1% of the total population in NBM PHN region indicated that they do not speak English well or do not speak English at all (n=3,708). The proportion of the population over 65 years of age and the proportion of the population who have access to the internet at home varies between the four LGAs.

Table 1: Demographic information of the Blue Mountains LGA, Hawkesbury LGA, Lithgow LGA, and Penrith LGA

	Blue Mountains	Hawkesbury	Lithgow	Penrith
Population (2014)	79,688	65,527	21,249	194,134
Male	48.59%	50.08%	51.55%	49.75%
Geographic land area	143,115 ha	227,646 ha	451,185 ha	40,463 ha
Access to Internet at home	78%	75%	63%	76%
Population Density (persons/km ²)	55.7	23.6	4.7	479.8
Age 65 and above	17.55%	13.04%	17.95%	10.96%
Indigenous population	1.70%	1.52%	4.50%	3.00%
CALD population	5.10%	5.30%	3.00%	14.60%
Those who do not speak English well and not at all	0.4%	0.51%	0.36%	1.65%

Note: CALD population estimates are based on the percentage of total population who speak a language other than English at home. Data on access to Internet at home, population density, 65+, Indigenous, CALD population, and those who do not

⁴² Nepean Blue Mountains Region Health Profile 2016

http://www.nbmphn.com.au/Resources/About/043_1115-Regional-health-profile-final-weba.aspx

speak English well and not at all are based on 2011 Census data.

How do the demographics of the NBM PHN compare with the rest of NSW and Australia as a whole?

The NBM PHN has a similar proportion of Aboriginal and Torres Strait Islander people (2.5%) as the rest of NSW (2.5%) and Australia (2.6%). Fewer people in NBM PHN spoke a language other than English at home (7%) compared to NSW (22.5%) and Australia (18.2%). Similarly, fewer people in NBM PHN also reported that they do not speak English well or do not speak English (0.73%) than the rest of NSW (3.9%) and Australia (2.7%). For NBM PHN people who having access to the internet at home (73%) is comparable to the rest of NSW (73%) and Australia (74%).

My Health Record Activities in NBM PHN Opt-out Trial Site

Contracting and design of the trial

The design of the trial in preparation for costing and contracting began in December 2015. This work was undertaken by the PHN within its existing resources. A total of \$1,459,440.40 (GST inclusive) was agreed between the Department and the PHN. Of the total funds provided to the PHN, they received seed funding of \$275,000 (GST inclusive) so they could commence recruitment to agreed positions.

Cross boundary issue between NBM PHN and WSNW PHN

As part of the planning for the implementation of the opt-out trials, it was decided that the trial areas should be defined by all postcodes that fall within the relevant PHN boundary, including those that fall only partially within the PHN boundary. This approach was taken as it was agreed that applying their postcode would be the easiest way for people living in or near the trial areas to confirm whether they were in the trial area or not. A small part of each of the Bathurst, Mudgee and Oberon postcode areas fall within the NBM PHN boundary. As a result, these areas were included in the trial.

What sort of workforce structure supported the implementation of the trial in NBM PHN?

Table 2 below outlines the key roles, responsibilities and distribution of workforce across the PHN footprint. These positions were progressively recruited from 15 February to May 2016. The model of recruitment was a mix of an open recruitment process to market and internal secondments and backfilling of existing PHN or local health service positions.

The PHN My Health Record team consisted of staff members who had experience in the healthcare system and implementing digital health activities in the region. Some of the team members were from specialty areas such as pharmacy and nursing, and they were allocated to target specific healthcare provider groups during the trial period. Additional staffing resources (Project Manager and Change Lead) were recruited by the NBM LHD to deliver engagement activities in the major hospitals and health services in their footprint (see Table 3).

Table 2. Roles and responsibilities of the NBM PHN team to support the implementation of the trial.

Role	Summary of responsibility	FTEs
My Health Record Program Manager	Lead the change and adoption strategy in primary care to increase use of the My Health Record system across the NBM PHN region. Responsible for key stakeholder engagement with priority health organisations across the region. Ensure engagement with individuals and organisations that work with individuals, with a focus on priority and hard to reach consumer groups.	1
Program	Provide directions to Project Officers (see below)	1.4

Role	Summary of responsibility	FTEs
Coordinators		
Project Officers	Along with and under the direction of the Program Coordinators, support primary healthcare providers with the meaningful use of the My Health Record and deliver educational and promotional events to individuals and organisations that work with individuals. Undertake a range of activities to support consumer engagement, communications and awareness, and behaviour change.	4.6
Communications Officer	Responsible for all communications activities within the region, including liaison with the Commonwealth Communications team to provide advice and feedback on communications materials to be implemented locally, development of appropriate local communication materials, identification of local hard to reach groups, dissemination of local communications, and development and updating information for the PHN website.	1.0
Project Support Officer	Administrative support for the PHN team.	0.8
Aged Care Project-Officer – Digital Health	Lead a focussed project involving one My Health Record enabled residential aged care facility to increase meaningful use of My Health Record. Identify current barriers for clinical information flows, and to identify strategies to overcome these barriers in the residential age care setting.	1.0

Table3. Roles and responsibilities of Project Manager and Change Lead for the trial in NBM LHD.

Project Manager	Change Lead
<p>Responsible for coordinating all activities for staff in NBM LHD to increase staff awareness and understanding of how they can use the My Health Record system in the context of HealthNet⁴³. The role included:</p> <ul style="list-style-type: none"> • acting as the single point of contact for the LHD in relation to the NBM trial; • Being the LHD representative on the governance committee with the NBM PHN, NSW Health and the Commonwealth; • Working closely with the NBM PHN to implement communications and awareness activities in line with the overall trial plan; • Working closely with NSW Health to ensure training activities for My Health Record are embedded into training activities for other NSW Health change activities to ensure maximum learning for minimum training time 	<p>Coordinate all activities required for staff in NBM LHD to raise awareness of My Health Record through HealthNet amongst stakeholders, including activities related to the My Health Record opt-out trial. This involved:</p> <ul style="list-style-type: none"> • Developing change and communications plans; • Relationship management; • Stakeholder engagement; • Leveraging communication and training materials from NBM PHN and the Department of Health; • Tracking and reporting on program progress; and • Facilitating workshops with end users within NBM LHD.

Source: NBM PHN My Health Record Opt-out Participation Trial DoV (executed on April 2016)

⁴³ HealthNet Clinical Portal is a web-based portal, and was integrated with the My Health Record system (previously known as Personally Controlled Electronic Health Record) in 2013. It enables clinicians within NBM LHD to view and share Discharge Summaries in the My Health Record system.

What activities were implemented during the trial period to support achievement of identified outcomes?

The work of the PHN locally was supported by a number of national activities undertaken by the Department or the Australian Digital Health Agency⁴⁴ (the Agency). These included:

- conducting software mapping for pharmacy, allied health professionals and other sectors as agreed with the PHN
- developing baseline participation and use data
- updating the National Health Services Directory by identifying the healthcare provider organisations who are registered with My Health Record
- mapping the registration process to understand the critical failure points and work to streamline/simplify from a healthcare provider's perspective
- understanding the critical failure points, work to simplify/streamline from a healthcare provider perspective and establish specific work flows for the trial sites
- mapping the national support line to understand the critical failure points, streamline/simplify from a healthcare provider perspective and establish specific workflows from the trial sites
- the official trial launch
- providing national support line to troubleshoot problems, and to provide support including advice regarding organisations/practitioners' registration, software connection, embedding the My Health Record system into workflow and viewing and uploading documentation
- engaging with the software vendors to understand the trajectory of development for upgrades and 'nudge' the market to resolve technical issues where necessary within the trial period
- delivering train-the-trainer sessions to the PHN staff
- disseminating the My Health Record creation notification letters to individuals and information about how to opt-out
- creating and implementing an online opt-out portal
- disseminating letters of confirmation to individuals who chose to opt-out of having a My Health Record created for them
- the Department working with key Departments at the national and state level who are responsible for veterans and members of the Defence Force and potentially hard to reach groups such as those in custodial settings, juvenile justice settings, child protection, forensic mental health settings, and those under the care of public guardians
- developing communication materials specifically for the trials and appropriately for different target segments
- engagement of third parties to distribute: brochures nationally; play My Health Record promotional videos in practice waiting rooms; to distribute, count and reconcile numbers of brochures; promote material in interactions with the practice managers

The activities planned by the PHN were:

- collaborate with NBM LHD to engage with local health and hospital services including (those with My Health Record conformant software) to increase views of My Health Records. Work to enable the upload of discharge summaries instantly – as this impacts the ability for pharmacists to view documents before dispensing prescriptions
- conduct a digital health mapping exercise of the My Health Record system connectivity and clinical information systems for all healthcare providers

⁴⁴ The Australian Digital Health Agency was established on 1 July 2016 with staff transferred from the Department of Health and the National eHealth Transition Authority (NeHTA).

- inform and assist healthcare providers/organisations with the registration process for the My Health Record system based on the digital health mapping exercise
- promote the availability of the online training modules
- arrange, coordinate and deliver face to face training as required
- provide targeted training for Aboriginal health professionals
- disseminate local communications and media campaigns to individuals and healthcare providers
- engage with key groups by engaging and providing communications materials to appropriately target local key consumer groups including, but not limited to, Indigenous populations, people with mental health conditions, parents of newborns, elderly people, people with chronic disease conditions, people with a disability, homeless, patients in public hospitals and individual members of the public
- conduct education sessions to educate key priority groups about My Health Record and the option to opt-out
- engage with individuals at point of care including brochures and posters
- conduct stakeholder engagement forums across the region for key stakeholder groups including, but not limited to general practices, Aboriginal medical services, allied healthcare providers, Indigenous populations, hospitals, other medical specialists, aged care facilities and other key healthcare provider groups
- distribute information materials/resources to healthcare providers
- distribute visual awareness collateral to registered healthcare providers
- identify practices using My Health Record and seek to share case studies or 'Good News Stories' demonstrating the benefits for patients and healthcare providers of My Health Record.

What was actually achieved in the five-month timeframe available to the trial is as follows:

Mapping of digital health capacity

The mapping of the digital health capacity of healthcare providers in the trial site was conducted and continually updated or extended throughout the trial period. The mapping exercises covered general practitioners/practices, pharmacies, allied healthcare providers, other medical specialists and residential aged care facilities. Different types of issues arose in different healthcare provider groups, such as: the types of clinical information software used, validated My Health Record registration, the currency of their digital certificate (NASH PKI)⁴⁵, their use of the My Health Record system, different types of benefits from use of the My Health Record system for different healthcare provider groups, and how the My Health Record can be integrated as part of the workflow in business operations. The results of the mapping were used to inform the strategy and approach for engagement activities with healthcare providers, to help with provider or practice registration, training and education activities and/or other additional support where required (e.g. providing technical support).

At the end of the evaluation period:

- of the 128 known general practices, the PHN found 86 were digital health enabled, and 22 were not computerised. Twenty did not want to participate in the trial for various reasons (including using manual records, not interested and retiring). Eighteen were progressing

⁴⁵ NASH certificates allow healthcare providers and supporting organisations to securely communicate and exchange health information electronically. It provides access to providers to the My Health Record system.

registration paperwork and 11 registered practices were not uploading documents to the My Health Record system.

- of the 89 known pharmacies in the region: one viewed documents through the Provider Portal; 24 were registered and uploading Dispense Records; 33 had non-conformant software; seven were configuring their software; 22 indicated that they would not be participating in the trial; and three that had access to the My Health Record system were not uploading documents.
- of the 38 allied healthcare providers working in general practices, 17 used the clinical information software in the practice and 24 received face to face visits from the PHN. Six allied healthcare providers working in general practices were registered with the My Health Record system.
- of the 520 identified other medical specialists in the region, 40 were found to have conformant software; one was registered with the My Health Record system and four were progressing registration or waiting for the outcome of their registration application. One specialist facility was also progressing to complete their paperwork.
- Of 27 known residential aged care facilities in the region: two were registered; 15 have conformant software; and 16 are part of a larger organisation that requires approval from head office to participate (11 are stand-alone). One corporate facility is in the process of registering its entire 17 facilities across NSW, including those in NBM region.

Education and Training

The delivery of face to face education and training to healthcare providers (general practitioners/general practices, pharmacies, allied healthcare providers, other medical specialists, residential aged care facilities and public hospitals) was the major focus of effort in NBM PHN.⁴⁶ This included using training materials provided from the national level, the development of resources locally to fill gaps in the material as they became apparent and the implementation of resource guides from some software vendors. There are various software issues for different products used in particular healthcare provider segments, and variances in the willingness or capacity of software vendors to collaborate with PHN staff in supporting training. NBM PHN had to adapt its activities accordingly. The training provided in NBM PHN also demonstrated how to use the My Health Record system via the Provider Portal to healthcare providers without conformant software. Efforts in the later part of the trial also included seeking approaches to link the training to Continuous Professional Development (CPD) points for healthcare providers. There were also limited or no Aboriginal medical services across the PHN's footprint. Consequently, the PHN focused its efforts in delivering training and education activities to other healthcare provider groups. Most training conducted by NBM PHN was conducted on an ad hoc basis during practice visits. It is, therefore, difficult to discern clearly the extent and nature of training delivered in the region.

A total of 133 training sessions were delivered in the trial site during the trial period. Of these, 126 were delivered to general practices/general practitioners and seven to pharmacies (in collaboration with Fred IT). Training delivered in general practices also targeted nurses and practice managers.

The provision of online training has been more of a challenge, partly due to a lack of promotion of its availability at the national level and partly due to less interest from healthcare providers in online training. A total of 28 healthcare providers in the NBM trial site registered to participate in the

⁴⁶ There was no effort on education and training delivered by the PHN to healthcare providers in the private hospitals. This was because either private hospitals within the PHN footprint were not connected to the My Health Record system, or if they were (e.g., in the case of Nepean Blue Mountains Private Hospital), the hospital wanted to deliver its own training and awareness raising activities.

online training from April to September 2016, representing 0.16% of the healthcare providers in the PHN footprint.

[Providing help to register with the My Health Record system for healthcare providers/organisations](#)

Efforts by NBM PHN to engage and help healthcare providers to register with and use the My Health Record system predominantly focused on GPs/ general practices (including after-hours general practices) and pharmacies. Its support also included resolving technical problems experienced by practices/healthcare providers to access and use the My Health Record system. Complex and difficult technical issues which were not resolved were then referred to the Agency. Awareness raising activities about the My Health Record system for general practices/GPs and pharmacies were conducted through practice visits and/or forums held by the PHN.

Work with other medical specialists, allied healthcare providers (who worked in a general practice) and residential aged care facilities in the beginning of the trial had limited success. This was due to limited understanding of how the My Health Record system could be embedded in the clinical workflow and how the My Health Record system could benefit them, especially for different allied healthcare providers. Revision of PHN approaches to better target these healthcare provider groups only increased in the last few months of the trial evaluation period. More face to face education and training sessions, forums and distribution of materials directly to these healthcare provider groups were conducted to increase participation in and use of the My Health Record system. Efforts to engage healthcare providers and individuals in Nepean Private Hospital were conducted by the hospital itself from the beginning of the trial with support from the PHN, when requested.

Efforts in the LHDs in NBM were governed by:

- The My Health Record Opt-out Trial NBM LHD Executive Leadership Group; and
- The My Health Record Opt-out Trial NBM LHD Governance Committee.

Owing to the late start of the trial activities in NBM LHD across the footprint, the trial activities only commenced in July 2016. The PHN collaborated with NBM LHD to support it in its engagement with individuals and healthcare providers, including the provision of resources/communication materials (e.g., brochures). The functionality of the HealtheNet clinical portal used in NBM LHD that allowed automatic uploads of Discharge Summaries to the My Health Record system had facilitated the use of the My Health Record system by clinicians in the hospitals.

[Dissemination of local communications and media campaigns](#)

In addition to the communication materials developed at the national level, the PHN worked with the National Engagement and Communications Team to develop and ensure consistent messaging in its local communication approaches. Various local communication channels were utilised to disseminate information about the My Health Record to healthcare providers and individuals, including:

- newspaper advertisements in six local papers (reaching approximately 171,235 people) in April, May and June. The advertisements were timed to be delivered at key points such as informing individuals that they would be receiving their My Health Record letters and the lead up time to the community forums
- cinema advertising in six local cinemas across the trial site for four weeks during the school holidays in June to target parents
- e-circulars to allied health professionals
- PHN weekly news
- Digital health bulletin as supplied by the Department. Local news and information was

added to the bulletin to ensure continued awareness and engagement with the My Health Record

- local editorial coverage targeting both individuals and healthcare providers
- mail outs
- faxes
- news updates on NBM PHN website
- PHN Clinical Council
- Practice nurse meetings
- Practice manager meetings
- GP advisory meetings
- PHN and LHD joint board meetings
- Local Council meetings.

The local communications developed by NBM PHN also targeted key priority groups in the population (people with a chronic disease, parents, elderly and Aboriginal and Torres Strait Islander people).

From February to October 2016, the PHN disseminated a total of 330 communication messages. Of these, 227 were directed at members of the public, 57 to healthcare providers and nine to a mixed audience group of healthcare providers and individuals. Channels of communication included: website, email, print, TV/cinema/radio and face to face. Most communication messages directed at members of the public were delivered face to face and most healthcare providers were reached through fax and emails. Of the communication messages directed at healthcare providers, most were disseminated to GPs (n=45 materials) and followed by allied healthcare providers (n=10). Fewer than 10 messages were directed at pharmacies, health services and hospitals and to a broader audience of healthcare providers.

Engagement with individual members of the public

Efforts to increase awareness in individuals by engaging consumer groups and other non-health service providers in the region (e.g. playgroups, childcare, associations, libraries, local community centres) were conducted in NBM PHN. Engagement with individuals also included the PHN's participation in various exhibitions and/or events held by other business portfolios within the PHN footprint. For example, NAIDOC day, Katoomba Public Hospital Fete, Aboriginal Community Garden, Aboriginal Outreach Day and the Disability Expo. During the trial period, the PHN also engaged key priority populations such as elderly people, veterans, homeless people and socially isolated individuals. Resources were distributed at these events, such as Indigenous materials, general brochures, posters, flyers and factsheets, targeted materials to specific populations (e.g. an aged care factsheet and carer factsheet), powerpoint slides, and PHN staff business cards were distributed in most of the engagement activities with individuals.

From February to September 2016, a total of 64 engagement activities occurred, and approximately 3,284 people were engaged across the trial site. The PHN's engagement with individuals increased from May to August 2016. Individuals were engaged through forums, informational stands, meetings and training. Over 104,000 individuals in NBM PHN region were reached in total through local media, and face to face meeting throughout the trial period.

Patient engagement at point of care

Overall, the PHN has engaged patients at point of care by providing resources/materials and equipping healthcare providers, including practice staff, to discuss the My Health Record with their patients. The PHN distributed patient-related materials such as brochures and posters to all general practices in the region. Other healthcare providers, such as allied healthcare providers and pharmacies, were also provided with resources/materials at the time of engagement to distribute to their clients.

Distribution of healthcare provider information pack and “visual awareness collateral”

Information about the My Health Record system and the opt-out trial were disseminated to healthcare providers within the PHN footprint from the start of the trial. Healthcare provider information packs consisting of letters and brochures about the My Health Record and the trial were distributed in early March 2016. Specific content packs and communication materials/resources were delivered to practices/healthcare providers when the PHN conducted its digital health mapping exercise. Other visual awareness materials such as posters, certifications and fold outs (TENTS) were also disseminated to healthcare providers for display throughout the trial period. Additionally, healthcare providers also received support guides that were developed by the PHN to assist healthcare providers to get ready and register with the My Health Record system.

Identification of champion and super users, and “Good News Stories”

In collaboration with other parties involved in the trial, the PHN sought out clinical “champions” and “Good News Stories” throughout the trial period. Due to the short timeframe for the trial, “Good News Stories” that illustrate immediate and long term benefits of the My Health Record to individuals and the healthcare system and local clinical “champions” for the My Health Record system were only just beginning to emerge at the time of reporting for the evaluation.

Stakeholder engagements with healthcare providers

From February to September, a total of 567 engagement activities were delivered to healthcare providers and practice staff. Engagement with healthcare providers at the beginning of the trial (February and March 2016) focused on raising awareness in healthcare providers about the My Health Record system, its benefits and ePIP. These engagement sessions were held in existing clinical meetings and forums (e.g., practice network meeting, nurses network meetings, GP advisory group meeting), and were attended by GPs, pharmacists, allied healthcare providers and practice staff. As the trial progressed, the engagement sessions included awareness raising activities, and education and training on elements of the opt-out approach and the necessary processes for healthcare providers to register or update certificates to participate. The engagement sessions also focused on educating healthcare providers on using the My Health Record as part of their workflow; and the security and privacy of the My Health Record system. Providers were engaged through forums, information stands, meetings, practice visits and training. Most engagement sessions were held in existing clinical meetings across the trial site while most practice visits were conducted in pharmacies. The engagement activities held by NBM PHN, WNSW PHN and NBM LHD also target various healthcare provider groups including general practitioners, other medical specialists, residential aged care providers, pharmacy, general practice (practice managers, administration staff and nurses), healthcare providers in the hospitals (including midwives, ward clerks, departmental heads/managers) and service providers.

Lessons learned from the opt-out trial in NBM PHN

Timing and duration

All stakeholders involved in the opt-out trial at NBM PHN felt that while the opt-out nature of the trial (the automatic creation of the My Health Records) clearly demonstrates the effectiveness of this method on widespread population registration and therefore increased participation in the My Health Record system; the length of the trial was too short to observe and document the full impact of efforts to change individuals' and healthcare providers' use of the My Health Record system.

There were lessons learned about:

- the timing and sequencing of activities and the need for a significantly longer lead time at both the national and local level. In particular, time available to alert and prepare healthcare providers about communication efforts targeting individuals caused some concerns at the PHN and healthcare provider levels
- a realistic timeframe of the trial to observe the full impact of the efforts conducted in public hospitals and health services is required. Stakeholders involved in NBM trial indicated that a full nine-months of concentrated efforts in the local hospitals and health services would be needed to see any change in clinician use of the My Health Record system.

Trial management and internal communication

There were key lessons learned from the opt-out trials about the importance of a balance between top-down input from the national level and bottom-up input from the trial site level in the direction, design and implementation of trial activities. These include: acknowledging local level expertise and knowledge about the detail of local circumstances and how they would impact on the implementation of the trial or local relationships with stakeholders; ensuring that high levels of content knowledge about the My Health Record, local health systems and the culture of health services and healthcare providers are available so that the support provided to PHNs is relevant and builds collegiately on local knowledge.

PHN & LHD scope and capacity

The scope of trial activities necessitated the PHN working outside its normal scope. For example, working with the secondary care sector (other medical specialists) and the tertiary care sector (private and public hospitals and residential aged care facilities). While most PHNs have experience of working collaboratively with these other sectors to ensure a more joined-up health system, other interactions and interventions in those sectors have not previously been part of the PHN brief. The PHN therefore had to build this capacity and the type of relationships, contacts, networks and content knowledge to support it in a very short time.

A longer trial period would have allowed for adequate preparatory work to enable them to understand these groups. They suggest that with this lead time, the PHNs would be able to develop a more targeted effort for these healthcare provider groups and for the public.

Having strong leadership and expertise in managing change within the health sector is the foundation for ensuring that My Health Record activities are tailored appropriately to each different sector of the health system.

Working with healthcare providers

The lessons learned from the trial activities in NBM suggest that understanding the workflow of different types of healthcare providers and the key benefit to each healthcare provider group is critical to overcoming healthcare providers' resistance to the My Health Record use.

Face to face engagement, training and education activities have been important to increasing awareness and understanding of the My Health Record in healthcare providers. Healthcare providers who were trained and educated about the My Health Record system were more confident to use it and explain it to others. Coupled with more engagement, training and education activities should also be provided to other healthcare providers, apart from those in general practices, future education and training efforts should also consider equipping providers to answer questions or clarifying any misunderstandings expressed by their patients.

Additionally, lessons about training healthcare providers suggest that training is best delivered when practices are registered with the My Health Record system and have conformant software. This means that the digital health mapping exercise of providers/practices across the PHN footprint should be completed prior to any engagement with healthcare providers in order to tailor the engagement activity to address the practice's needs.

The trial in NBM PHN suggests that future efforts should focus on improving the registration process and the online authentication process for healthcare providers and their organisations to access the My Health Record system. Support from the PHN in assisting practices/organisations in registering, connecting and using the My Health Record system was crucial in motivating healthcare providers to use the My Health Record system, and should continue.

Specific lessons learned with different healthcare provider groups:

Allied healthcare providers

There were lessons learned about the nature of allied healthcare providers' work practices and environments in the region. In particular, allied healthcare providers tend to be paper based, transient and reluctant to use the Provider Portal (unless they work with GPs). Even when offered a 6-month free trial of conformant software, there was a low uptake of the software by allied healthcare providers. Consequently, it was viewed that there is a need to deliver targeted efforts to each subgroup within the allied healthcare provider segment as each subgroup has different operational models and would use the My Health Record system for different purposes. This approach was found by the PHN to be more successful. For example, when the pharmacy provider segment was separated from others in the 'allied health' segment, the PHN had more success by focusing on their ways of working and business needs.

Other medical specialists

The lessons learned from activities with other medical specialists in NBM suggests that using peak professional associations/bodies or medical colleges might to be a more effective channel to reach this healthcare provider group. (Here it is noted, however, that national level responsibility rather than local would be more efficient and effective). Once being made aware, medical specialists in the trial site were supportive of the use of the My Health Record. However, the difficulties in registering for the My Health Record system was cited as a barrier for obtaining registration.

General practices/general practitioners

There were lessons learned about who would be best to target in general practices to ensure staff in the practice participate and use the My Health Record system appropriately. Key staff such as practice managers are important to target during engagement/training as they are responsible for operationalising the conformant software used in the practice on a day to day basis.

The digital health mapping exercise also provides key information to guide the types of engagement activities and how to approach each practice. For example, information from the exercise would inform whether the next engagement would be raising awareness or providing training.

Local Health District

The trial in NBM LHD demonstrates that healthcare providers are more receptive and inclined to use the My Health Record system when there is clinically useful content in it. In particular, the availability of patient's Medicare Benefits Schedule (MBS) and Pharmaceutical Benefit Scheme (PBS) data in the My Health Record system provides clinicians a rich picture of which medications have been prescribed and which healthcare providers a patient had visited.

Importantly, the trial in NBM LHD shows that enabling automatic upload of documents, particularly Discharge Summaries, to the My Health Record system through the organisation's clinical information system/clinical portal can facilitate healthcare providers' workflow.

The trial in NBM LHD suggests that future communication efforts targeting healthcare providers in LHDs should also include clear messages about the roles and responsibilities healthcare providers have in managing their patient's My Health Record. For example, whether clinicians have a duty of care to check the My Health Record.

Working with members of the public

There were also lessons learned about the awareness raising activities conducted at the trial site. More awareness raising activities for individuals should be conducted. The trial in NBM demonstrates that people are more positive about the My Health Record once they are informed about it, its benefits and the security and privacy aspects of the My Health Record. Some who already opted out indicated they would like to opt in again after understanding the My Health Record. This finding also extends to the PHN's engagement with members of key priority groups (e.g. refugees, elderly people, people who have migrated to Australia and people living with a disability).

Lessons learned from the trial in NBM also suggest that members of some key priority groups need to be educated about the My Health Record. Younger people should be educated about the My Health Record, especially how they can set privacy controls.

Importantly, improving the accessibility of the My Health Record through an individual's myGov account was viewed to be crucial in order to encourage people to access their My Health Record. The complexity and the required information to set up a myGov account and then link the My Health Record to an individual's myGov account discouraged individuals from proceeding further.

Training healthcare providers

Additional staffing resources and materials are required to assist in future education and training, including awareness raising activities in healthcare providers. Demonstrating how healthcare providers can access the My Health Record system, either through the clinical information software or Provider Portal, should be a part of training. Additional training materials and information, such as scenarios/examples of why and when a clinician would need to access information in the My Health Record system, and what types of information they will find in it, should be printed and disseminated. Additionally, clinicians need to be educated and be aware of the need to obtain consent from incoherent patients (or their carers) prior to uploading documents to the My Health Record.

The trial in NBM demonstrates that healthcare providers (particularly GPs) prefer face to face training than the online training. Offering CPD points in the training for My Health Record is also

important to increase participation. This approach could also potentially attract more healthcare providers to participate in the online training module.

Advice for future communication efforts

There were lessons learned about how to communicate with healthcare providers. Future communications strategies need to consider the style, content and timing of centralised communications directed to healthcare providers. In particular, separately developed ad hoc printed materials [that were generated during the trial, sometimes in piecemeal fashion and too late] should be made more manageable for healthcare providers. For example, a booklet/folder that compiles every document for healthcare providers, particularly GPs, so that every material/guide that is provided to them is located in one place.

Additionally, the lessons learned for any future communications approach from the trial at NBM suggest that more marketing and communication materials/resources, both at a national and local level, need to be disseminated to the public and healthcare providers at the beginning of the trial. In particular, individuals should be made aware of the My Health Record system, including any letter, prior to receiving it. Additionally, branding of the My Health Record should also be placed everywhere.

The trial in NBM also suggests that messages targeting members of the public need to be clear and simple, as well as considering the population's literacy level and health literacy level. Engaging key leaders in the community or service providers to disseminate information about the My Health Record to key priority groups in the population (e.g. CALD populations, homeless people, veterans) appeared to be effective in the region. Demonstrating the registration process in a step by step format including how people can set access controls and insert details of their medication and emergency contact can reduce misconceptions about the My Health Record. This would enable healthcare providers (especially in hospitals) to have easy access to this information during an emergency. Future messaging to members of the public should also include information about how sensitive information in the My Health Record for vulnerable patients (e.g. Patient with alcohol and drug disorders) would be shared with their healthcare providers.

Choosing an appropriate promotional event in which to participate is important. Participating in health-related events to disseminate information about the My Health Record was more effective in engaging the population in the region. Having a national event dedicated to digital health was also thought to increase awareness of the My Health Record in individuals.

The trial also demonstrates that consistent branding, messaging, templates and materials provided from the national level to the local delivery partners is crucial. Materials and templates provided at the national level should be designed to allow them to be altered and localised to the specific region and to target community segments.

From the trial in NBM, GPs appeared to be the most frequently identified trustworthy source to validate and promote the My Health Record system.

Achievements of the NBM trial

At the time of writing this case study, the following can be claimed as achievements of the opt-out trial in this location. Because the design of the evaluation did not include a comparison between relative effectiveness of the two opt-out trial sites and the results of the variables of interest were very similar across the two opt-out trial sites, the results of the surveys (individuals and healthcare

providers), focus groups and interviews, and the analysis of the de-identified data from the National Infrastructure Operator (NIO) about upload, participation and use are reported together.

The findings of the evaluation should be read and understood within the context of the length of the trial and the timing of the measurement period for the evaluation as outlined earlier.

Opt-out rate in the opt-out trial sites

Across both opt-out trial sites in Northern Queensland and Nepean Blue Mountains, 1.9% of the population opted-out of having a My Health Record automatically created for them. Table 4 below lists the reasons given for opting out from most to least frequent. The top four reasons are related to a person’s level of understanding of the My Health Record’s purpose, benefits and features (e.g. the benefits of having a My Health Record for them and the system and the personally controlled nature of the My Health Record with the capacity to set privacy settings). It is important to note that people were given the option of opting out over a fixed period (between 4 April and 27 May) and that local trial activities to support individuals in their awareness and understanding of the My Health Record were only properly underway from May 2016. This opt-out rate may have been less if there had been a longer lead time and more intense communication efforts at the national and local level to address these concerns.

Table4. Reasons for opting out in NBM and NQ PHN regions

Reasons for opting out ¹	Frequency
I have no use for a digital health record	24,242
I prefer to manage my medical records on my own	9,495
I prefer that my doctor manages my medical records	6,664
I am concerned about others having access to my private medical information	3,961
I am concerned about the security of my medical information stored online	2,286
I do not trust what the Government or others will do with my medical information	1,354

¹People could choose more than one reason for opting out.

Individual exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system

A stratified representative sample of the general population in the footprint of the PHN participated in an online survey at baseline (February 2016) and at follow up (September 2016). People were asked to indicate whether they had heard about the My Health Record and how and rate their understanding, confidence, participation and use of the My Health Record system. In addition, 111 members of the public participated in 10 focus groups across the PHN during the follow up period, including one Aboriginal and Torres Strait Islander specific focus group.

The online survey of individuals in the opt-out trial sites found that approximately one quarter of participants had heard about the My Health Record; however, participants in the opt-out trial areas were more likely to have heard about the My Health Record system during the trial period than the rest of Australia. Participants in the opt-out trial site were more likely to state that they had a My Health Record than the rest of Australia comparison site. 58% of the respondents in the opt-out trial site did not recall receiving a letter about the My Health Record, stating that they didn’t receive one or didn’t know if the received one.

Participants in the opt-out trial sites were more likely to increase their viewing of Prescription Records than the rest of Australia. However, this is based on low numbers and may be a result of

underpowered analysis, rather than a true difference. There were no differences in other indicators of use or participation in the opt-out trial sites compared to the rest of Australia. There were no differences in any indicators of confidence to use the My Health Record between the opt-out trial sites and the rest of Australia.

Qualitative responses to the survey included: the My Health Record system had allowed their treating team members to be 'on the same page' with them about their health; while they could not report any benefits from having a My Health Record at the time, they felt that the My Health Record provided an easy way for healthcare providers to access their health record and assist in clinical decision making. The main reasons provided by respondents who were not aware that they have a My Health Record created for them and said that they did not have a My Health Record were: they were unaware or not sufficiently informed about the My Health Record system or they believed that having a record was unnecessary.

The focus groups conducted allowed for both unprompted and prompted questioning of participants in relation to the same variables covered by the online survey. The focus group methodology allowed for more in depth discussion with individuals and to observe discussions between individuals about these issues. The focus groups in the opt-out trial sites suggested a very low level of awareness of the My Health Record system and its benefits. There was also very poor recall and recognition of any letters and other print, television or radio information about the My Health Record system. However, once focus group members had the My Health Record (its purposes and its benefits to individuals, the healthcare system and their families) explained to them: (i) there was a high level of support for the My Health Record and its purpose; and (ii) there was negligible concern about privacy/confidentiality and the capacity of the My Health Record system to be secure from external threats. Very few participants in the focus groups within the opt-out trial sites had used their My Health Record.

Those who had used it found it to be user friendly and functional. Many participants were surprised that they had to prompt their healthcare provider to use the My Health Record system, expecting this to be part of standard practice. Most participants in the focus groups expressed the view that use of the My Health Record by healthcare providers should be compulsory.

[Healthcare provider exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system](#)

A stratified representative sample of the healthcare providers in the footprint of the PHN participated in an online survey at baseline (in February 2016) and at follow up (in September 2016). Healthcare providers were asked to indicate whether they had heard about the My Health Record and how and to rate their understanding, confidence, participation and use of the My Health Record system. In addition, 14 healthcare providers across the footprint of the PHN during the follow up period volunteered to participate in interviews, including GPs, nurses, pharmacists, practice managers and clinical practice managers.

The online survey of healthcare providers in opt-out trial sites found that healthcare providers in the opt-out trial areas were more likely to have heard about the My Health Record system during the trial period than the rest of Australia. There was an increase in the number of respondents who reported their workplace as being registered on the My Health Record system in the opt-out trial sites and the rest of Australia. The increase during the trial was greater in the opt-out trial site relative to the rest of Australia although the difference was not statistically significant.

At follow up, there were no significant differences between the opt-out trial sites and the rest of Australia with regard to healthcare provider beliefs about the following attributes of the My Health Record system: access to information about patient health; ability to apply best practice care; informs medication management choices; saves time sourcing patient information; spend less time communicating to other healthcare providers; enables patients to better manage healthcare; adds time to upload data.

There was no statistical difference in respondents' intentions to use the My Health Record system over the next four months between the opt-out trial sites and the rest of Australia. There were no differences in any indicators of confidence to use the My Health Record system between the opt out trial sites and the rest of Australia.

Across both the opt-out trial sites and the rest of Australia, there was an increase in the proportion of respondents who had received training in the My Health Record System. The difference in the increased proportion between the opt-out trial sites and rest of Australia who had received training was statistically significant. Indeed, the proportion of participants who had received training remained relatively low with the majority of training provided face to face across the two groups. Overall, over 80% of respondents in both opt-out trial sites and the rest of Australia who had received training considered the training to be at least slightly effective or better. There was also an increase in the perceived effectiveness of the training between baseline and follow up across the opt-out trial sites and the rest of Australia with no statistically significant difference in the change of training effectiveness between the opt-out trial sites and the rest of Australia.

The interviews with healthcare providers allowed for both unprompted and prompted questioning in relation to the same variables covered by the online survey. The interview methodology also allows for more in-depth discussion with healthcare providers. The interviews with healthcare providers in opt-out trial sites demonstrate that all interviewees were aware of the My Health Record and understood its purpose, with some having used it prior to the commencement of the trial. Nearly all had participated in the trial activities delivered by the PHNs. Most healthcare providers interviewed could list benefits of using the My Health Record, including: reduce 'Doctor Shopping'; informs clinical decision making; improve multidisciplinary team care; facilitates medical information sharing amongst healthcare providers; becomes a place where important health information is easily accessible; and is useful when patients are travelling or when they present to the Emergency Department.

There were negligible concerns by healthcare providers about privacy and the capacity of the My Health Record system to maintain the confidentiality of the patients and the security to external threat once they understood the My Health Record. Healthcare providers believed that the benefits far outweighed any small risks to confidentiality and security. Those who said they were not confident said it was because: they were not computer literate; were mindful of the problems with the Census; or they had concerns about the use of the data in the My Health Record and that information would be available to patients they would not otherwise have (such as doctors' notes about a patient, or information in referral letters to or from specialists). Most healthcare providers interviewed stated they were using the My Health Record system to view and/or upload information. Those who had not used the My Health Record system felt it was underdeveloped and that there was little demand from patients to use it. Overall, all healthcare providers interviewed felt a combination of both public demand for the use of the My Health Record and the availability of more clinically useful information would encourage other healthcare providers to use it.

Healthcare providers noted that the ePIP eligibility criteria changed their use of the My Health Record system a little, but not to any great extent.

NIO data

Individuals:

As a result of the automatic creation of the My Health Records under the opt-out model, the opt-out trial sites had significant increases both in numbers of My Health Records and proportionally over the rest of Australia. Individuals, in general, were unlikely to restrict access to their My Health Record either by restricting documents or healthcare providers, with less than one percent doing so. Very few actively changed their MBS or PBS item uploading restrictions and this led to a large volume of MBS attendance items being uploaded to their My Health Record. These increases were proportionally higher in opt-out trial sites compared to the rest of Australia comparison site. Individuals also viewed documents in their My Health Record. Increases in documents viewed from baseline included: Consumer Entered Health Summary, Audit View, Diagnostic Imaging Report, Health Record Overview, Medicare Overview, Prescription Record View, and Prescription Dispensed View. Overall the level of viewing of these documents between baseline and follow up increased more in the opt-out trial sites and the rest of Australia comparison site, though these differences were low.

Healthcare providers:

There were additional healthcare provider organisations registered in the opt-out trial sites and in the rest of Australia. These increases in registrations were consistent throughout the trial period, with only a few sudden increases due to bulk registrations of HPI-Os. The majority of registered healthcare provider organisations in the My Health Record system were general practices with pharmacies being the next most common. Also, general practices were the healthcare provider organisations that had the most extra HPI-O registrations during the trial period. The opt-out trial sites had a proportional gain in healthcare provider registrations greater than in the rest of Australia. There were a number of documents that significantly increased in volume between baseline and follow up and increased significantly more in the opt-out trial sites compared to the rest of Australia, these included: Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Records. The increase in Shared Health Summary uploads is closely linked with the deadline of the ePIP, though the increases were greater in the opt-out trial sites than in the rest of Australia and maintained a higher proportion following on from this peak. The availability of My Health Records may have led to this prolonged increase and this may continue, though a longer follow up is needed to monitor for temporal/seasonal changes. The number of MBS uploads associated with attendances examined in the evaluation increased from baseline to follow up. The proportional increases were greater in the opt-out trial sites compared to the rest of Australia. Of note, there were only minimal differences between opt-out trial sites and the rest of Australia in the percentage of MBS attendance items with a Shared Health Summary upload. The level of accesses of documents increased dramatically during the trial evaluation period with accesses increasing significantly more in the opt-out trial sites than in the rest of Australia. Also of note there was an increase in the number of My Health Records accessed that had no clinical documents in them, with healthcare providers in opt-out trial sites more likely to access the My Health Records and upload the first clinical document than the rest of Australia.

Appendix 11 Western Australian Primary Health Alliance (WAPHA) Opt-in Trial Site

The opt-in trial in Western Australia was designed as an innovative approach to increase individual participation and healthcare provider use of the My Health Record system within existing opt-in participation arrangements. The activities in this trial site sought to use a Precedence Health Care product (cdmNet)⁴⁷ to drive participation and use of the My Health Record by chronic disease patients and their healthcare providers. cdmNet was used to prompt and enable authorised healthcare providers to register identified patients for a My Health Record and/or cdmNet record (where one did not already exist). Additionally, it allowed authorised care team healthcare providers to view a patient's My Health Record within cdmNet. Education and training on the My Health Record and cdmNet My Health Record functionality was also provided during the trial period.

These activities were hoped to contribute to the following outcomes:

- Increased awareness and understanding of the My Health Record system amongst users
Increased confidence to use the My Health Record system amongst users
- Increased participation in, and use of, the My Health Record system by users
- Increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system.

In November 2015, the Western Australian Primary Health Alliance (WAPHA) submitted a proposal to the Department of Health (the Department) to conduct an opt-in trial in Western Australia (WA). When WAPHA was shortlisted as an opt-in trial site, WAPHA, Precedence Health Care and the Department worked closely together to refine the trial approach. This refined approach was then submitted to the Minister for Health, the Hon Susan Ley, for consideration and was approved on 3 April 2016. A contract between WAPHA and the Department was then developed and signed on 29 April 2016. The planning phase for the trial in WA began in May 2016, and the trial was launched in July 2016.

WAPHA (together with Precedence Health Care) worked closely with the National Evaluator from May 2016 to implement the evaluation tools and templates, and assist with the recruitment of focus groups and healthcare providers for interviews during the follow up period. A final reflection workshop between WAPHA and the evaluation team drew together reflections and lessons learned across the total period covered by the trial evaluation (July to September 2016).

Non-program factors in the opt-in trial in WA

The trial in WA ran in the context of the following significant factors that were outside of the control of WAPHA, Precedence Health Care and the National Trials Team, and which could be argued to have an impact on the implementation and effect of trial activities:

- There were many general practices using Extensia (an alternative software tool for chronic disease management) in WA, specifically in regions like Albany where prior My Health Project projects had been implemented by the National eHealth Transition Authority (NEHTA). Those managing the trial felt that this was likely to have an impact on their ability to recruit participating practices during the trial period.

⁴⁷ cdmNet is a cloud-based digital platform connecting healthcare providers and patients across the entire care continuum for delivery of coordinated chronic disease management and preventative care. cdmNet was chosen due to its ability to facilitate use and engagement/coordination across the care continuum. The cdmNet also identifies and enables users (patients and healthcare providers) to access the My Health Record via cdmNet.

- Changes to the online Healthcare Identifier Service in Health Professional Online Services (HPOS) (managed by the Department of Human Services) during the trial period meant that those managing the trial had to redevelop guides that they had developed for practices to set up the cdmNet - My Health Record system linkage and functionality.

The demography and geography of the WAPHA region

Some key demographic and geographic characteristics of the WAPHA region are presented below so that the reader of this case study can judge how relevant and generalisable the experience in this site is to their own setting.

WAPHA consists of three PHNs: Perth North PHN, Perth South PHN, and Country WA PHN. It covers and represents the whole of WA (see Figure 1).

WAPHA covers over 2,458,684 km² and has a total population of 2,239,171. In 2011, 50.3% of the population were males (26,178) and 49.7% were females (1,112,992). Areas within the Perth South PHN and Perth North PHN footprint are classified as major cities, while most rural and very remote areas are located within the Country WA PHN footprint.⁴⁸



Figure1: Topographic map of WAPHA

Age and gender distribution

Table 1 shows that almost 50% of the population in WA lives in the Perth North PHN region. It also shows that the distribution of gender and age is similar across the three PHNs.

⁴⁸ http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Country_WA

Non-English speaking

In 2011, there were more people in Perth who spoke a language other than English at home and reported that they do not speak English well or at all than those in Country WA PHN (see Table 1).

Aboriginal and Torres Strait Islander peoples

Table 1 demonstrates the population of Aboriginal and Torres Strait Islander peoples in regional, rural and very remote areas of WA.

Internet Connectivity

When compared to the Perth North and Perth South PHNs, there were fewer people with internet connectivity in the Country PHN (see Table 1).

Table 1: Demographic information of the PHNs within WAPHA

	Perth North PHN	Perth South PHN	Country WA PHN
Geographic land area	2,975km ²	5,148km ²	2,477,561km ²
Regions	<ul style="list-style-type: none"> Perth City/ Osborne Park Joondalup/ Wannero Midland/Swan 	<ul style="list-style-type: none"> South Metropolitan Rockingham & Kiwinana South East Metropolitan Mandurah, Murray and Waroona 	<ul style="list-style-type: none"> Kimberley Pilbara Midwest Goldfields Wheatbelt Southwest Great Southern
Age Range¹			
0 to 4 n(%)	67,669 (7%)	63,530 (7%)	37,308 (7%)
5 to 24 n(%)	271,358 (26%)	250,511 (27%)	138,266 (25%)
25 to 64 n(%)	570,393 (55%)	504,355 (54%)	304,575 (56%)
65 and over n(%)	127,373 (12%)	121,822 (13%)	65,161 (12%)
Total n(%)	1,036,793 (100%)	940,218 (100%)	545,310 (100%)
Gender			
Male ² n(%)	530,405 (50.04%)	485,690 (50.14%)	287,413 (52.50%)
Female n(%)	529,606 (49.96%)	483,060 (49.86%)	260,017 (47.50%)
Aboriginal and Torres Strait Islander population n(%)	12,540 (1.18%)	14,738 (1.52%)	41,970 (7.67%)
Spoke language other than English at home n(%)	144,325 (13.9%)	132,591 (14.1%)	33,860 (6.21%)

	Perth North PHN	Perth South PHN	Country WA PHN
English proficiency 'not at all' or 'not well' n(%)	23,031 (2.22%)	19,169 (2.04%)	4,519 (0.83%)
Internet connectivity n(%)	256,723 (77.83%)	251,567 (76.25%)	130,496 (68.10%)

Source: Census 2011. 1. Data sourced from WAPHA website (based on 2013 data); 2. Department of Health PHN factsheets (based on Estimated Resident Population 2014).

How do demographics in the PHNs within WAPHA compare with WA and Australia as a whole?

The proportion of Aboriginal and Torres Strait Islander population in the Perth North and South PHNs (1.18% to 1.52%) is lower than the estimated Aboriginal and Torres Strait Islander population in WA (3.7%) and in Australia (3.0%). Compared to WA and the whole of Australia, Country WA PHN has a higher proportion of Aboriginal and Torres Strait Islander population.

Compared to WA (15%) and Australia as whole (18%), the proportion of people who spoke a language other than English at home was lower across the PHNs. More people reported difficulty speaking English (not well or not at all) in the Perth North and Perth South PHNs (2.32% - 2.58%) than in WA (2.1%), but fewer than in the whole of Australia (3.0%). Compared to WA and the whole of Australia, Country WA PHN has relatively low proportion of people who reported difficulty speaking English. Similarly, more people in Perth North PHN and Perth South PHN have internet access (78%, 76%) while fewer in Country WA PHN (68%) have access to the internet, when compared to WA as a whole (75%) and Australia as a whole (74%).

My Health Record Activities in the WA Opt-In Trial Site

Contracting and Design of the Trial

The design of the trial in preparation for costing and contracting began in February 2016. This work was undertaken by WAPHA within its existing resources. A total of \$401,500 (GST inclusive) was agreed between the Department of Health and WAPHA to execute the My Health Record Opt-in trial activities in WA, in collaboration with Precedence Healthcare. Precedence Healthcare was responsible for managing the technical elements of the trial.

What sort of staffing structure supported the implementation of the trial in WA?

A Project Manager was recruited to manage the opt-in trial in WA in late May 2016. To assist in the delivery of the trial activities, WAPHA collaborated with Precedence Healthcare. In addition to managing the technical aspects of the trial, Precedence Healthcare was responsible for communicating actively with users of their software (cdmNet) across the PHN footprint about the trial. WAPHA was responsible for:

- establishing and maintaining the project management framework including the program schedule and risk and issue management
- establishing and maintaining their contract with Precedence Health Care for the delivery of technical services throughout the trial
- providing education and training about assisted registration to patients, administrative and clinical staff in participating practices.

What activities were implemented during the trial period to support the achievement of the identified outcomes?

The activities planned by WAPHA were:

- recruit practices to participate in the opt-in trial
- develop additional functionality to cdmNet to prompt and enable authorised healthcare providers to register identified patients for a My Health Record and/or cdmNet record (where one did not already exist); and allow authorised healthcare team providers to view a patient's My Health Record within cdmNet.
- support participating practices in providing assisted registration to chronically ill patients.
- educate and train healthcare providers involved in the trial about the My Health Record system and the cdmNet My Health Record functionality.
- communicate with chronically ill patients, which included:
 - informing patients about the trial
 - working with different priority groups to ensure they were informed
 - tailored activities and approaches to fit with culturally and linguistically diverse patients
 - engaging at a partnership level with the local Aboriginal and Torres Strait Islander cooperatives and health services.
- Inform general practitioners and other healthcare providers involved in the treatment of chronically ill patients about the trial and highlight the value of the My Health Record for their patients and encourage them to view and upload to My Health Record as part of the trial.

Achievements in the three-month timeframe available to the trial are as follows:

Recruitment of practices to participate in the opt-in trial

The recruitment of eligible practices for the trial was conducted in two tranches. In the first tranche, WAPHA engaged with all active cdmNet user practices and collaborated with Independent Practice Network (IPN)⁴⁹ to recruit select practices within IPN network.⁵⁰

In the second tranche, WAPHA:

- promoted the trial and invited interested practices to participate through their e-newsletter (for GP, practice, industry/professional)
- directly approached corporate practice groups via face to face meeting or email
- targeted direct invitation to early adopters of the My Health Record system.

Practices that agreed to participate in the trial registered Precedence Health Care as a 'Contracted Service Provider'⁵¹ through the Health Professionals Online Services or through manual application. Where a practice did not already use cdmNet, the practice was assisted by Precedence Health Care to register for, install and configure cdmNet in the practice.

⁴⁹ IPN is commercially affiliated to Precedence Health Care.

⁵⁰ Note that most IPN practices recruited were not active cdmNet users prior to trial commencement.

⁵¹ A contracted service provider provides IT services or health information management services relating to the My Health Record system to a healthcare provider organisation. They will interact with the My Health Record system using their identity on behalf of the registered healthcare provider organisation. More information about a contracted service provider, please refer to <https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/contracted-serv-prov-reg>

The recruitment approach was revised at the end of the trial evaluation period to focus on general practices in the region that were already registered with the My Health Record system. This was done mindful of the remaining time in the trial period, and the time taken for practices to register with the My Health Record system.

At the end of the trial evaluation period, WAPHA had approached 105 practices to participate in the trial. Of those, 27 practices were recruited to participate (not all practices recruited were set up in time), 48 had not provided any response to the invitation to participate in the trial or were pending confirmation, and 30 practices declined/withdrawn. Those that declined to participate sighted reasons such as:

- using alternative chronic disease management tool/software
- workload and competing practice priority, and/or not enough workforce capacity
- GPs were not in favour of using the My Health Record/cdmNet
- the cost of the full cdmNet functionality
- not having compatible IT system/infrastructure

Develop an additional functionality to cdmNet

In the beginning of the trial period, Precedence Health Care developed a cdmNet record linkage to all cdmNet pop-ups to remind a GP or nurse to link and share eligible patients' My Health Record and cdmNet record. The additional functionality would also remind GPs to use the My Health Record system via cdmNet when they were establishing or maintaining care plans for their chronically ill patients.

Provide support to participating practices to provide assisted registration to chronically ill patients

WAPHA provided information to support participating practices to provide assisted registration to their patients. For example, WAPHA:

- developed and distributed a pre-information pack to prepare their patients to accept assisted registration upon presentation at the practice;
- disseminated communication materials directed at both individuals and healthcare providers to encourage registration, such as Chronic Disease My Health Record posters; and
- circulated assisted registration scripts and Frequently Asked Questions guidance and videos about the My Health Record.

WAPHA also developed a letter for participating practices to disseminate to their patients, to offer them the opportunity to participate in the trial.

Based on the progress reports provided by the trial site to the National Trials Team by the end of the trial evaluation period, a total of 848 My Health Records were newly created as part of the trial (through cdmNet prompted assisted registration). The trial site reports that this may be an overestimate as they were not able to verify how many of these records might have been created prior to the start of the trial.

Educate and train healthcare providers involved in the trial about the My Health Record system and the cdmNet My Health Record functionality

Staff of participating practices who attended the education and training delivered by WAPHA and Precedence Healthcare were provided with:

- cdmNet & My Health Record Quick Guide
- cdmNet My Health Record Opt-In Trial demonstration/slides

- cdmNet & My Health Record Opt-In Trial Guide
- practice scripts
- Frequently Asked Questions
- suggested workflow that incorporate the My Health Record system-cdmNet
- details of cdmNet helpdesk support line
- marketing materials and resources for patients.

Participating practices were provided with information about the new functionality of cdmNet and the benefits of the My Health Record system. They were also encouraged by WAPHA and Precedence Health Care to upload Shared Health Summaries to ensure the My Health Record contained clinically useful information.

Throughout the trial, Precedence Healthcare, in collaboration with the Department and WAPHA, assisted participating practices to register for, install and configure the cdmNet software and link the My Health Record system to cdmNet. WAPHA assisted participating practices to register with the My Health Record system. WAPHA found that most practices in the trial had already received some information about the My Health Record system and attended some form of training relating to assisted registration (which was delivered by WAPHA as usual digital health activities).

WAPHA also trained allied healthcare providers across the PHN footprint to use the My Health Record system. This included delivering training and education to inform them about the trial and the My Health Record system.

A total of 34 training activities were delivered in the trial site from June to September 2016. Of these, most were delivered to general practices (n=30) and four to allied healthcare providers. Most training sessions delivered in general practices were to practice nurses, practice managers and the person who was second in charge of the practice. 27 out of the 34 training activities were delivered in an individual format while seven were delivered in a group setting. Training relating to the use of cdmNet was delivered in an individual format to practice nurses, practice managers and the person who was second in charge of the practice. The group training focused on providing information about the My Health Record system, and the assisted registration process and tools. Most of the group training was attended by GPs, nurses, practice reception staff and allied healthcare providers

At the end of the trial evaluation period, WAPHA reported that a total of 112 GPs, 37 nurses, three practice managers and two nurse practitioners had access to information in the My Health Record system through cdmNet. 224 allied healthcare providers, 141 specialists and 21 pharmacies also had access to the My Health Record system through cdmNet. A total of 164 care team members had accessed information in the My Health Record via cdmNet. Of the total, 61% were practice nurses, 18% were podiatrists, 11% were GPs; 5% were care facilitators; 4% were diabetes educators; and 1% were nurse practitioners.

In the time between the measurement period for the evaluation and the finalisation of this case study, substantial efforts by WAPHA and Precedence Healthcare increased these numbers to 125 GPs, 44 nurses, 654 allied healthcare providers and 357 other medical specialists who have access to the My Health Record information in cdmNet.

Communicate with chronically ill patients

To increase awareness of the My Health Record system in the public, WAPHA presented to the Perth South and Perth North PHN's Clinical Commissioning and Community Engagement Committees at the beginning of the trial. They also distributed My Health Record brochures to participating GPs, and developed a targeted brochure that explains the trial to patients of participating practices.

Throughout the trial period, WAPHA delivered materials provided by the Department to participating practices in order to support the assisted registration process. As described above, additional resources to help practice staff register patients were delivered, including the Frequently Asked Questions sheet, assisted registration scripts and individual benefit factsheets. Resources directed at patients were also provided to participating practices, including:

- Patient information sheets to assist with patient recruitment into the My Health Record system. The information sheet explained the purpose of the trial and what My Health Record is. It also includes information about the benefits of sharing information with the whole care team.
- Modified My Health Record collateral targeted at chronic disease patients
- Resources for culturally and linguistically diverse (CALD) populations.

Due to the short trial period, WAPHA did not conduct specific activities for CALD patients, as they initially planned. Instead, WAPHA provided CALD specific resources to participating practices, as they were made available by the Department. WAPHA also liaised with stakeholders including the WA Humanitarian Entrants Health Service (HEHS) and local Aboriginal healthcare providers to submit language preferences for future brochure translations. Additionally, WAPHA found that very few WA Aboriginal Medical Services (AMS) and Aboriginal Community Controlled Health Services (ACCHS) were registered with the My Health Record system during the trial period. WAPHA continued to support digital health readiness and capacity in these AMS / ACCHS as part of its general business, but they were not included in the trial owing to the time constraints.

Inform general practitioners and other healthcare providers

Various communication channels were used to engage general practitioners, general practices, allied healthcare providers and other medical specialists about the trial and the My Health Record system. These channels included: face to face, brochures, eBulletin, email communication, display stand and website. Forums, workshop and education and information sessions with practice managers, chief operating officers of general practices, other medical specialists and allied healthcare providers were conducted throughout the trial.

WAPHA found that allied healthcare providers were interested in cdmNet functionality. They felt that the value to them would depend on the practice and patients' participation in the trial, and the availability of uploaded information within the patients' cdmNet record and My Health Record. They also found varied levels of digitalisation among allied healthcare providers and practices.

At the end of the trial evaluation period, WAPHA and Precedence Healthcare also logged 23 instances where they had disseminated materials and information about the My Health Record to healthcare providers. In 10 of the 23 instances materials were targeted to practices in the region; nine dissemination activities were not targeted to any specific healthcare provider groups, three were disseminated to allied healthcare providers, and one targeted other medical specialists. Of the 23 dissemination activities, 13 were conducted to deliver resources containing information about cdmNet, support helplines for healthcare providers, the My Health Record trial, and summary of the trial progress; 10 were conducted to raise awareness about the trial and the My Health Record system in the region. WAPHA most often

used emails (n=11), eBulletin (n=4) and face to face (n=4) to disseminate information/materials relating to the trial.

Lessons learned about activities conducted in Western Australia

Timing of the trial

All stakeholders involved in the trial believed the time period for the trial and the evaluation was too short to observe and document the full impact of efforts to change individuals' and healthcare providers' use of the My Health Record.

Trial management and design

The trial in WA demonstrates how a strong working relationship between all parties involved in the trial (both locally and nationally) is important to achieving the intended outcomes within a short timeframe. This is particularly important when communicating the changes in the scope of the trial from what was initially planned.

Efforts to provide assisted registration

The efforts to provide assisted registration to chronically ill patients during the trial period were noted to be resource intensive and time consuming. Assisted registration was particularly difficult when patients had little or no awareness of the My Health Record system. Practice staff then had to explain My Health Record to them prior to providing assisted registration, which increased the time taken to complete the process. For example, a practice nurse took 15 minutes to provide assisted registration to one patient. To address the low level of patients with existing My Health Record and/or cdmNet record, and a low understanding of both, WAPHA had implemented an 'Assisted Registration by mail' process (with a mail out to approximately 27,000 patients) and reported that they were monitoring its impact (at the finalisation of this case study).

Promotion and communication of the My Health Record system

Lessons learned from the trial in WA suggest that there is a need for national and local communication and marketing campaigns. It is also important to provide consistent branding, messaging, templates and materials at the national level to the local delivery partners. Materials and templates provided at the national level should be designed to allow them to be altered and localised to the specific region and target community segments.

The need to provide sufficient resources, particularly those targeting CALD populations, was also noted as a lesson learned. Those managing the trial said that the lack of these resources made it difficult for practices to engage this population group. The materials/resources targeting CALD populations which were reportedly provided during the trial period included 'My Health Record Essential' information sheets and posters in Arabic and Italian; and a short extract from 'Your Health' sheets on the Department of Human Service website containing My Health Record information in Arabic and Persian (Farsi).

Working with General Practices

WAPHA also believes that the trial drove a change of policy in IPN practices. Initially IPN policy only permitted GPs to create and upload Shared Health Summaries, however, in response to the experience in the trial practice workflow was redesigned to promote efficiency, in general, and allow uploads to be done by the CDM nurses.

Additionally, it was noted by the WAPHA that improving the functionality of the My Health Record system and cdmNet as the trial progressed attracted more healthcare providers to use the My Health Record system. For example, the new cdmNet My Health Record integration helped to improve practices' efficiency and patient care by querying My Health Record for any previous Medicare Chronic Disease Management items. The platform would inform patients' claims and eligibility, which therefore, saved healthcare providers' time in contacting Medicare to gather this information. This capability could be promoted to attract more healthcare providers to use the My Health Record-cdmNet linked system.

Having the corporate buy-in from the ownership of practices, GP and healthcare provider champions also facilitated the trial's progress.

The trial in WA identified reasons that practices did not want to participate in the opt-in trial. Those who were connected to cdmNet may not want to participate because they have limited or no knowledge of the My Health Record system, or did not have anyone in the practice who has the knowledge. Additionally, the education process was also perceived to be too labour intensive as there were competing priorities in the practices.

The trial period did not allow for those managing the trial to engage practices that were not digital health ready. It was suggested that with more lead time, more effort could be made to assist practices to be registered and connected with the My Health Record system. Efforts to set up the My Health Record system and link it with the cdmNet in participating practices were also viewed as time consuming.

The low level of engagement with the My Health Record system by healthcare providers and users was also noted to demotivate practices/healthcare providers to view/access documents from the My Health Record system via the cdmNet. Some healthcare providers also declined to participate in the trial due to the unfavourable legacy of the PCEHR and/or cdmNet.

Having the trial activities aligned to practice ICT investment and adopted as usual business practice was seen as a key enabler of success. For example, embedding the use of the My Health Record system into existing practice workflows during the trial period and aligning its use with revenue touch points for: GP Management Plan/ Team Care Arrangement (GPMP/TCA) creation and reviews. The external incentives such as ePIP and linking these internal business processes to the use of the My Health Record system was viewed to drive its increased use.

Working with allied healthcare providers and other medical specialists

The trial in WA also suggests that more training and education activities need to be delivered to healthcare providers to increase their awareness and understanding of the My Health Record system as awareness and understanding is the foundation for successfully persuading healthcare professionals to upload documents which in turn progressively makes the contents of the My Health Record more useful.

The trial demonstrated that, even when the My Health Record system is increasing its useful content, significant effort was still needed to alert other members of the chronic disease management team such as allied healthcare providers to the availability of the information about their patients. Views by allied healthcare providers and other medical specialists surged in the last weeks of the trial as a result of targeted communication (as preferred by fax, email or phone) to alert individual healthcare providers that specific patients had shared their My Health Record documents with them. This required intensive

work by the Precedence project team, but could be alleviated in future by customising automated cdmNet care team notifications sent to members of care teams.

From the trial in WA, there were lessons learned about the level of digital health readiness of allied healthcare providers and other medical specialists in the region. Many of these healthcare providers did not see the benefits of using the My Health Record system (which is linked with cdmNet) to their practice and patients.

The trial also demonstrated the importance of offering healthcare providers alternative ways to access the My Health Record system. As a cloud-based platform, cdmNet allowed allied healthcare providers and other medical specialists to connect the My Health Record system without having conformant software or having to undertake the registration process for the Provider Portal to access the My Health Record system. The alternative cdmNet access pathway appeared to have tripled the number of WA allied healthcare providers and other medical specialists who can now access the My Health Record information through the cdmNet.

cdmNet and alternative chronic disease management products

Several limitations to the trial's success were noted: minimum system requirements (for clinical software, bandwidth); some clinical software was incompatible with cdmNet; and the full functionality of the product was not utilised either because there was restricted functionality in the free 'trial product version' or a stepped approach to implementation was taken in newly licensed practices. The value of the cdmNet product to patients/healthcare providers was viewed to be greater when used to full care planning capacity.

There is also a need to test the security of any Contracted Service Providers as a requirement for them to link their product with the My Health Record system in order to ensure the integrity and security of the system.

Overarching lessons learned

The limited number of active practices who were using cdmNet within the last 12 months was noted to be an overarching barrier to the trial's success.

WAPHA believed that, based on the experience of the opt-in method in the trial, despite the achievements of the trial in Perth North and Perth South the opt-in method was neither scalable nor sustainable, and they believed that the opt-out method for driving participation and use would be more effective and cost effective.

Achievements of the trial in Western Australia

At the time of writing this case study, the following can be claimed as achievements of the opt-in trial in this location. Because the design of the evaluation did not include a comparison between relative effectiveness of the two opt-in trial sites and the results of the variables of interest were very similar across the two opt-in trial sites, the results of the surveys (individuals and healthcare providers), focus groups and interviews, and the analysis of the de-identified data from the National Infrastructure Operator (NIO) about upload, participation and use are reported together.

The findings of the evaluation should be read and understood within the context of the length of the trial and the timing of the measurement period for the evaluation as outlined earlier.

Individual exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system

A stratified representative sample of the general population in the WAPHA footprint participated in an online survey at baseline (in February 2016) and at follow up (in September 2016). People were asked to rate whether they had heard about the My Health Record and how, as well as their understanding, confidence, participation and use of the My Health Record system. In addition, 33 patients from participating practices in the trial participated in 10 focus groups across the footprint of the PHN during the follow up period.

The online survey of individuals in the opt-in trial sites found that participants were more likely to have heard about the My Health Record system during the trial period than people in the rest of Australia. There were no differences in any indicators of use or participation in the opt-in trial sites compared to the rest of Australia. There were no differences in any indicators of confidence to use the My Health Record system between the opt-in trial sites and the rest of Australia.

Qualitative responses to the survey included: the My Health Record system had allowed their treating team members to be 'on the same page' with them about their health; while they could not report any benefits from having a My Health Record at the time, they felt that the My Health Record provided an easy way for healthcare providers to access their health record and assist in clinical decision making. The main reasons provided by respondents without a My Health Record were that they were unaware or not sufficiently informed about the My Health Record system, or they believed that having a My Health Record was unnecessary.

The focus groups conducted allowed for both unprompted and prompted questioning of participants in relation to the same variables covered by the online survey. The focus group methodology also allowed for more in depth discussion with individuals and observation of discussions between individuals about these issues. Focus group participants in the opt-in areas noted that whilst they were approached for assisted registration, awareness and understanding of the My Health Record system, its usability and functionality remained low. The majority of opt-in trial site participants said that little or no information about the personally controlled aspects of the My Health Record was provided to them at the time of assisted registration. Once the nature and benefits of the My Health Record system were explained to focus group participants, there were no concerns expressed about: privacy; the capacity of the My Health Record system to maintain confidentiality; and the security of the My Health Record system to external threat.

Very few participants in the focus groups had accessed their My Health Record. This appeared to be for two reasons: lack of knowledge or understanding that they could access it themselves, and inconsistent automated follow up after completing assisted registration (not receiving a log in and further instructions). All those who had accessed the My Health Record after receiving assisted registration (or prompted by their invitation to the focus group) said that no information had been uploaded to their My Health Record by a healthcare provider. Most of those who said they had accessed the My Health Record said they had not added any information themselves. Most participants, however, were strongly supportive of the concept and suggested that the My Health Record system should be made compulsory for all healthcare providers.

Data from the My Health Record System Operator revealed there was an increase in registration across the opt-in trial sites and the rest of Australia. The opt-in trial sites had only a small proportional increase over the rest of Australia. Individuals, in general, were unlikely to restrict access to their My Health

Record either by restricting access to documents or healthcare providers, with less than one percent doing so. Very few actively changed their MBS or PBS item uploading restrictions and this led to a large volume of MBS attendances items being included in their My Health Record. These increases were proportionally higher in opt-in trial sites compared to the rest of Australia. Individuals also viewed documents in their My Health Record, with the key ones viewed and increased from baseline including; Consumer Entered Health Summary, Audit View, Diagnostic Imaging Report, Health Record Overview, Medicare Overview, Prescription Record View, and Prescription Dispensed View. The level of viewing of these documents between baseline and follow up increased more in the opt-in trial sites than in the rest of Australia, though these differences were low.

Healthcare provider exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system

A stratified representative sample of the healthcare providers in the footprint of WAPHA participated in an online survey at baseline (in February 2016) and at follow up (in September 2016). Healthcare providers were asked to rate whether they had heard about the My Health Record and how, their understanding, confidence to use, participation in and use of the My Health Record system. In addition, 33 GPs, practice managers, practice nurse and administrative staff in participating practices participated in interviews during the follow up period.

The online survey of healthcare providers in the opt-in trial sites found that participants in the opt-in trial areas were not statistically significantly more likely to have heard about the My Health Record system during the trial period than the rest of Australia. In the opt-in trial sites and the rest of Australia, there was an increase in the number of respondents who reported their workplace as being registered on the My Health Record system. At follow up, there were no significant differences between the opt-in trial sites and the rest of Australia with regard to healthcare provider beliefs about the following attributes of the My Health Record system: access to information about patient health; ability to apply best practice care; inform medication management choices; saves time sourcing patient information; spend less time communicating to other healthcare providers; enables patients to better manage healthcare; adds time to upload data. There was also no statistical difference in respondents' intention to use the My Health Record system over the next four months between the opt-in trial sites and the rest of Australia.

There were no differences in any indicators of confidence to use the My Health Record system between the opt-in trial sites and the rest of Australia. Across the opt-in trial sites and the rest of Australia, there was an increase in the proportion of respondents who had received training on the My Health Record system. The difference in the increased proportion of healthcare providers who had received training between the opt-in and the rest of Australia was not statistically significant. Indeed, the proportion of participants who had received training remained relatively low with the majority of training provided face to face across the two groups. There was no statistically significant difference observed in the reported effectiveness of the training received on the My Health Record between the opt-in trial sites and the rest of Australia. Over 80% of respondents who had received training considered the training to be at least slightly effective or better in the opt-in trial sites and in the rest of Australia.

The interviews with healthcare providers in the opt-in trial sites allowed for both unprompted and prompted questioning in relation to the same variables covered by the online survey. The interview methodology also allowed for more in-depth discussion with healthcare providers. The interviews with healthcare providers, general practitioners, practice managers and practice nurses in the opt-in trial sites demonstrated that those interviewed were aware of the My Health Record and understood its

purpose, with some having heard of it prior to the commencement of the trial. Nearly all had participated in the trial activities. Most interviewees reported that the trial activities had provided them with adequate knowledge to provide assisted registration to patients, although some thought that further training would have helped them answer more detailed questions raised by patients. Most people who were interviewed were confident that the My Health Record system could maintain the confidentiality of their patients and that the My Health Record system was secure from external threats, such as hackers. Many of those interviewed said anything online was vulnerable to external threats, but they believed that the benefits of having and using the My Health Record far outweighed the risk of any potential confidentiality and security risks.

Most interviewees stated they were using the My Health Record system in some capacity (either to upload or view documents). They had a positive view of the My Health Record system, and predicted that it would be of clinical benefit to healthcare providers and patients in the future as both healthcare provider and individual use increased. All interviewees believed their patients would not seek another provider if they did not use the My Health Record system. Asked whether the ePIP eligibility criteria changed their practices' use of the My Health Record system, most of those interviewed were unsure while some said it was a contributing factor.

Data from the My Health Record System Operator revealed that within the trial period, there were additional healthcare provider organisations registered in the opt-in trial sites and the rest of Australia. In particular, the opt-in trial sites had a proportional increase greater than the rest of Australia. There were significant increases in the number of Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Record documents uploaded to the My Health Record system between baseline and follow up in the opt-in trial sites. These increases were significantly greater in the opt-in trial sites compared to the rest of Australia. There was an increase in the number of My Health Records accessed that had no clinical documents in them, with healthcare providers in opt-in trial sites more likely to access My Health Records and upload the first clinical document than the rest of Australia. The level of accesses of documents also increased dramatically during the trial evaluation period for the opt-in trial sites with accesses increasing significantly more than the rest of Australia. There were a number of types of documents that significantly increased in viewing activity between baseline and follow up and increased significantly more in the opt-in trial sites compared to the rest of Australia, these included: Event Summary and Medicare overview. However, these differences were mainly due to the low level of baseline activity. Healthcare providers in the opt-in trial sites were less likely to view Shared Health Summaries than the rest of Australia.

Appendix 12 Western Victoria Primary Health Network (Ballarat Health Services) Opt-In Trial Site

The Western Victoria Primary Health Network – Ballarat Health Services Opt-In Trial (the Trial) was conducted to demonstrate an innovative approach to increase participation and use of the My Health Record system by:

- embedding assisted registration into the hospital admission process
- enabling automatic uploads of Discharge Summaries
- enabling use of the My Health Record system by healthcare providers within the hospital.

These activities were hoped to contribute to the following outcomes:

- Increased awareness and understanding of the My Health Record system amongst users
- Increased confidence to use the My Health Record system amongst users
- Increased participation in, and use of, the My Health Record system by users
- Increased understanding of the effectiveness of different approaches for driving participation and use of the My Health Record system.

In November 2015, the Western Victoria Primary Health Network (WVPHN) submitted a proposal to the Department of Health (the Department) detailing the approach that would be taken in the opt-in trial in the Ballarat region. When WVPHN was shortlisted as an opt-in trial site, the PHN and the Department worked closely together to prepare a final proposal. A brief was developed based on the final proposal of the opt-in trial in Ballarat Health Services (BHS) and was submitted for consideration by the Minister for Health, The Hon Susan Ley. Following the Ministers approval of the proposal on 3 April 2016, a contract between WVPHN and the Department was developed and signed on 28 April 2016. The planning phase for the trial in Ballarat Health Services began in May 2016, and the trial was launched in July 2016.

The WVPHN and BHS worked closely with the National Evaluator from May 2016 to implement the evaluation tools and templates, and assist with the recruitment of individuals to focus groups and healthcare providers for interviews during the follow up period. A final reflection workshop between BHS, WVPHN and the evaluation team drew together reflections and lessons learned across the total period covered by the trial evaluation (July to September 2016).

Non-program factors in the opt-in trial in Ballarat Health Services

The opt-in trial in BHS ran in the context of the following significant factors that were outside the control of WVPHN, BHS and the Department, and which could be argued to have an impact on the implementation and effect of trial activities.

- The transition from the National E-Health Transition Authority to the Australian Digital Health Agency occurred on 1 July 2016 which materially impacted the ability to approve policy and operational changes to support new approaches to assisted registration.
- A number of renovations and upgrades were occurring in the hospital during the trial period which had an impact on the appetite for change in healthcare providers and other staff in the hospital.
- A recent workforce survey in BHS found that hospital staff reported feeling overworked. Those managing the trial suggest that assisted registration in this context may be seen as adding to the workload.



- Separate to the trial, but in the same PHN footprint and at the same time, the WVPHN was conducting a ‘push’ to train and register general practices. This may have had an influence on the outcomes measured from the National Infrastructure Operator (NIO) data.

The demographic and geographic context of the opt-in trial site in WVPHN

Some key demographic and geographic characteristics of the four Local Government Areas (LGAs) closest to the BHS are presented below so that the reader of this case study can judge how relevant and generalisable the experience in this trial site is to their own setting. These figures are a subset of the broader population figures for the whole of WVPHN.

In 2011, 127,035 people were living across the four LGAs. All four LGAs are classified as regional⁵². Table 1 presents the population size and land area of each LGA.

Table1: Population size and land area of each LGA

	Ballarat	Central Goldfields	Hepburn	Pyrenees
Population size	93,504	12,495	14,366	6,670
Land area (km ²)	740	1,532	1,473	3,434

Age and gender distribution

The population in the trial site consists of 61,464 males (48.4%) and 65,571 females (51.6%). Table 2 presents the age and gender distribution across the four LGAs in WV PHN.

Table 2 Number of people in the trial site by age group and gender.

Age	Male				Female				Total
	Ballarat	Central Goldfield	Hepburn	Pyrenees	Ballarat	Central Goldfields	Hepburn	Pyrenees	
0-9	6,197	708	828	354	5,992	661	853	373	15,966
10-19	6,547	782	811	420	6,377	706	765	372	16,780
20-29	6,597	463	522	210	6,832	469	485	223	15,801
30-39	5,613	546	719	333	5,977	576	801	309	14,874
40-49	5,850	767	973	470	6,426	814	1,136	462	16,898
50-59	5,573	950	1,159	566	6,140	928	1,294	535	17,145
60-69	4,377	966	1,110	622	4,875	973	1,082	532	14,537
70-79	2,634	683	570	314	3,295	660	562	245	8,963
80-89	1,326	310	235	126	2,249	407	353	157	5,163
90-99	166	29	22	13	444	93	83	30	880
100 and over	3	0	0	0	14	4	3	4	28
Total	44,883	6,204	6,949	3,428	48,621	6,291	7,417	3,242	127,035

Aboriginal and Torres Strait Islander population

A total of 1,437 Aboriginal and Torres Strait Islander people reside in the trial site, mostly in Ballarat.

Non-English Speaking

Of the total population across the four LGAs, 0.5% people (n=626) could not speak English at all or not well in 2011. Additionally, 4% of the population across the four LGAs also speak another language at home apart from English (n=4,649). Most of them live in Ballarat (see Table 3).

⁵² Data sourced from <http://www.doctorconnect.gov.au/locator>



Internet connectivity

Table 3 shows the proportion of the population that have access to the internet at home. On average, 63% of the population across the four LGAs have access to the internet at home.

Table 3 Aboriginal and Torres Strait Islander peoples, people who do not speak English well or not at all, speak another language apart from English at home and proportion of the population that have internet connection, by LGA.

	Ballarat	Central Goldfields	Hepburn	Pyrenees
Indigenous populations (n)	1,139	144	91	63
Do not speak English at all or not well (n)	522	18	68	18
Speak another language apart from English at home (n)	3,699	217	607	126
Internet connectivity (% of the population)	71	57	69	62

How do the demographics of the WVPHN - Ballarat Health Services Opt-in trial compare with Victoria and Australia as a whole?

There were more Aboriginal and Torres Strait Islander peoples across the four LGAs (1.13%) compared to Victoria (0.7%), but fewer than in Australia (3%). Fewer people across the four LGAs spoke a language other than English at home in 2011 (4%) when compared to Victoria (23%) and Australia (18%). Fewer people reported difficulty speaking English across the four LGAs (3%) when compared to Victoria (4%) but a similar proportion when compared with the whole of Australia (3%). Fewer people across the four LGAs have internet connection (65%) than Victoria (74%) and Australia (74%).

My Health Record Activities in Opt-In Trial Site in Ballarat Health Services

Contracting and Design of the Trial

The initial proposal for the trial from WVPHN was received in November 2015. When WVPHN was shortlisted as an opt-in trial site, the PHN and the Department negotiated a refined proposal that best used available resources and would meet the goals of the trial within the trial period. The final proposal was agreed to by the Minister for Health, the Hon Susan Ley on 3 April 2016. A formal contract between the Department and WV PHN was signed on 28 April 2016. A total of \$344,300.00 (GST inclusive) was agreed between the Department and WVPHN to deliver opt-in trial in Ballarat Health Services.

The governance of the trial in Ballarat Health Services

The Health Information Committee (HIC) within BHS provided advice to and oversight of the implementation of the trial within the hospital. Representatives from WVPHN (i.e. the PHN Digital Health Manager) also provided oversight to the implementation of the trial in BHS. The roles and responsibilities of the representatives from the PHN in the trial are described in Table 4 below.

Staff roles in the trial in Ballarat Health Services

Table 4 below outlines the key roles and responsibilities in the trial at BHS. The personnel who were responsible for the trial in BHS were recruited in June 2016. The model of recruitment was a mix of an open recruitment process to market and internal secondments and backfilling of existing hospital staff.

Table 4. Roles and responsibilities of staff involved in the trial.

Role	Responsibilities
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Role	Responsibilities
BHS Project Manager	<ul style="list-style-type: none"> liaise between Vendors for BOSSnet and BHS liaise with Department Heads, Executive and CEO to advise the impact and benefits of the project ensure legislative requirements are adhered to manage patient consent for uploading of discharge summaries to the My Health Record maintain project communication across the project from a hospital perspective. develop training material and training programs for clinical and administrative staff involve in the design of the opt-in trial
BHS Project Officer (x2)	<ul style="list-style-type: none"> be the on the ground support for clinical and administrative staff who admit patients across the 24-hour period be responsible to collect the HPI-I of every clinician to author a discharge summary, this is a very large piece of work and may involve incorporating this into a HR process for sustainability post trial period. train staff in the use of assisted registration in BOSSnet train clinicians in the uploading of quality discharge summaries
WVPHN Digital Health Manager	<ul style="list-style-type: none"> oversee the trial activities in BHS direct liaison with the Department of Health to ensure communication channel remain open and transparent at every stage of the project.

What activities were implemented during the trial period to support the achievement of identified outcomes?

The activities implemented during the trial period were:

- develop the BHS My Health Record Policy and My Health Record Assisted Registration Policy
- provide assisted registration to patients upon admission to BHS through BOSSnet (a clinical portal used by the hospital) as part of their admission and pre-admission process in various areas/departments within the hospital.
- conduct stakeholder engagement/training with healthcare providers in the hospital (junior medical officers, interns, registrars, allied healthcare providers, nurses) and hospital staff providing assisted registration to patients.
- enable BOSSnet to automatically upload discharge summaries to the My Health Record.
- improve the process of linking healthcare providers' Healthcare Provider Identifier-Individual (HPI-I) to BHS' Healthcare Provider Identifier - Organisation (HPI-O).
- improve the matching process of an individual's Individual Healthcare Identifiers (IHI) in their My Health Record to their identification in BOSSnet to allow healthcare providers to upload documents to patient's My Health Record via BOSSnet.
- track the uploads of electronic discharge summaries to the My Health Record
- raise awareness of the My Health Record system to members of the public visiting the hospital/patients and healthcare providers in the hospital.

Develop the Ballarat Health Services My Health Record Policy

WVPHN and BHS developed a My Health Record Policy and My Health Record Assisted Registration Policy to ensure their clinical information system/clinical portal (BOSSnet) was compliant with the *My Health Record Act 2012*. The BHS My Health Record Policy came into effect on 26 July 2016.

Providing assisted registration to patients through BOSSnet

Following the trial going 'live' on 1 July 2016, training and testing of providing assisted registration to a selected patient group in the hospital was held in the beginning of the trial period (July 2016). Efforts were progressively made during the trial period to embed the assisted registration process (through BOSSnet) in various departments/units in the hospital. At the end of the trial evaluation period, assisted registration was being offered to patients at various points in the hospitals, including:

- Perioperative Day Unit, the primary admitting point for elective surgery
- Outpatients
- Maternity Outpatients
- Ballarat Regional Integrated Cancer Clinics
- Consulting Suites
- Chemotherapy Day Unit
- Dialysis Unit
- Medical Day Unit
- Community Rehabilitation,
- Community Health and Ambulatory Care Centre
- Emergency Department
- Preadmission Clinics
- Booking Office
- Ophthalmology Clinic
- Cardiology Clinic
- Fracture Clinic

Initially, assisted registration was provided in accordance with the existing known customer models. However, it became apparent that these models were not suitable for the hospital environment. Accordingly, a new known customer model was developed and made available for BHS which better reflected the hospital environment and enabled a streamlined approach to assisted registration in the hospital.

At the end of the trial evaluation period, efforts were also underway to finalise a combined Hospital Admission form/Assisted Registration form to reduce duplication and simplify the assisted registration process during patient admission. At the end of the trial evaluation, efforts to embed assisted registration into the admission processes at BHS were ongoing, with 1,200 combined hospital/assisted registration forms being circulated.

Assisted registration to minors was not offered in the hospital during the trial period as healthcare providers were concerned about how sensitive information about vulnerable children would be managed in the My Health Record system. Patients who were unable to provide informed consent were also not approached to offer assisted registration during the trial period.

At the end of the evaluation period, a total of 2,201 patients were approached for assisted registration. Of those approached, 913 accepted the offer while 314 already had a My Health Record. 602 patients refused the offer of assisted registration and information about the My Health Record system was left with 372 patients.



Improve the matching process of an individual's Individual Healthcare Identifiers (IHI) in their My Health Record to their identification in BOSSnet to allow clinicians to upload documents to patient's My Health Record via BOSSnet.

There were issues regarding the way BHS fill a patient's name in the registration form at the beginning of the trial period, where two names were captured in the same field on the registration form. This resulted in low success in matching a patient's IHI number in the My Health Record system to BOSSnet. Consequently, BHS (in collaboration with Core Medical Services⁵³) removed anything after the patient's first given name to improve the matching process.

Education and training

Education and training activities were delivered to staff in BHS (e.g. nurses, junior medical officers, registrars, consultants, ward clerks, admission clerks, allied healthcare providers, emergency staff and departmental heads/managers) during the trial period. Most training activities were delivered in existing clinical meetings, clinical education sessions, and/or administrative meetings.

From July to October 2016, a total of 30 training sessions were delivered to 255 clinicians and hospital administrative staff. Of the 30 training sessions, four delivered training about assisted registration to hospital admission staff while the rest focused on educating healthcare providers about the My Health Record system and its use.

Modification of BOSSnet to allow Discharge Summaries to be uploaded automatically to the My Health Record system

Efforts were made by BHS (in collaboration with Core Medical Solutions) to ensure their Discharge Summary templates were compliant with the clinical documentation architecture (CDA) in the hospital, which in turn would enable the templates to be uploaded to the My Health Record system. At the end of the trial evaluation period, most types of Discharge Summaries produced by the hospital were able to be uploaded to the My Health Record system through BOSSnet. Discharge Summaries for paediatrics and stroke patients were not able to be uploaded to My Health Record system during the trial period.

At the beginning of the trial, BHS changed the default permission in BOSSnet to enable automatic uploads of Discharge Summaries to the My Health Record system. Changes to the functionality of BOSSnet also enabled hospital staff to view documents in the My Health Record system via BOSSnet.

A channel was established with the parties at the national level to address any usability issues identified by BHS during the trial period.

Improve the process of linking healthcare providers' Healthcare Provider Identifier-Individual (HPI-I) to BHS' Healthcare Provider Identifier - Organisation (HPI-O)

BHS felt that its approach to registering healthcare providers with the My Health Record system was unsustainable. It had involved a manual search for their healthcare providers' (particularly junior medical officers) Australian Health Practitioner Regulation Agency (APHRA) number to identify their HPI-Is so the trial team could link it to BHS's HPI-O. As each department in BHS separately had details of healthcare providers within their team/department, the My Health Record Project Team in BHS felt that providing this information on a central platform would facilitate their work in matching HPI-Is to the hospital's HPI-O.

⁵³ The developer of BOSSnet

Track the uploads of electronic discharge summaries to the My Health Record

BHS monitored the quality of data that was uploaded to the My Health Record system throughout the trial period. Where errors were found in a Discharge Summary, healthcare providers were notified to resolve the error and re-upload the revised summary to the patient's My Health Record. Staff in the Emergency Department were also asked to include patients' date of discharge in their Discharge Summary uploaded to the My Health Record system via BOSSnet.

At the end of the evaluation period, a total of 537 Discharge Summaries had been uploaded to the My Health Record system via BOSSnet.

Communication about the My Health Record system to healthcare providers and patients

A Quick Guide about using the My Health Record via BOSSnet was developed and distributed to staff in the hospital in July 2016. Messages and information about the My Health Record system were also published on BHS's website and intranet in the beginning of the trial period.

BHS distributed My Health Record information packs for patients to various departments/units in the hospital. A total of 1,952 information packs were distributed to patients during the trial period. My Health Record posters were displayed in elevators and a banner was displayed in front of the hospital entrance. A TV slide about the My Health Record was presented in the Ballarat Regional Integrated Cancer Centre. In collaboration with WVPHN Communication Team, BHS produced two articles for media release in local newspaper/magazines. Social media was also utilised to reach individuals/patients during the trial period. The My Health Record Project Team in WVPHN also developed an informational tool to support patients to access their myGov account.

From July to October 2016, a total of 51 engagement activities were conducted with clinicians, hospital administration staff and patients in the hospital, with 92 people engaged overall.⁵⁴ The number of engagement activities conducted in the hospital increased as the trial progressed.

Lessons learned from the opt-in trial in Ballarat Health Services

Timing and duration of the trial

All stakeholders involved in the trial believed the time period for the trial and the evaluation were too short to observe and document the full impact of efforts to change individuals and healthcare providers' use of the My Health Record. Opt-in trials commenced later than opt-out trials and consequently had a shorter trial period. They believed that more preparatory time would assist in determining where and how assisted registration could be provided for patients in the hospital context and that more training could be provided to equip hospital administrative staff with information about the My Health Record and how to provide assisted registration to patients.

Trial management and design

The BHS My Health Record Project Team members were predominantly internal secondments, and the team was able to build on existing good relationships with healthcare providers and other staff within the hospital. They also believed that this facilitated the rollout of the opt-in trial in BHS within the very short timeframe available.

The need to have print and other education and information resources available in a sufficient quantity, in a timely way, prior to the beginning of trials was also noted as a lesson learned. The need to have readily available high levels of content knowledge and expertise in relation to the My

⁵⁴ Note that the total number of people engaged reported here is likely to underestimate the true total number of people engaged during the trial period.



Health Record from people who also have a deep understanding of the hospital context was noted as being a success factor.

The trial in BHS also demonstrates how a balanced top-down from the national level and bottom up from the trial site level in the direction, design and implementation of trial activities is important to achieving the intended outcomes within a short timeframe. Stakeholders felt that strong collaboration with the National Trials Team was a strength of the trial. A feedback mechanism could also be established for hospital staff/local healthcare partners to provide suggestions to improve the content or usability of the My Health Record system.

Providing assisted registration to patients

Overall, efforts to provide assisted registration to patients during the trial period were a resource intensive process. Offering assisted registration was time consuming because of the low levels of awareness about the My Health Record in hospital patients. Consequently, patients were educated and informed about the My Health Record system by the My Health Record Project Team at BHS prior to offering assisted registration. This approach proved to be more challenging when the assisted registration process was embedded in the admission process in different parts of the hospital. Therefore, future efforts should focus on conducting promotional activities to increase awareness prior to offering assisted registration. This approach would also assist patients to make an informed decision about having a My Health Record when being approach for assisted registration.

Future efforts should also be more selective when choosing the locations to provide assisted registration. The trial in BHS demonstrates that offering assisted registration in busy and noisy clinics and to patients who were too unwell or anxious about their treatment was not effective.

In the future, the approach to providing assisted registration should be streamlined, particularly when assisted registration is provided at different entry points to the hospital to avoid offering patients assisted registration on multiple occasions. There were instances during this trial where offering assisted registration in the many entry points to the hospital led to patients being offered assisted registration multiple times on the same day.

The experience of trialling assisted registration in this hospital context suggested that the most effective method was to embed the assisted registration form into existing admission form and processes within the hospital.

Communication materials

There were lessons learned about the communication materials provided from the national level. Sufficient communication materials/resources need to be provided to local delivery partners. In particular, sufficient communication materials that target culturally and linguistically diverse populations need to be provided. Messages about the My Health Record system should also be disseminated continuously to get traction and buy-in from patients and staff in the hospital to use the system.

Consistent branding, messaging, templates and materials should be developed and provided at the national level to the local delivery partners. Materials and templates provided at the national level should be designed to allow them to be altered and localised to the specific region and target community segments. Support and expert advice about how to best promote the My Health Record system in the hospital should be sought in the future.



Working with individuals

The experience in this trial site reinforces the need to make the registration process for a myGov account easier for people. The required information to set up a myGov account and link the My Health Record to it was observed to greatly lessen the likelihood that individuals would subsequently be able to use their My Health Record.

Lack of computer access was also observed to be a barrier for patients to complete their engagement with the My Health Record system after assisted registration.

Training with healthcare providers / hospital administration staff

Future approaches to engage healthcare providers or hospital admission staff involved in providing assisted registration in the hospital should also consider the timing of delivering training and education activities. Lessons learned from the trial activities in BHS suggest that training and education activities with healthcare providers need to occur as early as possible.

The very time constrained nature of this opt-in trial clearly demonstrates there is a need for greater lead time to allow for the necessary education and training activities to support hospital administration staff involved in assisted registration. In particular, with more lead time different approaches to training all staff in the hospital could be planned in advance to fit into the schedules of clinical meetings, clinical education sessions, and/or administrative meetings within the hospital. It was also noted that in a hospital context, where many staff are shift workers, visiting medical officers, trainees on rotation, here is a need for the promotion of the My Health Record and education and training of its use to be continuous rather than one off.

Overarching lessons

Based on their experience of the opt-in trial activities at BHS, stakeholders believed the opt-in approach was not sustainable without ongoing funding from the Department.

Achievements of the trial in Ballarat Health Services

At the time of writing this case study, the following can be claimed as achievements of the opt-in trial in this location. Because the design of the evaluation did not include a comparison between relative effectiveness of the two opt-in trial sites and the results of the variables of interest were very similar across the two opt-in trial sites, the results of the surveys (individuals and healthcare providers), focus groups and interviews, and the analysis of the de-identified data from the National Infrastructure Operator about upload, participation and use are reported together.

The findings of the evaluation should be read and understood within the context of the length of the trial and the timing of the measurement period for the evaluation as outlined earlier.

Demonstration of embedded assisted registration in hospital admission process

The opt-in trial in BHS, while short, demonstrated the potential to embed assisted registration into the admission process of a hospital. The opt-in trial demonstrated however that changes to the assisted registration governance mechanisms are necessary to further refine this process.

Demonstration of automatic uploads to My Health Record.

The trial demonstrated the feasibility of enabling automatic uploads to My Health Record, and the low administrative burden this functionality imposes.



Individual exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system

A stratified representative sample of the general population in WVPHN footprint participated in an online survey at baseline (February 2016) and at follow up (September 2016). People were asked to indicate whether they had heard about the My Health Record and how, and rate their understanding, confidence, participation and use of the My Health Record system. In addition, 101 patients from BHS participated in eight focus groups across the footprint of the PHN during the follow up period.

The online survey of individuals in the opt-in trial sites found that participants were more likely to have heard about the My Health Record system during the trial period than people in the rest of Australia. There were no differences in any indicators of use, participation or confidence to use the My Health Record system between the opt-in trial sites and the rest of Australia.

Qualitative responses to the survey included: the My Health Record system had allowed their treating team members to be 'on the same page' with them about their health; while they could not report any benefits from having a My Health Record at the time, they felt that the My Health Record provided an easy way for healthcare providers to access their health record and assist in clinical decision making. The main reasons provided by respondents without a My Health Record were that they were unaware or not sufficiently informed about the My Health Record system, or they believed that having a My Health Record was unnecessary.

The focus groups conducted allowed for both unprompted and prompted questioning of participants in relation to the same variables covered by the online survey. The focus group methodology also allowed for more in depth discussion with individuals and observation of discussions between individuals about these issues. Focus group participants in the opt-in areas noted that whilst they were approached for assisted registration, awareness and understanding of the My Health Record system, its usability and functionality remained vague and low. The majority of opt-in trial site participants said that little or no information about the personally controlled aspects of the My Health Record was provided to them at the time of assisted registration. Once the nature and benefits of the My Health Record system were explained to focus group participants, there were no concerns expressed about: privacy; the capacity of the My Health Record system to maintain confidentiality; and the security of the My Health Record system to external threat.

Very few participants in the focus groups had accessed their My Health Record. This appeared to be for two reasons: lack of knowledge or understanding that they could access it themselves, and inconsistent automated follow up after completing assisted registration (not receiving a log in and further instructions). All those who had accessed the My Health Record after receiving assisted registration (or prompted by their invitation to the focus group) said that no information had been uploaded to their My Health Record by a healthcare provider. Most of those who said they had accessed the My Health Record said they had not added any information themselves. Most participants, however, were strongly supportive of the concept and suggested that the My Health Record system should be made compulsory for all healthcare providers.

Data from the My Health Record System Operator revealed there was an increase in registration across the opt-in trial sites and the rest of Australia. The opt-in trial sites had only a small proportional increase over the rest of Australia. Individuals, in general, were unlikely to restrict access to their My Health Record either by restricting access to documents or healthcare providers, with less than one percent doing so. Very few actively changed their MBS or PBS item uploading restrictions and this led to a large volume of MBS attendance items being included in their My



Health Record. These increases were proportionally higher in opt-in trial sites compared to the rest of Australia. Individuals also viewed documents in their My Health Record, with the key ones viewed and increased from baseline including; Consumer Entered Health Summary, Audit View, Diagnostic Imaging Report, Health Record Overview, Medicare Overview, Prescription Record View, and Prescription Dispensed View. The level of viewing of these documents between baseline and follow up increased more in the opt-in trial sites than in the rest of Australia though these differences were low.

Healthcare provider exposure to awareness raising information, understanding, confidence, participation and use of the My Health Record system

A stratified representative sample of the healthcare providers in the footprint of WVPHN participated in an online survey at baseline (February 2016) and at follow up (September 2016). Healthcare providers were asked to indicate whether they had heard about the My Health Record and how, and rate their awareness, understanding, confidence to use, participation in and use of the My Health Record system. In addition, 16 staff in BHS (7 hospital administration staff and 9 healthcare providers) during the follow up period participated in interviews.

The online survey of healthcare providers in the opt-in trial sites found that participants were not statistically significantly more likely to have heard about the My Health Record system during the trial period than the rest of Australia. In the opt-in trial sites and the rest of Australia, there was an increase in the number of respondents who reported their workplace as being registered on the My Health Record system. At follow up, there were no significant differences between the opt-in trial sites and the rest of Australia with regard to healthcare provider beliefs about the following attributes of the My Health Record system: access to information about patient health; ability to apply best practice care; inform medication management choices; saves time sourcing patient information; spend less time communicating to other healthcare providers; enables patients to better manage healthcare; adds time to upload data. There was also no statistical difference in respondents' intention to use the My Health Record system over the next four months between the opt-in trial sites and the rest of Australia.

There were no differences in any indicators of confidence to use the My Health Record system between the opt-in trial sites and the rest of Australia. Across the opt-in trial sites and the rest of Australia, there was an increase in the proportion of respondents who had received training on the My Health Record System. The difference in the increased proportion of healthcare providers who had received training between the opt-in and the rest of Australia was not statistically significant. Indeed, the proportion of participants who had received training remained relatively low with the majority of training provided face to face across the opt-in trial sites and the rest of Australia. There was no statistically significant difference observed in the reported effectiveness of the training received on the My Health Record between the opt-in trial sites and the rest of Australia. Over 80% of respondents who had received training considered the training to be at least slightly effective or better in both the opt-in trial sites and in the rest of Australia.

The interviews with healthcare providers in the opt-in trial sites allowed for both unprompted and prompted questioning in relation to the same variables covered by the online survey. The interview methodology also allowed for more in-depth discussion with healthcare providers. The interviews with healthcare providers (and administration staff) in the opt-in trial sites demonstrated that those interviewed were aware of the My Health Record and understood its purpose, with some having heard of it prior to the commencement of the trial. Nearly all had participated in the trial activities. Most interviewees reported that the trial activities had provided them with adequate knowledge to provide assisted registration to patients, although some thought that further training would have



helped them answer more detailed questions raised by patients. Most people who were interviewed were confident that the My Health Record system could maintain the confidentiality of their patients and that the system was secure from external threats, such as hackers. Many of those interviewed said anything online was vulnerable to external threats, but they believed that the benefits of having and using the My Health Record far outweighed the risk of any potential confidentiality and security risks.

Most interviewees stated they were using the My Health Record system in some capacity (either to upload or view documents). They had a positive view of the My Health Record system, and predicted that it would be of clinical benefit to healthcare providers and patients in the future as both healthcare provider and individual use increased. All interviewees believed their patients would not seek another healthcare provider if they did not use the My Health Record system.

Data from the My Health Record System Operator revealed that within the trial period, there were additional healthcare provider organisations registered in the opt-in trial sites and the rest of Australia. In particular, the opt-in trial sites had a proportional increase greater than the rest of Australia. There were significant increases in the number of Shared Health Summary, Discharge Summary, Event Summary, Dispense Record and Prescription Record documents uploaded to the My Health Record system between baseline and follow up in the opt-in trial sites. These increases were significantly greater in the opt-in trial sites compared to the rest of Australia. There was an increase in the number of My Health Records accessed that had no clinical documents in them, with healthcare providers in opt-in trial sites more likely to access My Health Records and upload the first clinical document than the rest of Australia. The level of accesses of documents also increased dramatically during the trial evaluation period for the opt-in trial sites with accesses increasing significantly more than the rest of Australia. There were a number of types of documents that significantly increased in viewing activity between baseline and follow up and increased significantly more in the opt-in trial sites compared to the rest of Australia, these included: Event Summary and Medicare overview. However, these differences were mainly due to the low level of baseline activity. Healthcare providers in the opt-in trial sites were less likely to view Shared Health Summaries than those in the rest of Australia.



Appendix 13 Analysis of media monitoring and sentiment from the Baseline to Final Report

Methodology:

There are two purposes for including an assessment of media coverage over the life of the trials from an evaluation point of view. One is to assess the effectiveness of the communication efforts at national and PHN levels about the My Health Record and the trials. The second is to help the evaluation to monitor any non-program factors that may affect the success or otherwise of the trials. For example, significant negative press may increase the level of opt-out or decrease opt-in.

A number of different methods were used to capture and record media coverage relating to the My Health Record, the trial rollout and general media coverage of topics and issues related to implementation of the My Health Record at national, State, and regional/local levels.

The timeframe of follow up data collection period from baseline was 8 March 2016 to 30 September 2016. The data sourced included:

- A retrospective Google News⁵⁵ search
- A prospective Google Alerts⁵⁶ using the search terms:
 - “My Health Record”
 - “Personally Controlled Electronic Health Record”
 - “PCEHR”
 - “Nepean Blue Mountains”
 - “Nepean Blue Mountains PHN”
 - “Nepean Blue Mountains Primary Health Network”
 - “North Queensland PHN”
 - “North Queensland Primary Health Network”
 - “Northern Queensland PHN”
 - “Northern Queensland Primary Health Network”
- Articles from PulseIT
- Daily user monitoring of major metropolitan and regional print websites
- The Department’s collated media monitoring database (iSentia, Lexer, Google alerts and PHNs).

Overview

Noting the impact of the caretaker period from May to July 2016, where no significant new communication work could be conducted by the Department, it appears that, except for media coverage generated by the launch of the My Health Record in March, there was no significant difference in the amount of coverage or sentiment expressed in media coverage at a national or local level.

Content analysis report of media monitoring from March 2016 to September 2016

The date ranges of articles collected, collated and analysed are presented in Table 1 and Figure 1.

⁵⁵ <https://news.google.com.au/>

⁵⁶ <https://www.google.com.au/alerts>

Table 1. Date range of articles collected

Months monitored	Number of articles	Proportion (%)
March (2016)	25	19%
April (2016)	32	24%
May (2016)	18	14%
June (2016)	21	16%
July (2016)	14	11%
August (2016)	21	16%
September (2016)	2	2%
Total	138	100

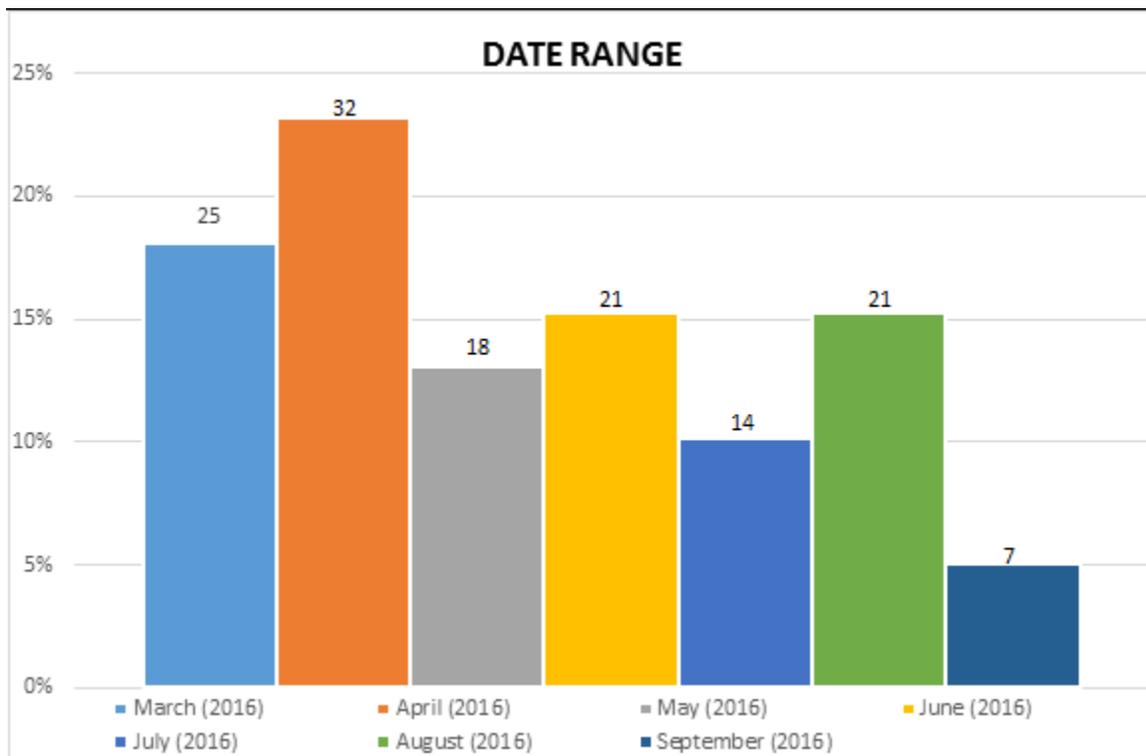


Figure 1: Date Range of articles collected.

A total of 138 media articles were collected between 8 March 2016 and 30 September 2016. Overall, media coverage regarding the My Health Record was most prominent in the months of March and April, following the announcement of the opt-out trials. This reduced slightly in May and June, which could potentially be attributed to the large amount of election media coverage taking precedence during this period. After a decrease in July, media coverage increased again in August, much of coverage across this period was about the appointment of the new CEO for the Australian Digital Health Agency, as well as the My Health Record system reaching an important milestone in which registrations exceeded 4 million. A number of articles in September reported issues surrounding ePIP and calls from general practitioners stating that up to 1,500 practices would lose out on ePIP payments due to system issues. The Government responded to these calls by granting a six-month extension to the deadline for ePIP registered general practices to upload Shared Health Summaries to the My Health Record system.

Media Sources

Different types of media sources were collated during the period from 8 March to 30 September 2016. These sources were defined in the Baseline Report. Table 2 and Figure 2 set out the type and number of media sources analysed in full (n=138).

Table 2. Number of Media source type.

Media source type	Number of sources	Proportion (%)
Online News Source	63	46%
Department/Organisation Media Release	5	3%
Print - Newspaper/Magazine/Journal	62	45%
Opinion/ Editorial	8	6%
Total	138	100

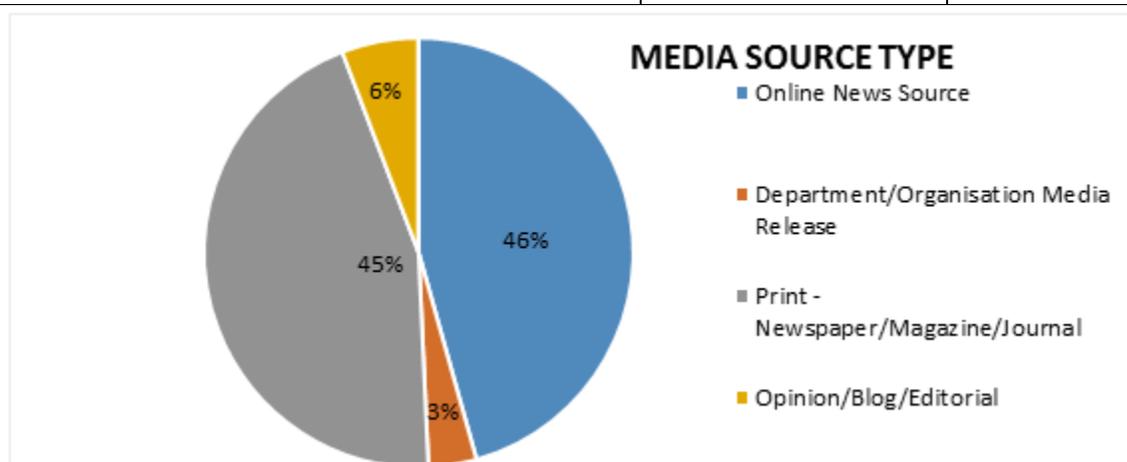


Figure 2: Media Source Type.

Much media coverage between March and September 2016 was in online news sources, but there was a significant increase in the number of print sources published during this period.

Broadcast Media

The content of the broadcast, radio and television coverage of the My Health Record and/or the trials cannot be accessed by the evaluation, under the current licensing arrangements between *Isentia's* Media Portal and the Department, therefore a sentiment analysis of these broadcast reports has not been undertaken. Topics discussed by broadcasters included: Government announcements, such as the launch of the trials; and subsequent announcements relating to access to My Health Records by healthcare providers and individuals, which were reported nationally and locally. The total number of broadcast media items generated during the March to September 2016 reporting period was 164. Table 3 and Figure 3 set out the broadcast media type (television, AM or FM radio).

Table 3. Broadcast Media Source Type.

Broadcast media source type	Number of sources	Proportion (%)
AM Radio	40	12%
FM Radio	31	9%
Television	93	28%

Broadcast media source type	Number of sources	Proportion (%)
Total	164	100%

BROADCAST MEDIA TYPE

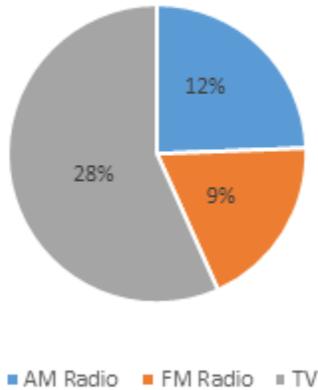


Figure 3: Broadcast Media Source Type.

Location

A shift in the regions covered by media sources was observed during the March 2016 to September 2016 period (see Table 4 and Figure 4). The Baseline Report said that about 81% (n=84) of the media sources had a national reach. This decreased to about 58% (n=80) between March and September 2016. About 35% of published articles had a local readership or target audience, far greater than the baseline period of October 2015 to March 2016 (baseline n=17 vs. final observation n=48).

During this period, residents involved in the opt-out trials were receiving mail about the My Health Record, and most of the media sources with a local reach therefore centred on informing residents about the My Health Record and the trials.

Table 4. Regions covered by media source.

Regions covered by media source	Number of articles	Proportion (%)
National	80	58
State	10	7
Local/Regional	48	35
Total	138	100

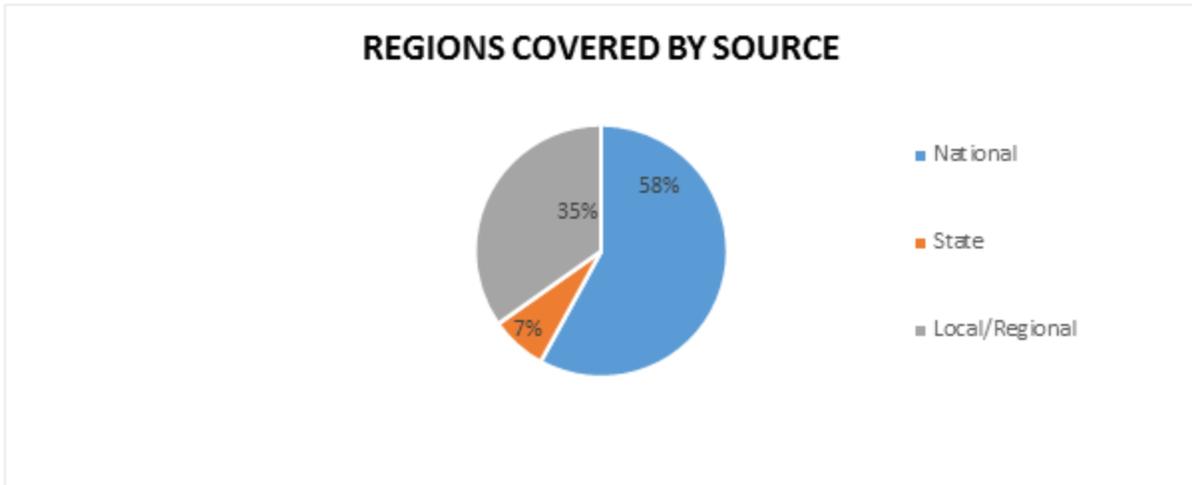


Figure 4: Regions covered by media.

Authorship

Patterns of authorship are of interest for media monitoring efforts for three reasons. First, when one reporter or only a small handful of reporters dominates coverage, any bias can be apparent. Secondly, if an area such as technology has specialised journalists reporting on it, these journalists can be usefully targeted to correct errors in either the public or professional mind, and used as effective credible sources for properly positioning the My Health Record system. Thirdly, monitoring can track whether the interest in the My Health Record system of this core group broadens over time into the mainstream, with higher profile coverage by senior journalists and publications.

Consistent with the Baseline Report, the primary source covering My Health Record topics and issues in Australia was Pulse+IT. Kate McDonald wrote 32 articles between March and September 2016, slightly fewer than in the Baseline Report (n=34). 17 of her articles were neutral in sentiment, similar to that at baseline, with the same writer authoring 15 neutral sentiment articles. Kate McDonald authored eight articles that were negative during the follow up data collection period and at baseline, these articles commonly reported the views of healthcare providers (medical practitioners) who did not support the implementation of the My Health Record system. Kate McDonald authored 11 positive articles during the baseline period compared to seven during the follow up.

A much larger number of articles with unknown authors was noted during this period (n=43) compared to the Baseline Report. Most of these unreferenced articles were short announcements about the My Health Record participation trial, particularly in the local trial areas of Northern Queensland and the New South Wales region of Nepean Blue Mountains.

Other authors included Sue Dunlevy of news.com.au/cairnspost.com.au with a total of 14 articles, all with a negative sentiment. Her articles focused on privacy and My Health Record system issues, and articles that highlighted the risk that doctors would lose money owing to the new ePIP requirements. Ilsa Cunningham of the Blue Mountains and Penrith Gazettes wrote three articles. Table 5 and Figure 5 below presents the most common authors cited, and the number of articles that they published between March 2016 and September 2016.

Table 5. Most common authors cited.

Author	Source title	Number articles published
Authors with only one article captured in baseline media monitoring activities	Multiple sources	34
Kate McDonald	Pulse+IT	32
Unknown/Uncited	Multiple sources	43
Sue Dunlevy	news.com.au/cairnspost.com.au	14
Ilsa Cunningham	Blue Mountains Gazette/Penrith Gazette	3
Josh Taylor	Crikey.com.au	2
Justine Doherty	Hawkesbury Gazette	2
Adrian Rollins	Australian Medical Association	2
Andrew White	The Australian	2
Asha McLean	ZD Net	2
Department of Health	Media Release	2
Total		138

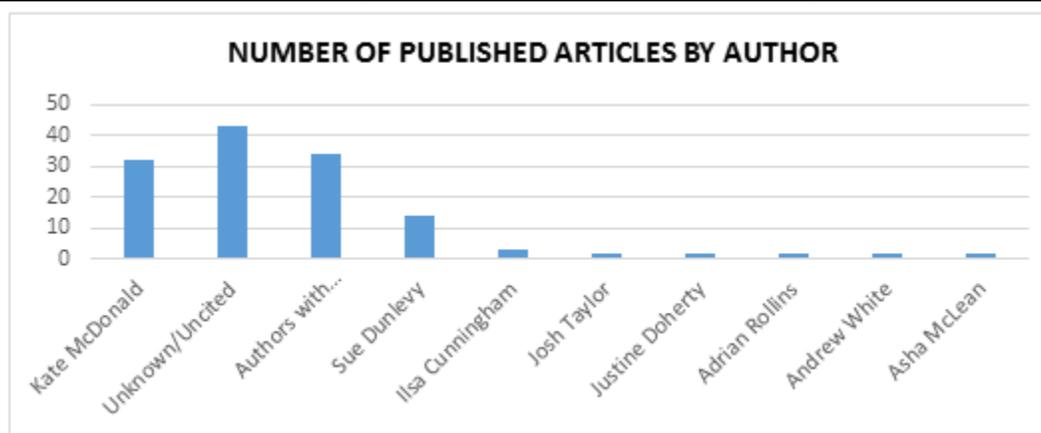


Figure 5: Most common authors cited.

Content Thematic and Sentiment Analysis

During the follow up data collection period, there were seven aspects of the My Health Record system on which the media often focused. Table 6 and Figure 6 present the distribution of media articles between March and September 2016 about these topics.

Table 6. Number of common topics or issues raised in media content.

Categories	Number of articles	Proportion (%)
Government policy and approach, announcement or issue	85	62
Privacy	9	7
Healthcare provider views, issues and concerns	12	9

Categories	Number of articles	Proportion (%)
System Issues (My Health Record)	13	9
ePIP	15	11
Technology development	2	1
Election / Opinion	2	1
TOTAL	138	100

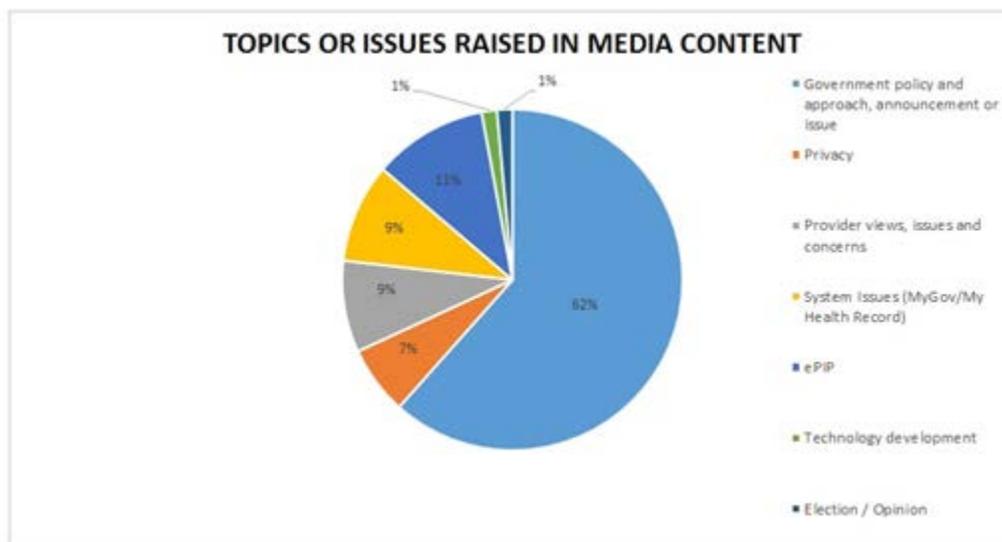


Figure 6: Common topics or issues raised in media content.

The content/messaging analysed was also coded as positive, neutral or negative sentiment. Those which did not present either a positive or negative view or reported balanced views were coded as neutral. Table 7 and Figure 7 below show the number and distribution of positive, neutral and negative reports collected during the media monitoring activities undertaken between March and September 2016.

Our analysis shows that the sentiment of media coverage between March and September 2016 remained relatively consistent in comparison with the Baseline Report, with only slightly more negative articles published (negative: baseline n=35 vs. final observations n=39;). Analysis of articles coded as neutral increased by 44% (baseline n=41 vs. September observations n=59). The increase in neutral articles can be attributed to an increase in published material in the months of March and April following the announcement of the opt-out trials.

Table 7. Media sentiment.

Sentiment	Number of articles	Proportion (%)
Positive	38	27
Negative	41	30
Neutral	59	43
Total	138	100

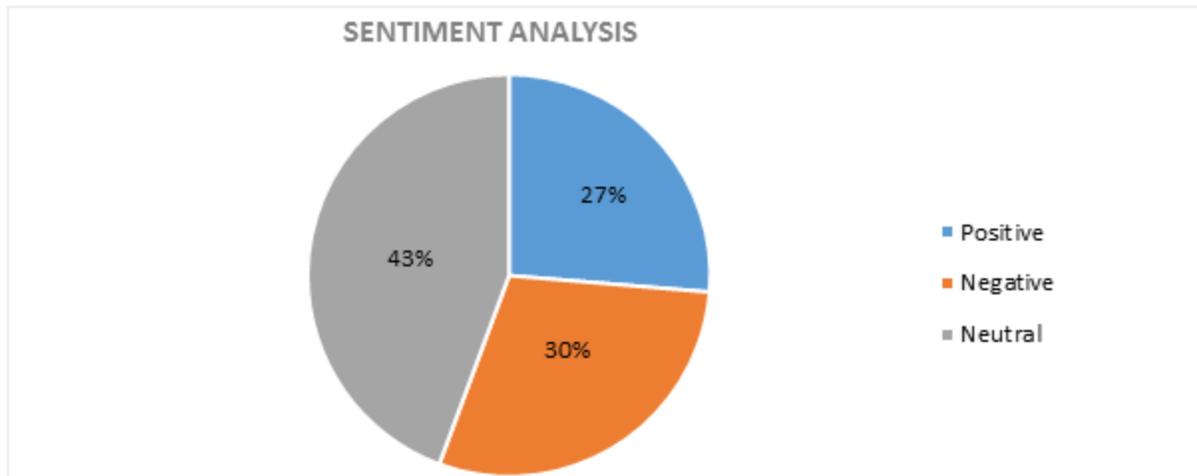


Figure7: Media Sentiment.

Further analysis was conducted to identify and report on the common topics or issues raised in the media content, as well as analysis of the reported sentiment towards these topics and issues. Since the Baseline Report, our analyses revealed a shift in the topics of focus by the media, which is presented by common topic groupings below.

Government policy and approach, announcements or issue

Of the 138 pieces of media collected, collated and analysed between March and September 2016, the most common categories concerned: Government policy and approach to the trials; announcements; or issues within Government. This was consistent with the Baseline Report, although the proportion of articles containing relevant information greatly increased. From March to September 2016, about two thirds of the articles concerned Government policy. Many of these had a national reach (n=44, 52%) as they were published online. National articles published in August focused mostly on the appointment of the new CEO for the Australian Digital Health Agency and his responsibility for the My Health Record system, as well as highlighting that registrations had reached 4 million.

A proportion of articles were also aimed at a local or regional audience (n=39), providing information to residents about their involvement in the opt-out trials. In total, all but two of these articles attracted either a neutral (n=52) or positive stance (n=31).

Privacy

During the March to September 2016 period, nine articles discussed privacy at the Government, healthcare provider, and individual level. All these nine articles conveyed a distinctly negative sentiment. On 26 March 2016, four articles published in state and local/regional newspapers detailed the perceived potential risk that having a My Health Record poses on individuals who wish to keep their health information private. All these articles focused on the fact that individuals would be unable to opt out of the My Health Record system until 4 April 2016, after which time a My Health Record would have already been created for them. They raised the possibility that information contained in an individual's My Health Record might be disclosed to lawyers, insurance companies and law enforcement bodies.

Four of the nine articles were syndicated articles by Sue Dunlevy, five of them in March 2016. Three articles quoted the Australian Privacy Foundation's Health Committee Chair, Dr Bernard Robertson-

Dunn, who expressed negative comments about the My Health Record, including that the My Health Record puts patient data at risk.

Healthcare provider views, issues and concerns

Articles that discussed healthcare provider views, issues and concerns in March to September 2016 (n=12) increased compared to the Baseline Report (n=7). Four articles were positive in sentiment, two were neutral, and six were negative.

Two of the six negative articles were interviews conducted by Pulse+IT with the presidential candidates for the Royal Australian College of General Practitioners (RACGP). Both candidates were highly supportive of eHealth/digital health technologies. One candidate expressed the view that the My Health Record was a waste of time and budget with little benefit for patients, whilst the other was against an opt-out system. Two of the negative articles reported on the survey results of 400 healthcare providers conducted in May and June 2016 by practice management software vendor MedicalDirector. Although 83% of the practices they surveyed agreed that electronically accessing or sending patient medical records would be beneficial to them, only 18% said the My Health Record appealed to them. The two remaining negative articles related to the Australian Medical Association's (AMA) stance that doctors would not be able to rely on the My Health Record due to it being patient-controlled, as well as a detailed description of clinicians' concerns related to several facets of the My Health Record.

However, four articles based on the views of healthcare providers reported positive views of the My Health Record and its implementation. In particular, a survey conducted by Pulse+IT of 362 readers found that 56% thought it likely that the My Health Record would succeed under the Australian Digital Health Agency. Although this sample group consisted of readers in general, the Pulse+IT website is largely aimed at healthcare providers.

System Issues (My Health Record)

An increase in system issues in the My Health Record system was noted, from two articles at Baseline to 13 between March and September 2016. One of the articles was neutral in sentiment, while the rest were negative. 10 of the 13 articles were released in April, and commented specifically on incidents where individuals had received letters informing them that My Health Records had been created for deceased relatives. One of the articles related to a security update that prevented documents from being uploaded to the My Health Record system, although it highlighted that no complaints had yet been received. An opinion piece from the website "Crikey" reported an issue where, for individuals to opt out of the My Health Record system, they were required to provide personal information to the Department of Health using an unencrypted website. However, it also noted that the Department had rectified this problem overnight.

In addition, there was an extremely negative article on *news.com.au*, a national web-based news site, about the appointment of Tim Kelsey as the new CEO of the Australian Digital Health Agency. This article focused on "downfalls" of the My Health Record system, including issues with the opt-out trial implementation.

ePIP

Media coverage relating to ePIP or changes to ePIP decreased marginally from March to September 2016 compared with the Baseline Report (n=15 vs. n=17 respectively). Apart from one article (with information about updates to practice management software to help practices calculate whether they

were reaching their ePIP targets, all the articles about the ePIP were negative. These articles stated that the new ePIP policy was putting GPs at risk of losing “tens of thousands of dollars a year”. Four articles released by the same author within 24 hours said GPs might have to recover this lost revenue by introducing patient fees. Three articles detailed the views of the AMA president where he urged the Department of Health to postpone implementing the My Health Record system, and to change the ePIP. His opinion was that GPs should not be penalised for not uploading enough Shared Health Summaries when, in his view, the My Health Record system was not yet fit for purpose.

In mid-September 2016, several online news sources, such as Pulse+IT and Australian Doctor, published negative stories reporting issues with ePIP payments to 1,500 doctors who had registered for ePIP but were unable to upload Shared Health Summaries to the My Health Record system owing to compliance and system issues. The Government responded to these calls by granting a six-month extension to the deadline for ePIP registered general practices to upload Shared Health Summaries to the My Health Record system. The article which reported the Department’s response was categorised as positive.

Technology Development

Over the last few months there were only two articles that discussed technology development, centred on Telstra being awarded a contract to construct and run the new Australian National Cancer Screening Register. The articles informed readers that this new register would link to individuals’ My Health Records.

Media monitoring analysis at the local level

Northern Queensland Primary Health Network (NQ PHN)

Based on the media monitoring database provided by the National Communications Team through NQ PHN, a total of 24 pieces of media content were collected and analysed from March 2016 to September 2016. It should be noted that, for the months of August and September, no local pieces of media content were generated (see Table 8 and Figure 8).

Table 8. NQ PHN local level media date range.

Month	Number of Articles	Proportion (%)
March	11	46%
April	7	29%
May	3	13%
June	2	8%
July	1	4%
Total	24	100%

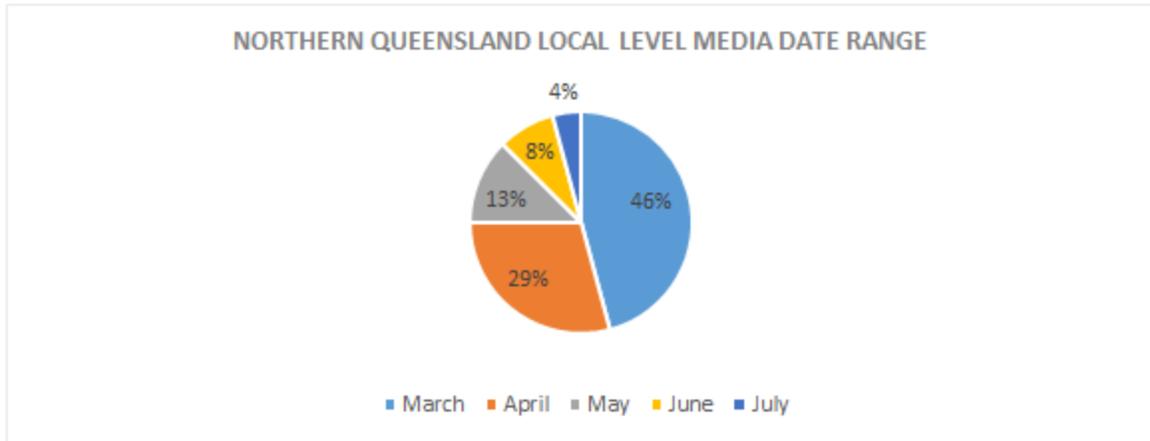


Figure 8: NQ PHN local level media date range.

Table 9 and Figure 9 show that 71% (n=17) of these related to Government or PHN announcements regarding the trials. These included several syndicated news stories in local papers across Northern Queensland, announcing that the trials were going live, and that individuals and healthcare providers had access to their My Health Records during the trial.

Table 9: NQ PHN local level media topics or issues raised in media content.

Media Topics	Number of Articles	Proportion (%)
Government policy and approach, announcement or issue	17	71%
Privacy	3	13%
Healthcare provider views, issues and concerns	1	4%
System Issues (myGov/My Health Record)	2	8%
Technology development	1	4%
Total	24	100%

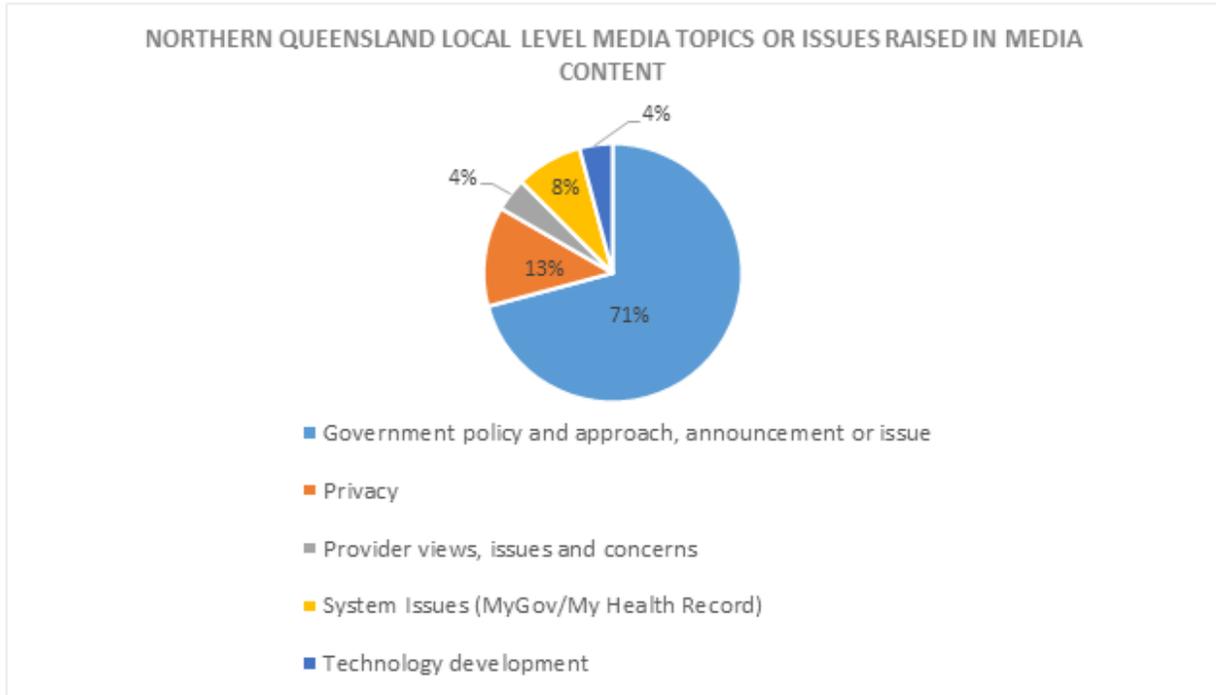


Figure 9: NQ PHN local level media topics or issues raised in media content.

As Table 10 and Figure 10 show, the majority of these articles were deemed to be of positive or neutral sentiment. Positive articles outlined how the My Health Record system could create health benefits for individuals. Neutral articles did not express a specific view, generally announcing an event or action and were balanced in their reporting. Three of the local pieces reflected privacy concerns of individuals and were drawn from syndicated news stories that did not cover the effect of the trials at a local level. Two reported that letters were being sent to deceased persons due to an "administrative error" and provided anecdotal stories from those who had received letters for their deceased loved ones and the impact on them. These two articles were deemed negative in sentiment as they were critical of the My Health Record system and the rollout of the trials.

Table 10: NQ PHN local level sentiment analysis.

Sentiment	Number of Articles	Proportion (%)
Positive	6	25%
Negative	5	21%
Neutral	13	54%
Total	24	100%

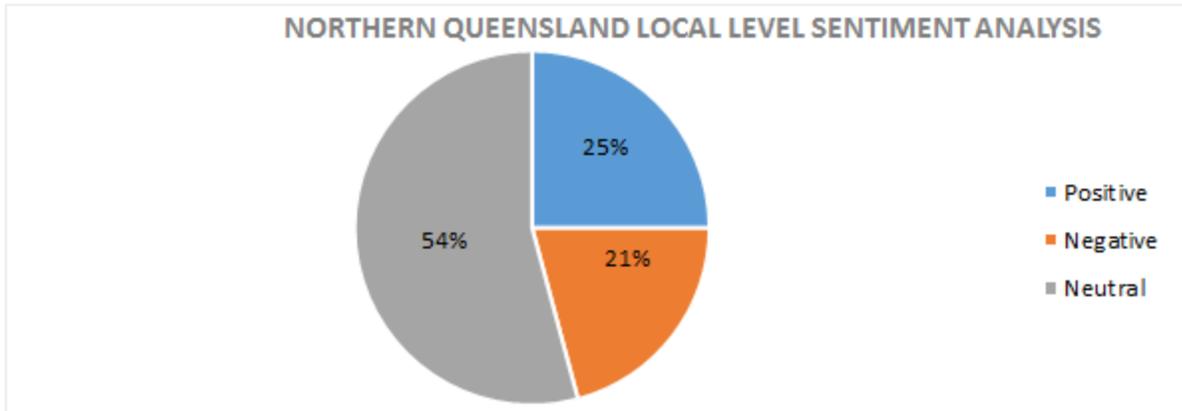


Figure 10: NQ PHN local level sentiment analysis.

Nepean Blue Mountains Primary Health Network (NBM PHN)

Based on the media monitoring database provided by the National Communications Team through NBM PHN, a total of 22 pieces of media content were collected and analysed between March 2016 and September 2016. It should be noted that, for the months of August and September, no local pieces of media content were generated (see Table 11 and Figure 11).

Table 11. Nepean Blue Mountains local level media date range.

Date	Number of Articles	Proportion (%)
March	10	45%
April	5	23%
May	4	18%
June	2	9%
July	1	5%
Total	22	100%

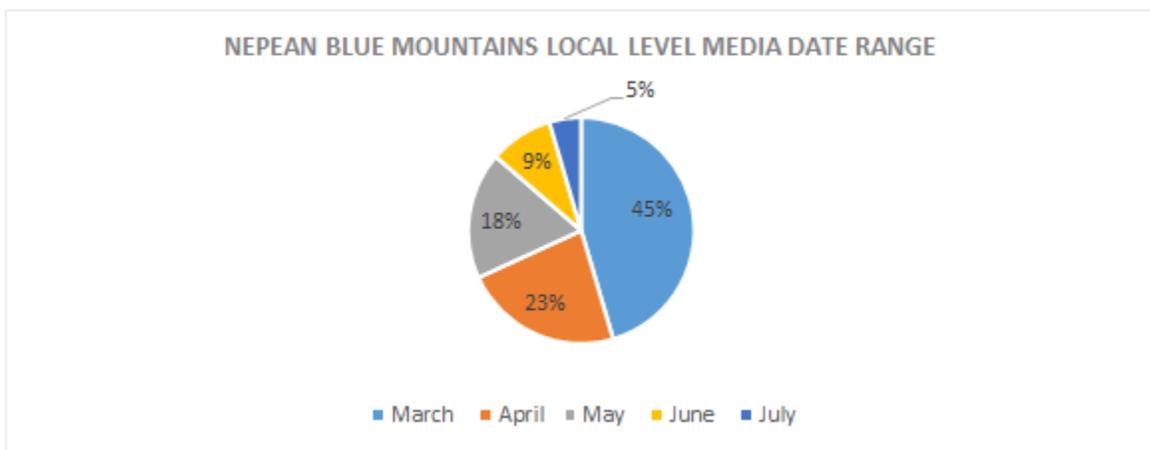


Figure 11: Nepean Blue Mountains date range.

Table 12 and Figure 12 show that all coverage was through print newspapers, with 19 of the 22 items about Government or PHN announcements regarding the trials. These included several syndicated news stories which appeared in a local paper across Nepean Blue Mountains and announced the trials going live and individuals and healthcare providers having access to their My Health Records during the trial.

Table 12. Nepean Blue Mountains local level media topics or issues raised in media content.

Media Topics	Number of Articles	Proportion (%)
Government policy and approach, announcement or issue	19	86%
Healthcare provider views, issues and concerns	2	9%
System Issues (myGov/My Health Record)	1	5%
Total	22	100%

NEPEAN BLUE MOUNTAINS LOCAL LEVEL MEDIA TOPICS OR ISSUES RAISED IN MEDIA CONTENT

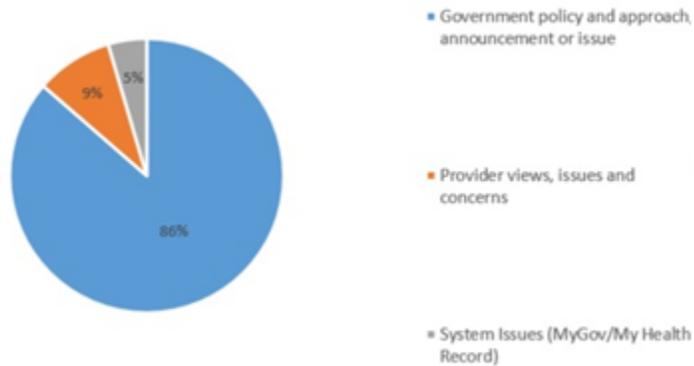


Figure 12: Nepean Blue Mountains local level topics or issues raised in media content.

As shown in Table 13 and Figure 13, the majority of these articles were deemed to be of positive or neutral sentiment. Positive articles outlined how the My Health Record could create health benefits for individuals in the Nepean Blue Mountains community. Neutral articles did not put forward a specific view and were generally categorised as announcing an event/action taking place or were balanced in their reporting. Two of the local pieces related to healthcare provider views, and highlighted the capabilities of the My Health Record system and its benefits to patient care. These articles were deemed to be of positive sentiment.

Table 13. Nepean Blue Mountains local level sentiment analysis

Sentiment	Number of Articles	Proportion (%)
Positive	10	45%
Negative	2	9%
Neutral	10	45%
Total	22	100%

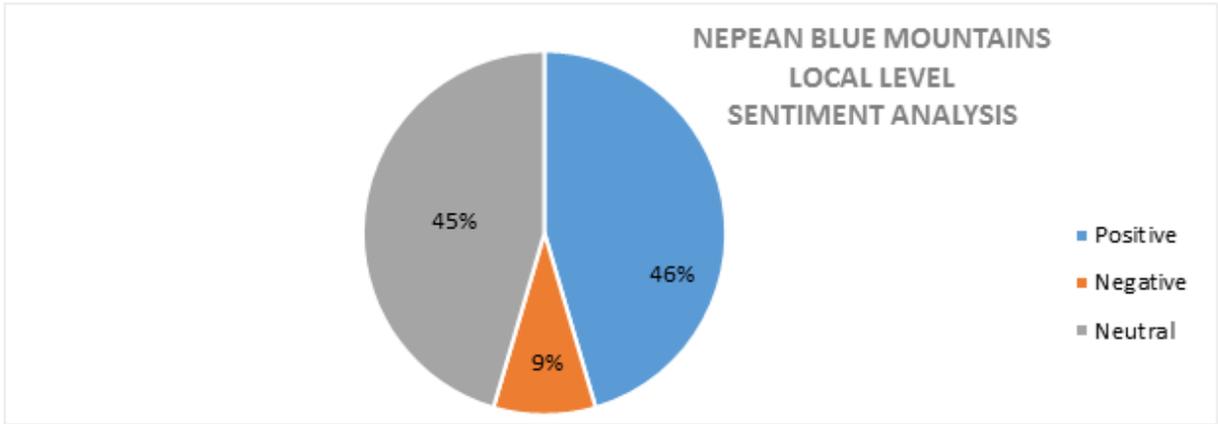


Figure 13: Nepean Blue Mountains local level sentiment analysis.

Appendix 14 Aboriginal and Torres Strait Islander Pen and Paper Survey in North Queensland

An Aboriginal and Torres Strait Islander pen and paper version of the online survey was used at baseline (in March 2016) and at follow up (in September 2016).

In February 2016, the NQ PHN organized consultations with the CEOs (or their delegates) of the Aboriginal Community Controlled Health Services (ACCHS) within the PHN to discuss the need to ensure adequate Aboriginal and Torres Strait Islander representation in the evaluation. On the advice from that meeting, and with the assistance of the Aboriginal and Torres Strait Islander health team of the NQ PHN, the evaluation team contacted the CEOs of nine ACCHS to invite them to help distribute and complete a pen and paper version of the baseline online survey. Four of the nine services agreed to participate.

These services were:

- Apunipima Cape York Health Council
- Aboriginal and Torres Strait Islander Community Health Service Mackay Ltd
- Mamu Health Service
- Mulungu Aboriginal Corporation Medical Centre

In August 2016, the four services were again invited to help with the pen and paper version of the follow up survey. It was administered by Aboriginal Health Workers, or by a person allocated by the health service to conduct interviews in clinics or community settings appropriate to the location. The surveys were conducted as semi-structured interviews, allowing for explanation to, and support of, respondents.

Respondents were recruited from nine clinics in eight places:

- Mackay
- Innisfail
- Ravenshoe
- Babinda-Tully
- Mareeba
- Mossman Gorge
- Mapoon

DoctorConnect⁵⁷ was used to classify communities by remoteness setting:

- Regional: Mackay, Innisfail, Ravenshoe, Babinda, Tully
- Rural: Mareeba, Mossman Gorge
- Remote: Mapoon

Respondents were offered a small financial incentive to participate in the baseline and follow up surveys. The nature of the incentives was discussed with the CEOs or representatives of the participating ACCHS. The agreed incentives included food vouchers, phone call credit cards, and utility vouchers.

The pen and paper survey was conducted only in the NQ PHN, rather than in both opt-out trial sites. The online survey in the NBM PHN achieved adequate representation of Aboriginal and Torres Strait Islander respondents relative to their representation in the general population in that location. The opt-in trial sites

⁵⁷ DoctorConnect: <http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator>

had been not formally announced at the time of baseline data collection. Some concerns were also expressed to the NBM PHN by local Aboriginal groups who were approached, but representation was not achieved because there wasn't adequate time for appropriate consultation with local communities, and they did not think the draft pen and paper survey could go ahead unchanged. However, the NQ PHN had built in consultation with ACCHS healthcare providers from the beginning of their processes and invited the evaluation team into those. This allowed modifications to be made in the time available.

Approach to data analysis

Routine descriptive methods and statistical tests (independent sample t-tests and Chi-Square Goodness-of-Fit test) were performed to examine whether observed differences between baseline and follow up surveys reached levels of statistical significance. Statistical analyses of responses to some questions within the baseline and follow up surveys were not conducted and reported when there was an inadequate sample size for each question. Responses which indicated "Others" or "Prefer not to say" in both baseline and follow up surveys⁵⁸ were excluded from the statistical analyses.

The approach to the analysis of qualitative data generated by the healthcare provider surveys was based on Krueger's Framework Analysis (1994, 2000).^{59,60} The Framework outlines five key stages: familiarisation, identifying a thematic index, charting, mapping and interpretation. Qualitative data in the pen and paper surveys were analysed by coding the information provided by the respondents. Codes were used as a means of identifying categories and patterns in the data. The analysis of qualitative data was overseen by a lead coder and the process involved:

- segmenting the data
- identifying key categories and patterns in the data (coding)
- discussing emerging categories and patterns across multiple coders
- moderating categories and patterns in line with group discussion
- summarising data in key categories

When responses to the qualitative questions (i.e. open-ended questions) could be classified under two different categories, they were coded in both of those categories. Thus, the total responses described in the following section do not reflect the total number of respondents who answered the question. Rather, it represents the total number of concepts or categories respondents provided to answer a particular question.

It should also be noted that the percentages reported within each question (when presented) can only be interpreted for that question, as they account for the percentage of total number of categories expressed in response to a question, rather than the total number of people who responded to the question. Responses that did not directly address the questions or could not be interpreted were categorised as "Other".

⁵⁸ Items applicable are: Gender; living arrangements; education level; total household income; employment status; health problems that has lasted for more than six months;

⁵⁹ Krueger RA (1994) *Focus Groups: A Practical Guide for Applied Research*. Thousand Oaks, CA: Sage Publications.

⁶⁰ Krueger RA & Casey MA (2000) *Focus Groups: A Practical Guide for Applied Research*, 3rd ed. Thousand Oaks, CA: Sage Publications.

Summary of the results from the Aboriginal and Torres Strait Islander pen and paper surveys (baseline and follow up) in North Queensland

Respondents – all settings

Overall, 197 respondents (60 males and 137 females) participated in the pen and paper survey at baseline (March 2016) and a total of 171 respondents (44 males, 124 females and 1 other) participated in the pen and paper survey at follow up (September 2016). This section describes results from the baseline and follow up surveys for each of the three settings: regional, rural and remote/very remote.

Table 1: Gender and age distribution of the total number of respondents at baseline and follow up

	Baseline	Follow up
Males	60	44
Females	137	124
Other gender (e.g., transsexual)	0	1
Age mean (SD) ⁶¹	42.9 (15.79)	42.9 (15.73)
Age range	17 to 88	18 to 83

Awareness and understanding of the My Health Record

Most respondents at both baseline and follow up said they had not previously heard or received any written information about the My Health Record. Respondents were more likely to receive information about the My Health Record from their healthcare providers than from other sources such as the mass media, the myGov website, or other government websites.

Very few respondents recalled having received a letter about the My Health Record. Those who knew they had a My Health Record were more likely to recall receiving such letter.

Respondents at baseline and follow up identified several benefits of the My Health Record, including: having a My Health Record would contribute to receiving high quality of care; allows healthcare providers easy access to their health information; and that there would be one centralised medical record for individuals and healthcare providers.

Confidence to use the My Health Record

At baseline and follow up, the majority of respondents who indicated that they had a My Health Record were confident in their ability to use the My Health Record.

As the My Health Record can only be accessed through the myGov platform, a key aspect of confidence to use the My Health Record is whether or not individuals have a myGov account. The findings demonstrate that the majority of respondents had a myGov account. This means that these individuals are potentially able to access and use their My Health Record. Respondents who did not have a myGov account said the reasons why they did not have one included: being unaware that they could have one; had no information about it; or that having an account was either not a priority or not necessary.

The other aspect of confidence to use the My Health Record is people's confidence in the Government's capacity to maintain the confidentiality of their My Health Record and the security of the system from external threats, such as hackers. Respondents at follow up were somewhat confident: in the ability of

⁶¹ SD=standard deviation

the My Health Record system to maintain the confidentiality and security of their information; that the My Health Record system is secure from external threats such as hackers; and that the Government/others would treat the medical information contained in their My Health Record appropriately.

Participation and use of the My Health Record

When asked whether they have a My Health Record, most respondents said they did not have a My Health Record, or were unsure if they had one.

Of the respondents who indicated that they did not have a My Health Record (or were unsure), only eight had opted out. The reasons given by these respondents for opting out included: unsure about how to use the My Health Record system; did not see a need for it and concerns about the My Health Record system's security.

Of those who indicated that they had a My Health Record at baseline and follow up, most had not set privacy settings, had not accessed their My Health Record in the last four weeks and were unsure of their intention to access their My Health Records in the future. These individuals also believed that, to some extent, they had been able to observe members of their healthcare provider team working better together because of the My Health Record.

At baseline and follow up, there were similar numbers of respondents who thought that a healthcare provider's use of the My Health Record system would or would not influence the likelihood that they would use them as their healthcare provider of choice.

Respondents - regional settings

In regional settings, a total of 87 respondents participated in the baseline pen and paper survey in March 2016, and another 86 respondents participated in the follow up survey in September 2016. Respondents from both baseline and follow up surveys were recruited from the regional areas of NQ PHN (Mackay, Innisfail, Ravenshoe, Babinda and Tully).

More females than males participated in both surveys. Females represented 78.16% and 77.01% for the baseline and follow up surveys respectively (Table 3). The pattern of results is consistent across the two surveys, $\chi^2(1, n = 84) = .15, p = .697(NS)$.⁶² There was also no significant difference in respondents' ages between the baseline and follow up surveys, $t(171) = .33, p = .745(NS)$. Table 2 also demonstrates that the mean age and age range of respondents were similar across both surveys.

Table 2: Gender and age distribution of respondents in the baseline and follow up surveys

	Baseline	Follow up
Male	19	17
Female	68	67
Other	0	1
Age mean (SD)	45.2 (17.1)	44.3 (17.3)
Age range (years old)	19 to 83	17 to 88

In both surveys, most respondents did not have private health insurance.

⁶² NS=not statistically significant.

Table 3: Number and proportion of respondents by types of private health insurance

Private Health Insurance	Baseline		Follow up	
	n	%	n	%
No	71	83	77	90
Yes - hospital only	3	4	1	1
Yes- hospital and extras	7	8	4	5
Prefer not to say	5	6	4	5
Total	86	100	86	100

In both the baseline and follow up surveys, most respondents spoke only English at home.

Table 4: Number and proportion of respondents in the baseline and follow up surveys who indicated whether they speak another language apart from English at home

Response	Baseline		Follow up	
	n	%	n	%
Yes	3	4	5	6
No, I speak only English	77	93	74	87
Prefer not to say	3	4	6	7
Total	83	100	85	100

Figure 1 below shows the living arrangements as indicated by respondents in the two surveys. There was no significant difference in the proportion of respondents living alone and living with others (including partners and children) between baseline and follow up, ⁶³ $\chi^2(1, n = 58) = .71, p = .398$ (NS).

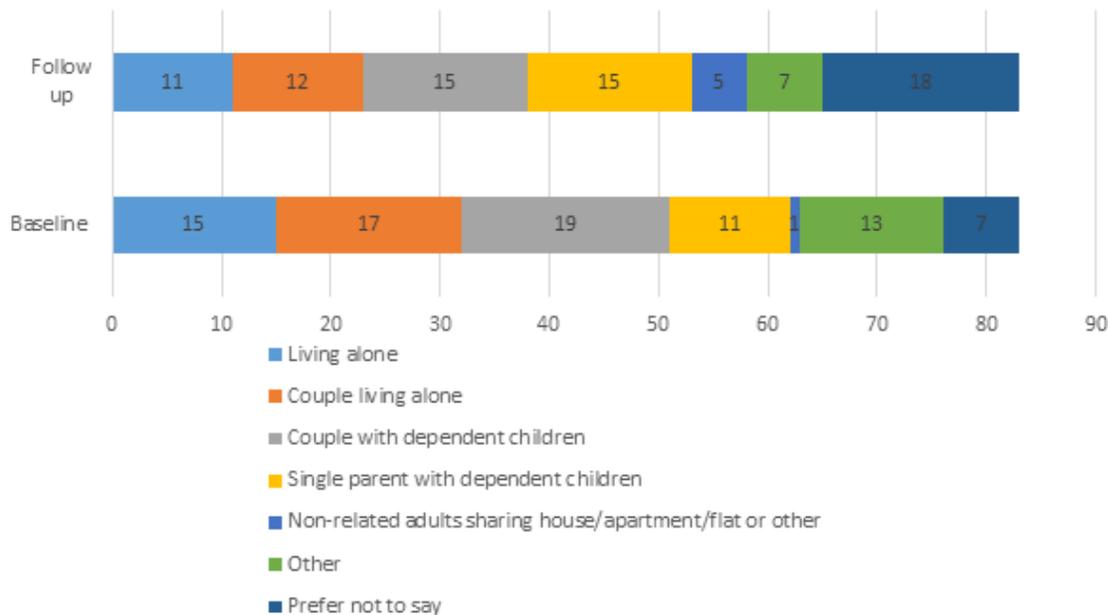


Figure 24: Living situation as indicated by respondents in the baseline and follow up surveys

⁶³ The analysis excluded responses categorised as “Others” and “Prefer not to say”.

At both survey time-points, about half of the respondents had received a pension from the Government.

Table 5: Number and proportion of respondents who had or had not received a pension from the Government

Response	Baseline		Follow up	
	n	%	n	%
Yes	48	57	33	47
No	28	33	31	44
Prefer not to say	8	10	7	10
Total	84	100	71	100

Figure 2 presents the education level of respondents in the baseline and follow up surveys. Compared to the baseline cohort, respondents in the follow up cohort had more commonly achieved a level of education of “Certificate I to IV” or above. However a Chi-square Goodness-of-Fit test indicated no significant difference in the proportion of respondents who achieved a “Certificate I to IV or above” and those who achieved an education level of “High school or below” between the baseline and follow up surveys, $\chi^2(1, n = 72) = .11, p = .743$ (NS).

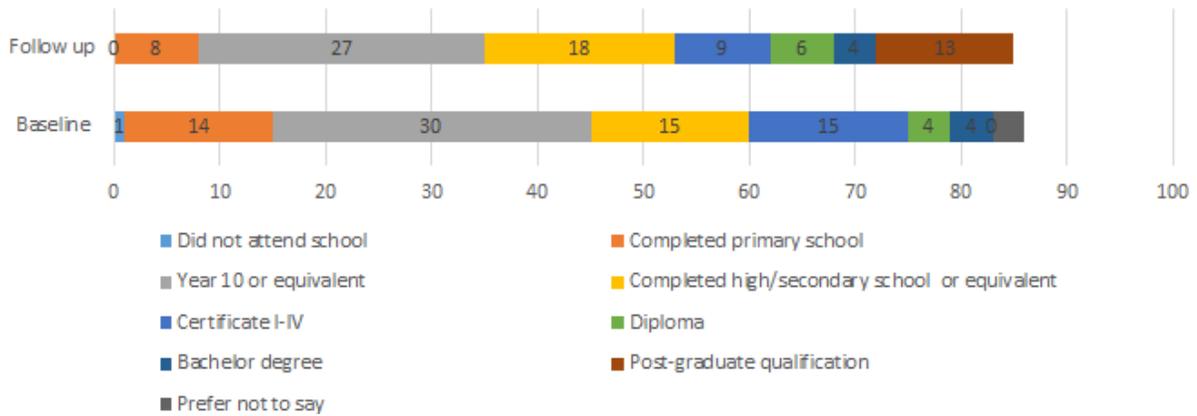


Figure 25: Education level of respondents at baseline and follow up

Figure 3 below presents the total weekly income level reported by respondents in the baseline and follow up surveys. In both surveys, more respondents reported total household income of \$380-\$769 per week than other income levels.

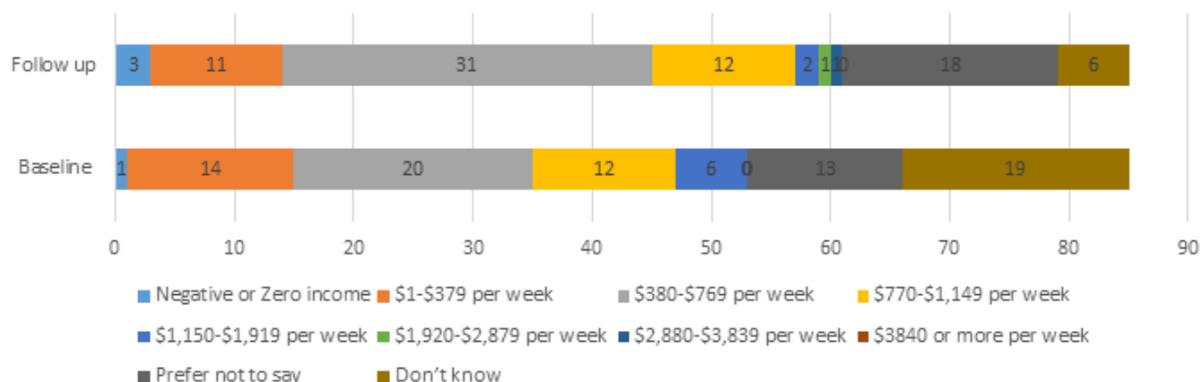


Figure 26: Total household income of respondents at baseline and follow up

In both surveys, more respondents were unemployed than those who were employed⁶⁴ (Table 6). However, a Chi-Square Goodness-of-Fit test shows no significant difference in respondents' employment status between baseline and follow up⁶⁵, $\chi^2(1, N = 68) = 3.09, p = .079$ (NS).

Table 6: Number and proportion of respondents by employment status

Employment status	Baseline		Follow up	
	n	%	n	%
Self-employed (full time)	0	0	0	0
Self-employed (part time)	3	4	0	0
Employed for 30 hours or more per week for wages, salary or payment in kind	18	31	16	19
Employed for less than 30 hours per week for wages, salary or payment in kind	8	10	8	9
Unemployed	17	20	21	24
Solely engaged in home duties	7	8	5	6
Solely engaged in studies	1	1	1	1
Retired	17	20	10	12
Volunteer/charity work	3	4	7	8
Unable to work	5	6	7	8
Other	3	4	3	4
Prefer not to say	2	2	15	17
Total	84	100	86	100

The following demographic questions were only asked in the follow up survey. Most respondents in the follow up survey identified themselves as having Aboriginal heritage. Respondents were more likely to report two adults living at home, and no children living at home the previous night.

Table 7: Number and proportion of respondents who, in the follow up survey, identified as Aboriginal and/or Torres Strait background and non-Indigenous

Aboriginal and Torres Strait Islander background	n	%
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⁶⁴ Respondents who are unemployed included: those solely engaged in home duties or studies; retired; volunteers; working for charity; and unable to work. Those who are employed included individuals who are employed for wages; payment in kind or salary; and those who are self-employed, regardless of how many hours they worked. The analysis also excluded those who indicated "Prefer not to say".

⁶⁵ The analysis excluded those who responded "Prefer not to say" and "Others".

Aboriginal and Torres Strait Islander background	n	%
Aboriginal	47	56
Torres Strait Islander	11	13
Aboriginal and Torres Strait Islander	15	18
Non-Indigenous	11	13
Total	84	100

Table 8: Number and proportion of adults and children in respondents' households.

Number of adults living at home	Number of responses	Number of children living at home	Number of responses
0	2	0	36
1	23	1	18
2	39	2	12
3	11	3	5
4	7	4	6
11	1	5	1
		6	2
Total	83	Total	80

Health Status:

Most respondents in the baseline and follow up surveys reported having “fair” or “very good” health). There was no significant difference in respondents’ rating of their health status at baseline (M = 2.61, SD = 0.71) and follow up (M = 2.56, SD = 0.76), $t(161) = .56$, $p = .578$ (NS). Table 10 shows that, in both baseline and follow up surveys, more people had health problems that has lasted for more than six months than those who did not, $\chi^2(1, N = 75) = .01$, $p = .933$ (NS).

Table 9: Respondents' current health

Health Status	Baseline		Follow up	
	n	%	n	%
Excellent	4	5	7	8
Very Good	31	36	28	33
Fair	41	47	39	46
Poor	7	8	6	7
Prefer not to say	4	5	5	6
Total	87	100	85	100

Table 10: Number and proportion of responses about health problems that have lasted for more than six months

Response	Baseline		Follow up	
	n	%	n	%
Yes	44	51	39	47
No	41	48	36	43
Prefer not to say	1	1	8	10
Total	86	100	83	100

Internet connectivity:

Most respondents who participated in the baseline survey stated they had some form of internet access. The follow up cohort shows a more even distribution, with approximately half of the respondents indicating they do not (or don't know if they do) have internet. A Chi-Square Goodness-of-Fit indicated a significant difference in the proportion of respondents with internet access between baseline and follow up, $\chi^2(1, n = 83) = 55.44, p < 0.05$.

The most common channel used by respondents to access the internet was through their mobile phones (Tables 11 and 12).

Table 11: Internet access

Response	Baseline		Follow up	
	n	%	n	%
Yes	60	82	42	51
No / Don't know	13	18	41	49
Total	73	100	83	100

Table 12. Types of internet connections indicated by respondents in the regional setting (in the baseline survey)

Types of internet connection	Number	Proportion (%)
DSL	8	8
Cable	2	2
Mobile broadband on laptop, tablet device or desktop computer (includes 3G/4G via USB/dongle)	33	32
Broadband on mobile phone or smartphone (includes 3G,4G)	38	38
Dial-up	1	1
Fibre	0	0
Satellite	1	1
Other (e.g., None)	3	3
Don't know	13	13
Total	99	100

Table 13: Type of internet connection respondents have in the regional setting (in the follow up survey)

Internet connection	At home	On the phone	Somewhere else
Frequency	20	33	4

Expectations to share health information:

Compared to the baseline cohort, at follow up a significantly lower proportion of respondents expected their healthcare centres to share their health information with other centres and hospitals as part of their healthcare, $\chi^2(1, n = 82) = 16.76, p < 0.05$.

Table 14: Number and proportion of respondents who expected their healthcare centres to share their health information with other centres and hospitals as part of their healthcare

Response	Baseline	Follow up
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	n	%	n	%
Yes	68	82	53	64
No	15	18	30	40
Total	83	100	83	100

myGov account:

In both surveys, approximately half of the respondents indicated that they had a myGov account, $\chi^2(1, n = 70) = .54, p = .461$ (NS).

In both surveys, those who indicated that they did not have a myGov account were asked to provide reasons for not having one. There were differences in the pattern of responses expressed by respondents in the baseline survey when compared to responses in the follow up survey. In the baseline survey, the top three common reasons for not having a myGov account were: “creating an account is not a priority”; “lack of awareness”; and “lack of internet/computer access.” In the follow up survey, the top three common reasons for not having a myGov account were: “lack of awareness”; “having an account is unnecessary” and “creating an account is not a priority”.

Table 15: Number and proportion of respondents who had a myGov account

Response	Baseline		Follow up	
	n	%	n	%
Yes	44	51	38	47
No	31	36	32	40
Don't know	12	14	11	14
Total	87	100	81	100

Table 16: Reasons for not creating a myGov account

Baseline		Follow up	
Category	n	Category	n
Creating an account is not a priority	8	Lack of awareness/information	9
Lack of awareness/information	6	Having an account is unnecessary	4
Lack of internet/computer access	5	Creating an account is not a priority	2
Never used government services	3	Lack of internet/computer access	1
Having an account is unnecessary	2	Never used government services	1
Unsure	2	Internet illiterate	1
Others (e.g. prefer face to face communication, was not prompted by the Government)	3	Other (e.g., not registered with Centrelink)	1
Total responses	29	Total responses	19

My Health Record:

In both surveys, just under half of the respondents had previously heard about My Health Record (Table 17), $\chi^2(1, n = 66) = .33, p = .568$ (NS).

Respondents in the follow up survey were also asked to indicate whether they had received any written information about the My Health Record, and most indicated that they had not (Table 18).

Those who indicated that they received written information or had heard about the My Health Record were asked to indicate *where* they had heard or received the information. For both baseline and follow up surveys, respondents were more likely to have received information or heard about the My Health Record through their healthcare providers than other outlets (e.g. national or local media) (Table 18).

Table 17: Frequency and proportion of respondents who had previously heard about the My Health Record system

Response	Baseline		Follow up	
	n	%	n	%
Yes	33	39	28	42
No	52	61	38	58
Total	85	100	66	100

Table 18: Number and proportion of respondents who indicated that they had received written information about the My Health Record system in the follow up survey

Responses	n	%
Yes	26	31
No	57	69
Total	83	100

Table 19: Sources of information about the My Health Record system

Sources of information	Baseline	Follow up
	n	n
National media	4	10
Local media	11	7
myGov website	5	8
Other Government website	0	3
Other website	7	0
Healthcare provider (e.g., GP, nurses, etc)	21	29
Others (e.g., Social media, word of mouth, local community carers, government workers, letters)	5	3

Note: respondents could endorse multiple responses in this item.

Most respondents in the baseline survey did not have a My Health Record or did not know that they had a My Health Record (Table 20). There was a slight increase in the proportion of respondents registered for a My Health Record at follow up. A Chi-Square Goodness-of-Fit test shows the difference in proportion of respondents who had a My Health Record⁶⁶ between baseline and follow up to be significant, $\chi^2(1, n = 85) = 5.52, p < .05$.

⁶⁶ For the baseline and follow up survey, respondents without a My Health Record are defined as those who responded “No” and “Don’t know”. For the follow up survey, respondents with a My Health Record are defined as those who had a My Health Record prior to 31 March 2016 and those who had a My Health Record created since 31 March 2016.

Table 20: Number and proportion of respondents who have registered for a My Health Record

Baseline			Follow up		
Response	n	%	Response	n	%
Yes	9	10	Yes (prior to March 31)	5	6
No	78	90	Yes (created since March 31)	10	12
			No	45	53
			Don't know	25	29
Total	87	100	Total	85	100

Respondents with a My Health Record

In the follow up survey, respondents who indicated that they had a My Health Record were also asked whether they had attempted to register for one. Of those respondents who indicated that they had a My Health Record (n=11), nine said that a My Health Record was created on their behalf as part of the trial (Table 21).

When asked whether they received a letter informing them that a My Health Record was created for them, six out of 14 respondents said 'Yes' (Table 22).

At baseline, respondents mostly spent 0 to 15 minutes to set up their My Health Records; whereas at follow-up, most respondents indicated they spent 0 to 9 minutes to set up their My Health Records (Table 23). At both baseline and follow up, most respondents had not set up their privacy settings (Table 24), and had not accessed their My Health Record (Table 25).

Very few people indicated whether the information in the My Health Record was useful (≤ 5 responses in both surveys (Table 26).

Table 21: Number and proportion of respondents, in the follow up survey, who attempted to register for a My Health Record

Attempt to register for a My Health Record	n	%
Yes	2	14
No - a My Health Record was created on my behalf as part of the trial	9	64
Don't know	3	21
Total	14	100

Table 22: Number and proportion of respondents who, at the follow up survey, indicated that they received a letter informing them that a My Health Record was created for them, at follow up

Receiving a letter about the automatic creation of a My Health Record	n	%
Yes	6	43
No	5	36
Other	1	7
Don't know	2	14
Total	14	100

Table 23: Time taken to set up a My Health Record

Time taken to set up a My Health Record	Baseline	Follow up
0 - 9 minutes	2	6
10 - 15 minutes	5	3

Time taken to set up a My Health Record	Baseline	Follow up
16 - 30 minutes	1	1
31 - 60 minutes	1	0
Total	9	10

Table 24: Frequency and proportion of respondents who had set up privacy settings in their My Health Record at baseline and follow up

Setting up privacy settings for the My Health Record	Baseline		Follow up	
	n	%	n	%
Yes	1	11	1	8
No	5	56	10	77
Prefer not to say	3	33	2	15
Total	9	100	13	100

Table 25: Frequency and proportion of respondents who had accessed their My Health Record

Accessed My Health Record	Baseline		Follow up	
	n	%	n	%
Yes	1	11	1	8
No	6	67	10	77
Don't know	2	22	2	15
Total	9	100	13	100

Table 26: Frequency and proportion of respondents who indicated whether they found useful information in the My Health Record at baseline and follow up

Any useful information in the My Health Record?	Baseline		Follow up	
	n	%	n	%
Yes	3	75	2	40
No	1	25	3	60
Total	4	100	5	100

There were similar patterns in usage and attitudes among those with a My Health Record at both survey points (Tables 27 and 28).

As in the baseline survey, most respondents in the follow up survey were unsure about their intentions to access the My Health Record in the next four months (Table 29).

Table 27: Number of respondents who had used the functions within the My Health Record system

Activity conducted when using the My Health Record	Baseline (n)	Follow up (n)
View documents completed by healthcare provider	1	1
View information about any current or past prescriptions	1	0
Upload a document	0	0
Provide any information about current or past health	0	0
Other	2	2
None of the above	1	2

Activity conducted when using the My Health Record	Baseline (n)	Follow up (n)
Prefer not to say	0	3

Note: respondents could endorse multiple responses in this item.

Table 28: Respondents' attitudes to the My Health Record

Because of the My Health Record, respondents were:	Baseline (n)	Follow up (n)
More informed about the health care received	4	4
More involved in making decisions about healthcare	1	2
More aware about own health	3	2
Actively attempting to improve own health	0	4
Other	1	1
None of the above	0	5

Note: respondents could endorse multiple responses in this item.

Table 29: Respondents' intention to access the My Health Record

Participants' intention in the next four months	Baseline		Follow up	
	n	%	n	%
Increase the number of times accessing My Health Record	2	22	1	7
Decrease the number of times accessing My Health Record	0	0	1	7
Access My Health Record about the same number of times	1	11	1	7
Cancel My Health Record	1	11	0	0
Don't know	5	56	12	80
Total	9	100	15	100

Table 30 presents respondents' confidence rankings in their ability to use the My Health Record for a range of functions (1 = "total lack of confidence" to 5 = "extremely confident"). Overall, respondents at baseline and follow up said they were 'somewhat confident' (i.e. 2) and 'confident' (i.e. 3) in their ability to: view documents; discuss their My Health Record with doctors or healthcare providers; and cancel their My Health Record. Respondents at baseline were "confident" to "very confident" in their abilities to change privacy settings and upload documents or update details; whereas, respondents at follow up were "somewhat confident" to "confident" in their ability to do those tasks in their My Health Record.

Table 31 demonstrates respondents' indication of whether they had observed that members of their healthcare provider team had worked better together because of the My Health Record from 1 = 'Not at all' to 5 = 'To a great extent'. On average, respondents indicated that they "somewhat" had observed that members of their treating had worked better together because of the My Health Record.

Table 32 shows the most common response in the baseline survey was that there were no benefits from having a My Health Record, while most respondents in the follow up survey stated they were unsure of its benefits.

Table 30: Respondents' level of confidence to use the My Health Record system

Respondents' confidence in using My Health Record to:	Baseline			Follow up		
	People who responded	Confident to "Very confident"	"Don't know"	People who responded	"Confident to "Very Confident"	"Don't know"
Change privacy setting	9	4	2	13	4	4
View documents	8	3	1	13	5	0
Upload documents or update details	8	4	2	12	5	0
Discuss with doctors or other healthcare providers	9	6	0	12	7	0
Cancel My Health Record	8	4	1	12	5	2

Note: inferential statistical tests could not be conducted due to inadequate sample size.

Table 31: Respondents' indication, at follow up, of whether they had observed that having a My Health Record has meant that members of their healthcare provider team have worked better together

Has having a My Health Record meant that members of their healthcare provider team have worked better together?	People who responded	"Somewhat to "A great extent"	"Don't know"
	14	12	2

Table 32: Frequency and proportion of responses about the benefits from having a My Health Record

Baseline			Follow up		
Category	n	%	Category	n	%
No benefit	2	33	Don't know the benefits	3	50
To have easy access of My Health Records for healthcare providers	1	17	All medical information is stored in one location	2	33
Don't know the benefits	1	17	To have easy access of My Health Records for healthcare providers	1	17
Other (e.g., Faster service, knowledge, lost weight)	2	33			
Total	6	100	Total	6	100

People who indicated not having a My Health Record (or unaware they have one)

Of the 70 respondents who indicated that they did not have a My Health Record or were unsure whether they had one in the follow up survey, 40 reported they had not received a letter informing them that a My Health Record was being created for them (Table 33). As in the baseline survey, at follow up most respondents without a My Health Record had not attempted or did not know whether they had attempted to register for a My Health Record (Table 34).

In the follow up survey, those who had not attempted to register for a My Health Record were asked to indicate whether they had opted out from having a My Health Record. Only seven out of 70 respondents indicated that they had opted out (Table 35). Respondents who indicated that they had opted out from having a My Health Record were asked to provide reasons for doing so. Of the seven who indicated that they had opted out, five provided their reasons: two opted out because they were unsure how to use it,

another two felt that they do not need it, one respondent was concerned about how the My Health Record system would ensure the confidentiality of their health information (Table 36).

Respondents in both surveys were also asked to describe the expected benefits from having a My Health Record. The top two most common benefits described by respondents in the baseline and follow up surveys were: being unsure of the benefits and that the My Health Record system and provides healthcare providers easy access to their health information (Table 37).

Table 33: Number and proportion of respondents, in the follow up survey, who received a letter informing them that a My Health Record had been created for them

Did respondents receive a letter informing them that a My Health Record was being created for them?	n	%
Yes	7	10
No	40	57
Don't know	23	33
Total	70	100

Table 34: Number and proportion of respondents who had attempted to register for a My Health Record

Baseline			Follow up		
Response	n	%	Response	n	%
Yes	5	7	Yes	1	1
No	71	93	No	24	34
			Don't know	45	64
Total	76	100	Total	70	100

Table 35: Number and frequency of respondents in the follow up survey who had opted-out from having a My Health Record

Respondents who opted out from having a My Health Record	n	%
Yes	7	30
No	17	70
Total	24	100

Table 36: Reasons for opting out of a My Health Record (identified in the follow up survey)

Reasons for opting out	n	%
Unsure about how it works	2	40
Don't need it	2	40
Concerns about how the My Health Record system would ensure confidentiality	1	20
Total	5	100

Table 37: Expected benefits from having a My Health Record expressed by respondents

Baseline			Follow up		
Category	n	%	Category	n	%
Have easy access of records for healthcare providers	27	42	Don't know the benefits	16	36
Don't know the benefits	16	25	Have easy access of records for healthcare providers	9	20
To share information between healthcare providers	5	8	For consumers to have control over the access/view and personalised records	6	14
Have one centralised medical record for	4	6	Have one centralised medical record for	5	11

Baseline			Follow up		
Category	n	%	Category	n	%
individuals and healthcare providers			individuals and healthcare providers		
For consumers to have control over the access/view and personalised records	4	6	To share information between healthcare providers	3	7
For individuals to better monitor their own health	3	5	To provide high quality healthcare	2	5
To have access to up-to-date and accurate information for individuals and healthcare providers	3	5	To have access to up-to-date and accurate information for individuals and healthcare providers	2	5
Other (e.g., accurate data and statistics to close the gap with indigenous health issues, don't have to fill the forms out)	3	5	No benefit	1	2
Total	65	100	Total	44	100

Level of confidence in the security and confidentiality of the My Health Record system

All respondents in the follow up survey were asked to rate their level of confidence (1 = “total lack of confidence” to 5 = “extremely confident”) regarding the security and confidentiality aspects of the My Health Record system (Table 38). Of the 84 respondents, most were ‘somewhat confident’ (i.e., 2).

Table 38: Respondents’ their level of confidence in the confidentiality and security of the My Health Record, at follow up

Respondents’ level of confidence in the confidentiality and security of the My Health Record	Follow up			
	n			Mean (SD)
	Number of responses	“Confident” to “Extremely confident”	“Don’t know”	
The ability of the My Health Record system to maintain your information as confidential and secure	81	33	12	2.41 (0.93)
That the My Health Record is secure from external threats (e.g. safe from hackers or online breaches)	80	26	14	2.23 (0.84)
The Government’s capacity to keep your personal information held in the My Health Record confidential	80	25	14	2.23 (0.87)

Respondents in the follow up survey were also asked to indicate their level of trust in the Government and others to treat their medical information appropriately (on a rating scale of 1 = ‘Not at all’ to 5 = ‘To a great extent’). Most respondents “somewhat” trusted the Government or others to treat their medical information appropriately (Table 39).

Table 39: Respondents' level of trust, in the follow up survey, in the Government/others to treat their medical information appropriately

Level of trust in the Government/others to treat their medical information appropriately	Follow up			
	n			Mean (SD)
	Number of responses	Number of “Somewhat” to “To a great extent” responses	Number of “Don’t know” responses	

Level of trust in the Government/others to treat their medical information appropriately	Follow up			
	n			Mean (SD)
	Number of responses	Number of "Somewhat" to "To a great extent" responses	Number of "Don't know" responses	
	84	53	12	2.97 (1.05)

Most respondents in both baseline and follow up surveys indicated that they were more likely to visit a healthcare provider who uses the My Health Record system (Table 40). A notable proportion of respondents across the two surveys (53%,62%) were either unsure or felt that a healthcare provider's use of the My Health Record system would not influence their decision to use them.

Table 40: Respondents' likelihood of visiting a healthcare provider who uses the My Health Record system

Likelihood of visiting a healthcare provider who uses a My Health Record	Baseline		Follow up	
	n	%	n	%
Increase the likelihood of using them	38	46	29	34
Decrease the likelihood of using them	1	1	3	4
Does not affect decision to use them	19	23	25	29
Don't know	25	30	28	33
Total	83	100	85	100

Respondents - rural settings

A total of 69 respondents participated in the baseline survey in March 2016, and another 54 participated in the follow up survey in September 2016. Respondents in both surveys were recruited from rural settings of Far North Queensland.

More females than males participated in both surveys. (Females represented 65.2% and 74.1% for the baseline and follow up surveys respectively). The proportion of females and males were similar across baseline and follow up, $\chi^2(1, n = 54) = 1.95, p = .162$. There were no significant differences in respondents' ages between the baseline and follow up surveys, $t(121) = .17, p = .869$ (NS). Table 41 demonstrates the gender and age distribution of respondents in both the baseline and follow up surveys.

Table 41: Gender and age distribution of respondents in the baseline and follow up surveys

	Baseline	Follow up
Male	24	14
Female	45	40
Age (mean; years old)	41.5 (SD = 14.6)	41.0 (SD = 13.8)
Age range (years old)	17 to 72	18 to 71

In both surveys, most respondents did not have private health insurance (Table 42).

Table 42: Number and proportion of respondents by types of private health insurance

Private Health Insurance	Baseline	Follow up
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	n	%	n	%
No	53	80	41	76
Yes - hospital only	6	9	1	1
Yes- hospital and extras	4	6	6	11
Yes- extras only	1	2	3	6
Prefer not to say	2	3	3	6
Total	66	100	31	100

In both surveys, the majority of respondents indicated they “speak only English at home” (Table 43).

Table 43: Number and proportion of respondents who indicated whether they speak another language apart from English at home

Response	Baseline		Follow up	
	n	%	n	%
Yes	25	38	18	33
No, I speak only English	40	61	32	59
Prefer not to say	1	1	4	8
Total	66	100	54	100

Figure 4 below shows that respondents in the baseline and follow up surveys were more likely to identify that they were living with their partners (living with or without dependent children). A Chi-Square Goodness-of-Fit test indicated no significant difference in the proportion of individuals who lived alone and those who lived with others (including their partners and/or children) between baseline and follow up $\chi^2 (1, n = 34) = .53, p = .466$ (NS).

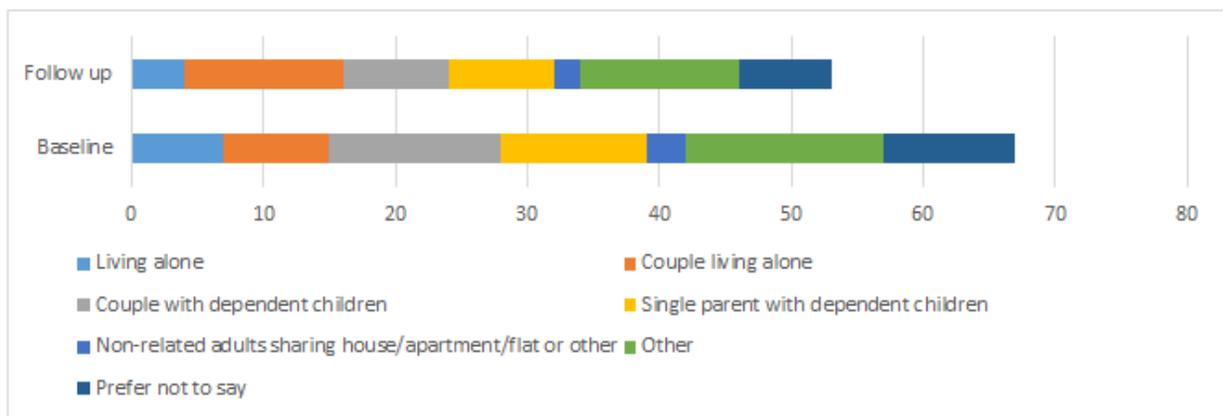


Figure 27: Living arrangements as indicated by respondents at baseline and follow up

In both surveys, most respondents had not received pension from the Government (Table 44).

Table 44: Number and proportion of respondents who had or had not received a pension from the Government

Response	Baseline		Follow up	
	n	%	n	%
Yes	26	38	15	28
No	40	59	34	64
Prefer not to say	2	3	4	8
Total	68	100	53	100

Figure 5 presents the education level of respondents in the baseline and follow up surveys. In both surveys, respondents were more likely to state that that they had completed ‘Year 10 or equivalent’ or a higher education level. A Chi-Square Goodness-of-Fit test indicated no significant difference in respondents’ education level (categorised as “those who had completed high school and under” and “those who completed Certificate I to IV and over”) at baseline and follow up, $\chi^2(1, n = 46) = 2.35, p = .125$ (NS).

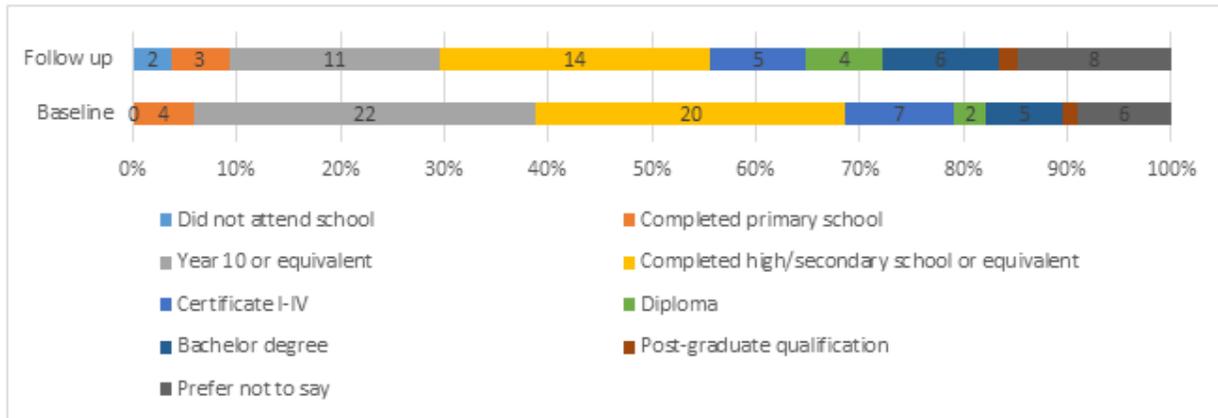


Figure 28: Respondents' education level at baseline and follow up

Figure 6 below presents the total income level reported by respondents in the baseline and follow up surveys. In both surveys, respondents were more likely to indicate that their total household income was \$380-\$769 per week.

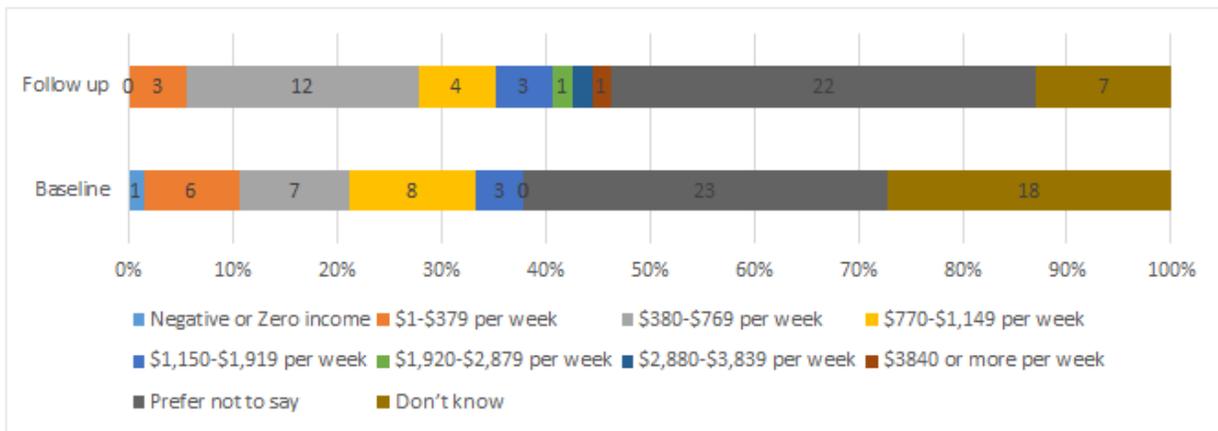


Figure 29: Respondents' income level at baseline and follow up

Figure 7 presents the number and proportion of respondents by their employment status. In both surveys, most respondents were employed for wages, salary or payment in kind or self-employed. There were more respondents in the baseline survey who indicated that they were unemployed or were not working for wages, salary or payment in kind than those in the follow up survey. A Chi-Square Goodness-of-Fit test indicated that, compared to the baseline, significantly fewer respondents were unemployed (including those engaged in home duties, studies and retired) at follow up, $\chi^2(1, N = 48) = 9.03, p < .05$.

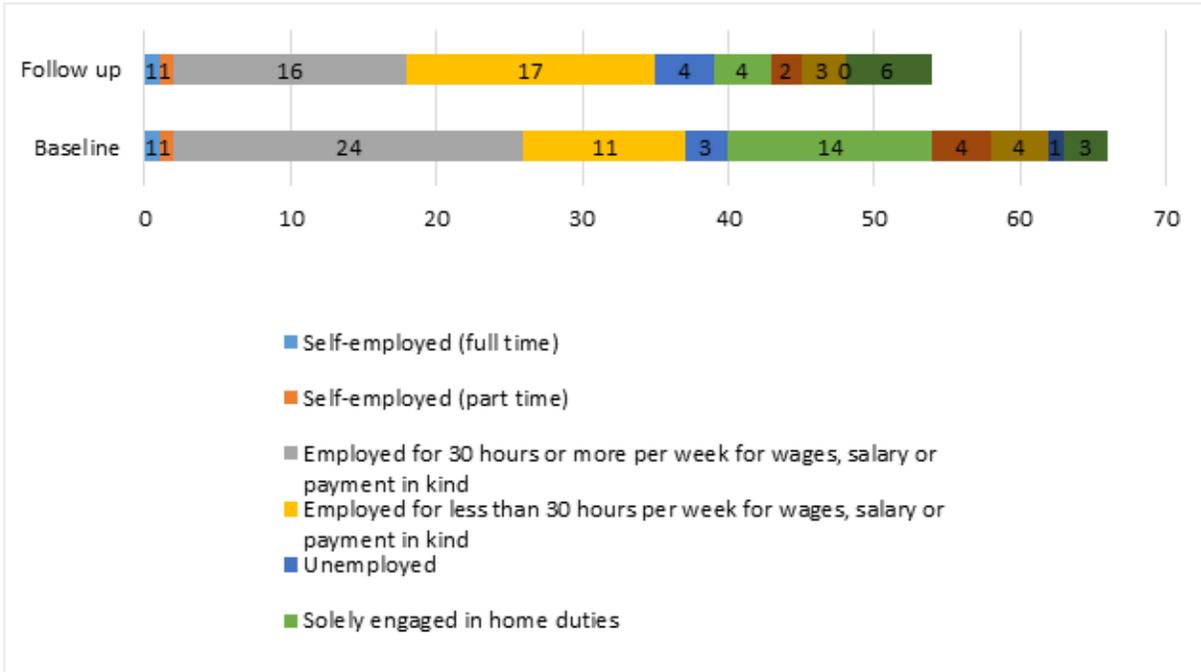


Figure 30: Respondents' employment status at baseline and follow up

In both surveys, most respondents identified as Aboriginal and/or Torres Strait Islander (Table 45).

Table 45: Number and proportion of respondents who identified as Aboriginal and/or Torres Strait Islander and non-Indigenous

Aboriginal and Torres Strait Islander background	Baseline		Follow Up	
	n	%	n	%
Aboriginal	45	79	42	79
Torres Strait Islander	2	3	2	4
Aboriginal and Torres Strait Islander	5	9	4	8
Non-Indigenous	5	9	5	9
Total	57	100	53	100

Consistent across both surveys, respondents were more likely to state that one or two adults lived in their home the previous night, with zero to three children in their home the previous night (Table 46).

Table 46: Number and proportion of adults and children living in their respondents' households

Number of adults living at home	Baseline	Follow Up	Number of children living at home	Baseline	Follow up
	n	n		n	n
1	15	15	0	18	20
2	19	21	1	14	9
3	7	11	2	10	17
4	7	4	3	9	2
5	4	1	4	3	2
6	2	0	5	0	0
7	1	0	6	2	1
12	1	0			
Total	56	52	Total	56	51

Health Status:

In both surveys, most respondents reported having “very good” health (Table 47), and did not have health problems that had lasted (or were expected to last) for six months or more (Table 48). There were no significant differences in respondents’ rating of their health status at baseline (M = 2.33, SD = 0.10) and follow up (M = 4.19, SD = 13.04), $t(121) = -1.18$, $p = .077$ (NS). Similarly, there was no significant difference in the proportion of respondents with health problems between baseline and the follow up surveys, $\chi^2(1, n = 52) = .03$ $p = .871$ (NS).

Table 47: Respondents' current health status

Health Status	Baseline		Follow up	
	n	%	n	%
Excellent	14	20	7	13
Very Good	28	41	23	43
Fair	19	27	18	33
Poor	6	9	4	7
Prefer not to say	2	3	2	4
Total	69	100	54	100

Table 48: Number and proportion of responses about health problems that have lasted for more than six months

Response	Baseline		Follow up	
	n	%	n	%
Yes	25	36	20	38
No	38	55	32	60
Prefer not to say	6	9	1	2
Total	69	100	53	100

Internet connectivity:

In both the baseline and follow up surveys, most respondents reported they had internet access. A Chi-Square Goodness-of-Fit test indicated no significant difference in the proportion of respondents with internet access between baseline and the follow up surveys, $\chi^2(1, n = 54) = .25$, $p = .619$ (NS).

The most common channel used by respondents to access the internet was through their mobile phones (Table 49).

Table 49: Internet access

Response	Baseline		Follow up	
	n	%	n	%
Yes	41	71	40	74
No / Don't know	17	29	14	26
Total	58	100	54	100

Table 50: Location of internet connection

Internet connection	Baseline			Follow Up		
	At Home	On the phone	Somewhere else	At Home	On the phone	Somewhere else
Frequency	11	47	2	18	27	11

Expectations to share health information:

In both surveys, most respondents expected their healthcare centres to share their health information with other healthcare centres and hospitals as part of their healthcare (Table 51). A Chi-Square Goodness-of-Fit test indicated no significant difference in the proportion of responses between baseline and follow up surveys, $\chi^2(1, n = 54) = .07, p = .797$ (NS).

Table 51: Number and proportion of respondents who expected their healthcare centres to share their health information with other healthcare centres and hospitals as part of their healthcare

Response	Baseline		Follow up	
	n	%	n	%
Yes	56	81	43	80
No	13	19	11	20
Total	69	100	54	100

myGov account:

In the baseline survey, approximately half of the respondents indicated that they did not have a myGov account, and one-third of respondents indicated they had a myGov account (Table 52). In the follow up survey, close to half of the respondents indicated that they had a myGov account (Table 52). However, a Chi-Square Goodness-of-Fit test indicated that the difference in the proportion of responses to be non-significant, $\chi^2(1, n = 47) = 2.54, p = .111$ (NS).

In both surveys, those who indicated that they did not have a myGov account were asked to provide reasons for not having one. There were differences between the pattern of responses in the baseline survey and the results in the follow up surveys. In the baseline survey, the top three common reasons for not having a myGov account, apart from “other” and “unsure”, were: “lack of awareness/information”, “creating an account is not a priority”, and “difficulties accessing/creating an account”. In the follow up survey, the top three common reasons for not having a myGov account, apart from “unsure”, were: “creating an account is not a priority”; “having an account is unnecessary”; and “lack of computer/internet access” (Table 53).

Table 52: Number and proportion of respondents who had a myGov account

Response	Baseline		Follow up	
	n	%	n	%
Yes	20	29	23	43
No	33	48	24	44
Don't know	16	23	7	13
Total	69	100	54	100

Table 53: Reasons for not creating a myGov account

Baseline			Follow up		
Category	n	%	Category	n	%
Unsure	6	20	Creating an account is not a priority	7	28
Lack of awareness/information	5	17	Having an account is unnecessary	5	20
Creating an account is not a priority	4	13	No internet/computer access	5	20

Baseline			Follow up		
Category	n	%	Category	n	%
Difficulties accessing/creating an account	4	13	Unsure	5	20
Not prompted by Government/healthcare providers to create one	1	3	Lack of awareness/information	2	8
Having an account is unnecessary	1	3	Others (e.g., forgotten the details; have not created an account yet; prefer traditional method)	1	4
Others (e.g., forgotten the details; have not created an account yet; prefer traditional method)	9	31			
Total	30	100	Total		100

My Health Record:

Table 54 shows that in the baseline survey, most respondents (68%) had not previously heard about the My Health Record system. In the follow-up survey, close to half of the respondents had. However, a Chi-Square Goodness-of-Fit test indicated the difference in proportion of responses between baseline and follow up to be non-significant, $\chi^2(1, n = 45) = 2.16, p = .142$ (NS).

Respondents were also asked to indicate whether they had received any written information about the My Health Record. Most respondents stated they had not (Table 55). The response pattern is consistent across both surveys, $\chi^2(1, n = 50) = .54, p = .464$ (NS).

Those who indicated that they received written information or had heard about the My Health Record system were asked to indicate where they had heard or received information about the My Health Record system. In both surveys, respondents were most likely to state that they received information or heard about the My Health Record system through other sources (e.g. social media, word of mouth). In both surveys, approximately one-fifth of respondents received information or had heard about the My Health Record system from their healthcare providers (Table 56).

Table 54: Number and proportion of respondents who had previously heard about the My Health Record system

Response	Baseline		Follow up	
	n	%	n	%
Yes	19	32	19	42
No	40	68	26	58
Total	59	100	45	100

Table 55: Number and proportion of respondents who indicated that they had received written information about the My Health Record system

Response	Baseline		Follow up	
	n	%	n	%
Yes	22	37	16	31
No	37	63	35	69

Response	Baseline		Follow up	
	n	%	n	%
Total	59	100	51	100

Table 56: Sources of information about the My Health Record system

Sources of information	Baseline		Follow up	
	n	%	n	%
National media	2	6	6	16
Local media	7	22	4	10
myGov website	3	9	5	13
Other Government website	0	0	1	3
Other website	0	0	0	0
Healthcare provider (e.g. GP, nurses, etc)	6	19	8	21
Others (e.g., Social media, word of mouth, local community carers, government workers, letters)	14	44	14	37
Total responses	32	100	38	100

Note: respondents were not limited to a single response

Table 57 demonstrates that in both surveys, most respondents did not have a My Health Record. A Chi-Square Goodness-of-Fit test indicated no significant difference the proportion of respondents who indicated that they have a My Health Record⁶⁷ at baseline and follow up, $\chi^2(1, n = 53) = .10, p = .920$ (NS).

Table 57: Respondents who have registered for a My Health Record

Baseline			Follow Up		
Response	n	%	Response	n	%
Yes	6	17	Yes (prior to March 31)	3	6
			Yes (since March 31)	5	9
No	24	92	No	33	62
Don't know	1	4	Don't know	12	23
Total	26	100	Total	53	100

Respondents with a My Health Record

In the follow up survey, respondents who indicated that they had a My Health Record were also asked whether they had attempted to register for one. Responses were relatively equally distributed (Table 58).

When asked whether they received a letter informing them that a My Health Record was created for them, six out of nine respondents said 'Yes' (Table 59).

At both baseline and follow up surveys, those respondents who indicated they had a My Health Record were asked to state how long it took them to set it up, with relatively evenly distributed responses

⁶⁷ For the baseline survey, respondents without a My Health Record are defined as those who responded "No" and "Don't know" in the follow up survey. For the follow up survey, respondents with a My Health Record are defined as those who had a My Health Record prior to 31 March 2016 and those who had a My Health Record created since 31 March 2016.

across both survey time-points (Table 60). Most respondents at both baseline and follow up had not set up their privacy settings (Table 61), and had not accessed their My Health Record (Table 62).

At both baseline and follow up surveys, very few respondents indicated whether the information in their My Health Record was useful (≤ 5 responses at each time point; see Table 63).

Table 58: Number of respondents at follow up who had attempted to register for a My Health Record

Attempted to register for a My Health Record	n
Yes	3
No – a My Health Record was created on my behalf as part of the trial	2
Don't know	3
Total	8

Table 59: Number of respondents, in the follow up survey, who indicated that they received a letter informing them that a My Health had been created for them

Receiving a letter about the automatic creation of a My Health Record	n
Yes	6
No	0
Don't know	2
I already have a My Health Record prior to receiving the letter	1
Total	9

Table 60: Time taken to set up a My Health Record

Time taken to set up a My Health Record	Baseline	Follow up
	n	n
0 - 9 minutes	2	2
10 - 15 minutes	2	2
16 - 30 minutes	2	1
31 - 60 minutes	1	2
Total	7	7

Table 61: Number of respondents who had set up privacy settings in their My Health Record

Setting up privacy settings for the My Health Record	Baseline	Follow up
	n	n
Yes	2	1
No	5	7
Total	7	8

Table 62: Number of respondents who had accessed their My Health Record in the previous 4 weeks

Accessed My Health Record	Baseline	Follow up
	n	n
Yes	3	0
No	4	9
Total	7	9

Table 63: Number of respondents who indicated there was useful information in their My Health Record

Any useful information	Baseline	Follow up
	n	n
Yes	2	1
No	2	1
Total	4	2

Table 64 shows very few respondents indicated how they used their My Health Record in the baseline and follow up surveys (≤7 responses for each activity in the follow up survey).

Two respondents in the baseline survey indicated that they were more informed about the healthcare they received because of the My Health Record (Table 65). More respondents in the follow up survey than those at baseline indicated that they were actively attempting to improve their own health because of the My Health Record.

Similarly, to the baseline survey, most respondents in the follow up survey were unsure about their intentions to access the My Health Record in the next four months (Table 66).

Table 64: Number of respondents who used the functions within the My Health Record system

Activity conducted when using the My Health Record system	Baseline	Follow up
	n	n
View documents completed by healthcare provider	2	1
View information about any of current or past prescriptions	2	0
Upload a document	0	0
Provide any information about current or past health	0	0
Other	1	0
None of the above	1	1
Prefer not to say	1	0

Note: respondents were not limited to a single response

Table 65: Respondents' attitudes towards the My Health Record

Because of the My Health Record, respondents were:	Baseline	Follow up
	n	n
More informed about the health care received	4	3
More involved in making decisions about healthcare	2	1
More aware about own health	2	1
Actively attempting to improve own health	2	5
Other	0	2
None of the above	2	0

Note: respondents were not limited to a single response

Table 66: Respondents' intention to access the My Health Record in the next four months

Intended usage of the My Health Record in the next four months	Baseline	Follow up
	n	n
Increase the number of times accessing My Health Record	1	0

Intended usage of the My Health Record in the next four months	Baseline	Follow up
	n	n
Decrease the number of times accessing My Health Record	0	0
Access My Health Record about the same number of times	1	1
Cancel My Health Record	0	0
Don't know	5	8
Total	7	9

Table 67 demonstrates respondents' confidence in their ability to use the My Health Record system for a range of functions (1 = "total lack of confidence" to 5 = "extremely confident"). In the baseline survey, respondents were overall "Confident" (i.e. 3) to "Very Confident" (i.e. 4) in their ability to use the My Health Record. Overall, respondents at follow up were 'Confident' (i.e. 3) in their ability to use it.

Respondents in the follow up survey rated, on a scale of 1 = "not at all" to 5 = "to a great extent", whether they had observed that members of their healthcare provider team had worked better together because of the My Health Record. (Table 68).

Table 69 shows that in both surveys, very few respondents commented on the benefits of My Health Record system.

Table 67: Respondents' level of confidence to use the My Health Record system

Respondents' confidence in using My Health Record to	Baseline				Follow up			
	n			Mean (SD)	n			Mean (SD)
	Number of responses	"Confident" to "Very Confident"	"Don't know"		Number of responses	"Confident" to "Very Confident"	"Don't know"	
Change privacy setting	5	4	2	4.71 (1.25)	8	3	1	3.00 (1.63)
View documents	6	3	0	3.71 (1.25)	8	5	0	3.00 (1.31)
Upload documents or update details	7	4	0	3.57 (1.40)	8	5	0	3.00 (1.31)
Discuss their My Health Record with doctors or other healthcare providers	7	6	0	4.57 (1.51)	8	5	0	3.00 (1.31)
Cancel My Health Record	5	4	2	3.57 (1.40)	8	4	0	2.75 (1.17)

Table 68: Number and proportion of respondents, in the follow up survey, who had observed that having a My Health Record has meant that members of their healthcare provider team have worked better together

Observed that having a My Health Record has meant that members of their healthcare provider team have worked better together	People who responded	"Somewhat" to "A great extent"	"Don't know"	Mean (SD)
	9	5	0	2.78 (1.20)

Table 69: Benefits to respondents of having a My Health Record

Baseline		Follow up	
Category	n	Category	n
Don't know	2	Don't know	2
To monitor/keep track of my health	1	To provide high quality of care	1
To have access to up-to-date and accurate information for individuals and healthcare providers	1	Have easy access of records for healthcare providers	1
For individuals to have control over the access/view and personalised records	1	Don't see any benefits	1
Don't see any benefits	1		
Other (e.g., easy and useful)	1		
Total	7	Total	5

Respondents who did not have a My Health Record (or were not sure)

In both the baseline and follow up surveys, most respondents without a My Health Record had not attempted to register for one (Table 70). Of the 45 respondents in the follow up survey who indicated that they did not have a My Health Record or were unsure whether they had one, 38 had not received a letter informing them that a My Health Record was being created for them (Table 71).

In the follow up survey, those who had not attempted to register for a My Health Record were asked to indicate whether they had opted out from having a My Health Record. None of the respondents indicated that they had opted out (Table 72).

Respondents in both surveys were asked to describe the expected benefits from having a My Health Record. The two most common benefits reported in the baseline survey were: “don't know”, and “sharing of information between healthcare providers”. In the follow up survey, the most common responses were: “easy access to records for healthcare providers”, and “don't know” (Table 73).

Table 70: Number and proportion of respondents who had not attempted to register for a My Health Record

Baseline			Follow Up		
Attempted to register for a My Health Record	n	%	Attempted to register for a My Health Record	n	%
Yes	5	8	Yes	2	4
No	56	92	No	36	80
Don't know	0	0	Don't know	7	16
Total	61	100	Total	45	100

Table 71: Number and proportion of respondents who, in the follow up survey, received a letter informing them that a My Health Record was being created for them

Did respondents receive a letter informing them that a My Health Record was being created for them?	n	%
Yes	2	4
No	38	84
Don't know	5	11
Total	45	100

Table 72: Number and proportion of respondents who opted out from having a My Health Record

Respondents who opted out from having a My Health Record	n
Yes	0
No	36

Respondents who opted out from having a My Health Record	n
Total	36

Table 73: Expected benefits from having a My Health Record expressed by respondents

Baseline		Follow up	
Category	n	Category	n
Don't know	32	To have easy access to records for healthcare providers	13
Sharing of health information between healthcare providers	6	Don't know	9
To have easy access to records for healthcare providers	3	Have one centralised medical record for individuals and healthcare providers	6
For individuals to better monitor their own health	3	Do not see any benefits	3
To have access to up-to-date and accurate information for individuals and healthcare providers	3	Sharing of health information between healthcare providers	2
For individuals to have control over the access/view and personalised records	2	For individuals to better monitor their own health	2
Other (e.g., accurate data and statistics to close the gap with Indigenous health issues)	2	To have access to up-to-date and accurate information for individuals and healthcare providers	1
To provide high quality of care	1	For individuals to have control over the access/view and personalised records	1
Do not see any benefits	1		
Total Responses	53	Total Responses	37

Level of confidence in the confidentiality and security of the My Health Record

All respondents in the follow up survey were asked to rate their level of confidence (1 = “total lack of confidence” to 5 = “extremely confident”) regarding the security and confidentiality aspects of the My Health Record system (Table 74). Overall, respondents at follow up were “Somewhat confident” (i.e., 2) or “Confident” (i.e. 3).

Table 74: Respondents' level of confidence, in the follow up survey, in the confidentiality and security of the My Health Record

Respondents' level of confidence in the confidentiality and security of the My Health Record	Follow up			
	n			Mean (SD)
	Number of respondents	“Confident” to “Extremely confident”	“Don't know”	
The ability of the My Health Record system to maintain your information as confidential and secure	54	26	9	2.64 (0.91)
That the My Health Record is secure from external threats (e.g., safe from hackers or online breaches)	56	22	9	2.41 (1.04)
the Government's capacity to keep your personal information held in the My Health Record confidential	53	23	7	2.33 (0.94)

Respondents in the follow up survey were also asked to indicate their level of trust in the Government and others to treat their medical information appropriately (on a rating scale of 1 = ‘not at all’ to 5 = ‘to

a great extent'). On average, respondents "Somewhat" (i.e., 3) trusted the Government or others to treat their medical information appropriately (Table 75).

Table 75: Respondents' level of trust, in the follow up survey, in the Government/others to treat their medical information appropriately in the follow up survey

Level of trust in the Government/others to treat their medical information appropriately	Follow up			Mean (SD)
	n			
	Number of respondents	"Don't know"	"Somewhat" to "To a great extent"	2.94 (1.20)
	54	32	8	

In both surveys, most respondents indicated that a healthcare provider's use of the My Health Record would either increase their likelihood of using these healthcare providers, or not influence their decision to see a particular healthcare provider (Table 76). Slight difference in reporting response was noted between the baseline and follow up survey.

Table 76: Respondents' likelihood of visiting a healthcare provider who uses a My Health Record

Likelihood of visiting a healthcare provider who uses the My Health Record system	Baseline		Follow up	
	n	%	n	%
Increase the likelihood of using them	14	22	16	30
Decrease the likelihood of using them	0	0	1	2
Does not affect decision to using them	29	46	20	38
Don't know	20	32	16	30
Total	63	100	53	100

Respondents - remote setting

A total of 41 respondents participated in the baseline pen and paper survey in March 2016, and another 31 responded participated in the follow up survey in September 2016. Respondents in both surveys were recruited from remote areas in North Queensland.

More females than males participated in both surveys. (Females represented 58.5% and 54.8% for baseline and follow up surveys respectively) (Table 77). A Chi-Square Goodness-of-Fit test shows no significant difference in the gender split between baseline and follow up surveys $\chi^2(1, n = 30) = .07, p = .795$ (NS). There was also no significant difference in respondents' age between the baseline and follow up surveys, $t(70) = -0.95, p = .345$ (NS).

Table 77: Gender and age distribution of respondents in the baseline and follow up surveys

Gender	Baseline	Follow up
Male	17	13
Female	24	17
Age mean (SD)	40.0 (14.4)	41.9 (14.4)
Age range (years old)	18 to 73	18 to 68

In both surveys, most respondents did not have private health insurance.

Table 78: Number and proportion of respondents by types of private health insurance

Private Health Insurance	Baseline		Follow up	
	n	%	n	%
No	40	98	27	87
Yes - hospital only	0	0	0	0
Yes- hospital and extras	1	2	3	10
Prefer not to say	0	0	1	3
Total	41	100	31	100

In both surveys, most respondents also indicated that they speak only English at home.

Table79: Number and proportion of respondents who indicated whether they speak another language apart from English at home

Response	Baseline		Follow up	
	n	%	n	%
Yes	5	12	1	3
No, I speak only English	36	88	27	91
Prefer not to say	0	0	1	3
Don't know	0	0	1	3
Total	41	100	30	100

Figure 8 below shows the living arrangements indicated by the respondents in the baseline and follow up surveys. Compared to the baseline, there were more respondents in the follow up survey who lived alone. A Chi-Square Goodness-of-Fit test indicated a significant difference in number of respondents living alone and those living with others (including their children)⁶⁸ between baseline and follow up surveys, $\chi^2(1, n = 26) = 4.27, p = .04$.

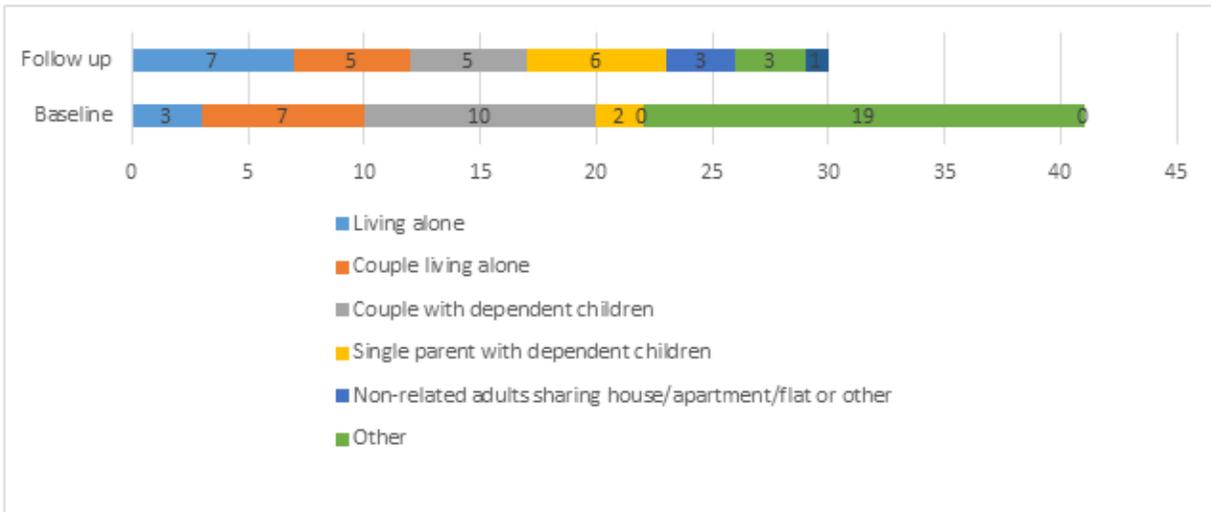


Figure 31: Living situation as indicated by respondents in the baseline and follow up surveys

At both survey time-points, most respondents indicated that they did not receive any pension from the Government (Table 80).

⁶⁸ The analysis excluded those who stated "Others".

Table 80: Number and proportion of respondents who had or had not received a pension from the Government.

Response	Baseline		Follow up	
	n	%	n	%
Yes	5	12	7	24
No	36	88	22	76
Prefer not to say	0	0	0	0
Total	41	100	29	100

Figure 9 also shows that most respondents in the baseline and follow up surveys indicated that their highest education level was ‘Year 10 or equivalent’. A Chi-Square Goodness-of-Fit test indicated no significant difference in the proportion of respondents who achieved an education level of “Certificate I to IV or above” between baseline and follow up surveys⁶⁹, $\chi^2(1, n = 31) = 2.78, p = .095$.

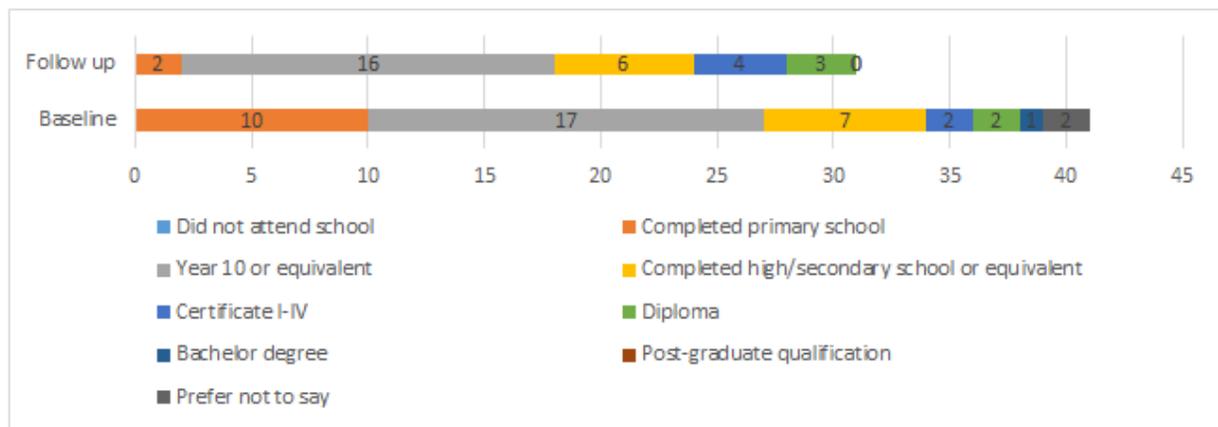
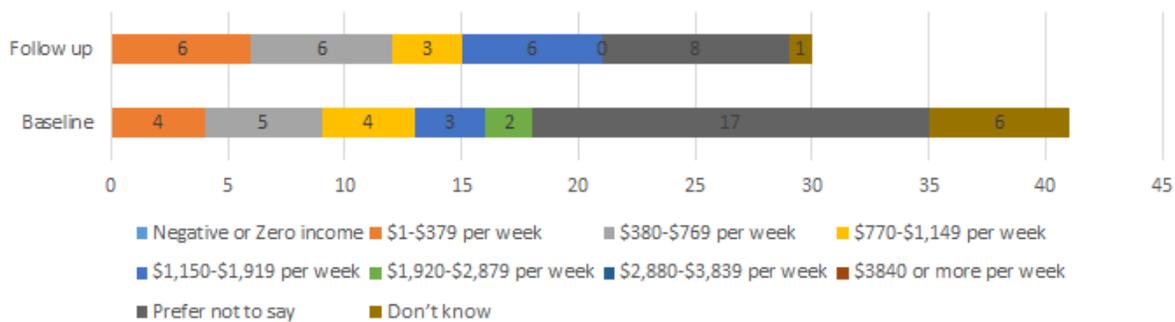


Figure 32: Education level of respondents at baseline and follow up

Figure 10 presents the total household income reported by respondents in both baseline and follow up surveys. Apart from those who did not indicate their levels of household income, defined as “prefer not to say” and “other”, respondents’ levels of household income were similar between baseline and follow up.⁷⁰



⁶⁹ The analysis excluded respondents who indicated “Others” and “Prefer not to say”.

⁷⁰ Chi-Square Goodness-of-Fit Test could not be conducted due to inadequate power for the other categories.

Figure 33 Income level of respondents at baseline and follow up

Figure 11 demonstrates that, compared to the follow up survey, more respondents in the baseline survey were employed for fewer than 30 hours per week for wages, salary or payment in kind. A Chi-square Goodness-of-Fit test indicated no significant difference between baseline and follow up surveys in the proportion of respondents who were employed and those who were unemployed^{71,72}, $\chi^2(1, n = 28) = .58, p = .447$ (NS).

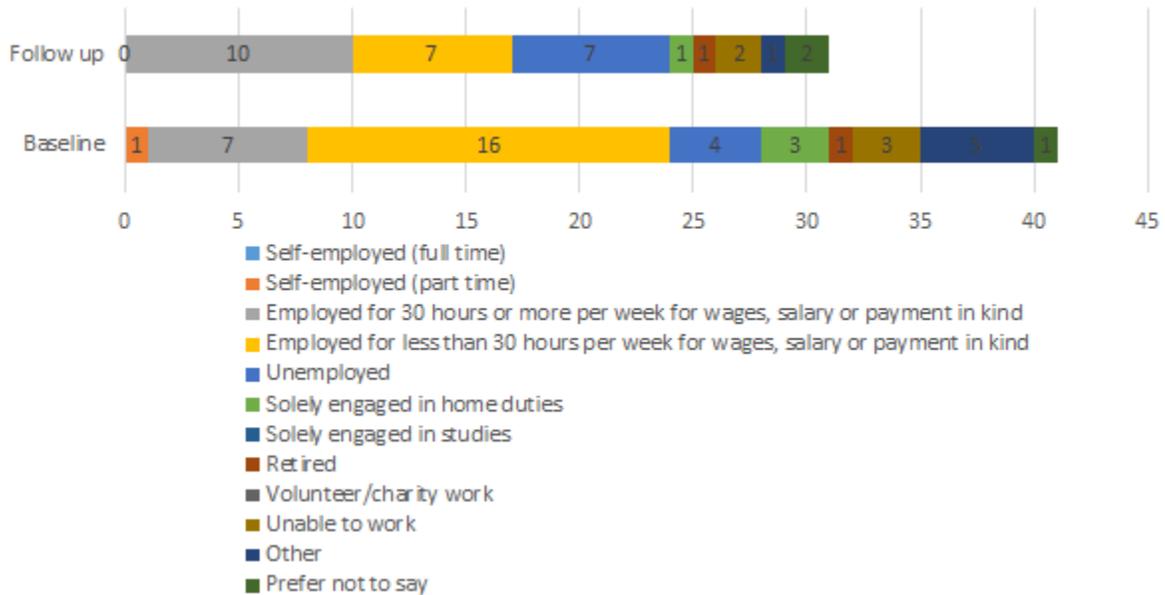


Figure 34: Employment status at baseline and follow up

In both surveys, most respondents identified as Aboriginal and/or Torres Strait Islander (Table 81).

Table 81: Number and proportion of respondents who identified as Aboriginal and/or Torres Strait background and non-Indigenous

Aboriginal and Torres Strait Islander background	Baseline		Follow Up	
	n	%	n	%
Aboriginal	27	66	16	54
Torres Strait Islander	1	2	0	0
Aboriginal and Torres Strait Islander	11	27	13	43
Non-Indigenous	2	5	1	3
Total	41	100	30	100

10 respondents in the follow up survey indicated that they lived alone whereas 13 respondents in the baseline survey indicated that three adults were living at home the night prior to the survey being undertaken. In both baseline and follow up surveys, over 10 respondents lived without children at home (Table 82).

⁷¹ Those who were unemployed included people who are: retired, unable to work, solely engaged in home duties or studies and volunteers. People who are self-employed and employed for wages, salary or payment in kind, regardless of the hours they worked were classified as those who were employed.

⁷² The analysis excluded respondents who indicated “Others” and “Prefer not to say”.

Table 82: Number and proportion of adults and children in the respondents' households

Number of adults living at home	Baseline		Follow up	
	n	%	n	%
0	1	2	0	12
1	4	10	1	3
2	8	5	2	4
3	13	5	3	4
4	6	5	4	2
5	7	1	5	2
6	1	1	6	1
Total	40	29	Total	38

Health Status:

Most respondents in the baseline and follow up surveys reported having “excellent” or “very good” health (Table 83). There was no significant difference in respondents’ rating of their health status in the baseline survey (M = 2.32, SD = 1.01) and follow up survey (M = 2.24, SD = 0.83), $t(68) = .34$, $p = .733$ (NS).

In the baseline survey, most respondents indicated that they did not have any health problem that has lasted for more than six months (Table 84). A Chi-Square Goodness-of-Fit test indicates there was no significant difference in the proportion of follow up survey respondents with a health problem lasting more than six months (53.3%) compared with 37% of respondents at the baseline, $\chi^2(1, n = 30) = 3.10$, $p = .078$ (NS).

Table 83: Respondents' current health status

Health Status	Baseline		Follow up	
	n	%	n	%
Excellent	8	19	6	21
Very Good	18	44	11	38
Fair	11	27	11	38
Poor	2	5	1	3
Prefer not to say	2	5	0	0
Total	41	100	29	100

Table 84: Number and proportion of responses about health problems that have lasted for more than six months

Response	Baseline		Follow up	
	n	%	n	%
Yes	15	37	16	53
No	25	61	14	47
Prefer not to say	1	2	0	0
Total	41	100	30	100

Internet connectivity:

Just over half of the respondents in the baseline survey had internet access; whereas in the follow up survey most respondents had internet access. The difference in the proportion of respondents with and without internet access between baseline and follow up surveys was significant, $\chi^2 (1, n = 29) = 8.23, p < .05$ (Table 85). This finding could be a maturation effect, in that internet became more accessible with time.

In both surveys, most respondents reported accessing the Internet through their mobile phones.

Table 85: Internet access

Response	Baseline		Follow up	
	n	%	n	%
Yes	23	56	24	83
No / Don't know	18	44	5	17
Total	41	100	29	100

Table 86: Location of internet connection

Internet connection	Baseline			Follow Up		
	At Home	On the phone	Somewhere else	At Home	On the phone	Somewhere else
Yes	7	20	5	9	17	3

Expectations to share health information:

Across both surveys, most respondents expected their healthcare centres to share their health information with other healthcare centres and hospitals as part of their healthcare.

Table 87: Number and proportion of respondents who expected their healthcare centres to share their health information with other centres and hospitals as part of their healthcare

Response	Baseline		Follow up	
	n	%	n	%
Yes	35	85	27	90
No	6	15	3	10
Total	41	100	30	100

myGov account:

Compared to the baseline survey, more respondents in the follow up survey were registered for a myGov account. A Chi-Square Goodness-of-Fit test indicated a significant difference in the proportion of responses between the baseline and follow up surveys, $\chi^2(1, n = 28) = 18.3, p < .05$.

In both surveys, respondents who did not have a My Health Record were asked to provide reasons for not having one. In the baseline survey, the top three common reasons for not having a myGov account were: "having an account is unnecessary"; "lack of internet/computer access"; and "creating an account is not a priority". Respondents in the follow up survey were more likely to indicate that "creating an account is not a priority"; "having an account is unnecessary"; and "lack of awareness".

Table 88: Number and proportion of respondents who had a myGov account at the baseline and follow up surveys

Response	Baseline		Follow up	
	n	%	n	%
Yes	12	30	19	63
No	27	68	9	30
Don't know	1	2	2	7
Total	40	100	30	100

Table 89: Reasons for not creating a myGov account

Baseline		Follow up	
Category	n	Category	n
Having an account is unnecessary	7	Creating an account is not a priority	3
Lack of internet/computer access	6	Having an account is unnecessary	2
Creating an account is not a priority	2	Lack of awareness/information	1
Lack of awareness/information	1	Difficulties accessing/creating an account	1
Unsure	1	Other	2
Others (e.g. prefer face to face communication; was not prompted by the Government)	4		
Total responses	21	Total responses	9

My Health Record:

Table 90 shows that in both the baseline and follow up surveys, approximately half of the respondents indicated that they previously heard about the My Health Record system. A Chi-Square Goodness-of-Fit test indicated the difference in the proportion of responses to be non-significant, $\chi^2(1, n = 25) = .160, p = .689$.

Respondents in the follow up survey were more likely to state that they had not received any written information about the My Health Record system than those in the baseline survey (Table 91). The difference in the proportion of responses between the baseline and follow up surveys was significant, $\chi^2(1, n = 30) = 9.73, p < .05$. This is likely to be the respondents' recall error. It is also possible that some respondents did not receive any written information about the My Health Record system.

The respondents who had indicated that they received written information or had heard about the My Health Record system were asked to indicate where they had heard or received this information. Of those who responded in the baseline and follow up surveys, most indicated that they heard or received information about the My Health Record system from their healthcare providers (Table 92).

Table 90: Number and proportion of respondents who had previously heard about the My Health Record system

Response	Baseline		Follow up	
	n	%	n	%
Yes	15	48	13	52
No	16	52	12	48
Total	31	100	25	100

Table 91: Number and proportion of respondents who indicated that they had received written information about the My Health Record system

Response	Baseline		Follow up	
	n	%	n	%
Yes	25	64	11	37
No	14	36	19	63
Total	39	100	30	100

Table 92: Sources of information about the My Health Record system

Sources of information	Baseline	Follow up
	n	n
National media	2	5
Local media	1	0
myGov website	1	3
Other Government website	1	1
Other website	1	1
Healthcare provider (e.g., GP, nurses, etc)	3	6
Others (e.g., Social media, word of mouth, local community carers, government workers, letters)	17	9
Total responses	26	25

Note: Respondents were not limited to a single response.

Respondents who indicated that they have a My Health Record

Only one respondent in the baseline survey indicated that they had a My Health Record. The number of respondents in the follow up survey who attempted to register for a My Health Record is shown in Table 93.

Only 14 respondents in the follow up survey responded to the question about whether they had attempted to register for a My Health Record and whether they had received a letter informing them that a My Health Record was created for them. 10 respondents indicated that they did not attempt to register for a My Health Record because they were created on their behalf as part of the trial (Table 94). Nine respondents indicated that they did not receive any letter informing them that a My Health Record was created for them (Table 95).

Table 93 presents the frequency and proportion of respondents who indicated whether they had a My Health Record. Compared to the baseline survey, a significantly higher proportion of respondents in the follow up survey indicated that they have a My Health Record⁷³, $\chi^2(1, n = 31) = 116.18, p < .001$.

Table 93: Number and proportion of participants who indicated that they have and have a My Health Record

Response	Baseline		Follow Up		
	n	%	Response	n	%
Yes	1	4	Yes (prior to March 31)	2	6

⁷³ The categories used for the statistical analysis were classified as the following: for the baseline survey, respondents without a record is defined as those who responded “No” and “Don’t know” in the follow up survey. For the follow up survey, respondents with a record is defined as those who had a record prior to March 31 and those who had a record created since March 31.

Baseline			Follow Up		
Response	n	%	Response	n	%
			Yes (created since March 31	11	36
No	24	92	No	12	39
Don't know	1	4	Don't know	6	19
Total	26	100	Total	31	100

Table 94: Number and proportion of respondents at follow up who had attempted to register for a My Health Record

Attempted to register for a My Health Record	n	%
Yes	4	29
No – a My Health Record was created on my behalf as part of the trial	10	71
Total	14	100

Table 95: Number and proportion of respondents, at follow up, who indicated that they received a letter informing them that a My Health Record was created for them

Receiving a letter about the automatic creation of a My Health Record	n	%
Yes	3	21
No	9	65
Other (e.g., through a pamphlet)	2	14
Total	14	100

Table 96: Time taken to set up a My Health Record

Time taken to set up a My Health Record	Baseline	Follow up
	n	n
0 - 9 minutes	0	7
10 - 15 minutes	1	1
16 - 30 minutes	0	1
31 - 60 minutes	0	1
Total	1	10

The single respondent in the baseline study took 10 to 15 minutes to set up his/her My Health Record. Most respondents in the follow up survey took 0 to 9 minutes to set up their My Health Record (Table 96). Table 97 also shows that 10 out of 12 respondents in the follow up survey had not set up the privacy settings in their My Health Record. The respondent who had a My Health Record at baseline also had not set up privacy settings in their My Health Record.

Table 97: Number and proportion of respondents who had set up privacy settings in their My Health Record

Setting up privacy settings for the My Health Record	Baseline	Follow up
	n	n
Yes	0	2
No	1	10
Total	1	12

In both surveys, none of the respondents had accessed their My Health Record in the previous 4 weeks.

Table 98: Number and proportion of respondents who had accessed their My Health Record in the previous 4 weeks

Accessed My Health Record	Baseline	Follow up
---------------------------	----------	-----------

	n	n
Yes	0	0
No	1	12
Total	1	12

None of the respondents in the baseline survey responded to the question about usefulness of information in their My Health Record. Very few respondents in the follow up survey indicated whether they found useful information in their My Health Record (Table 99).

Table 99: Number and proportion of respondents in the follow up survey who indicated whether they found useful information in their My Health Record

Any useful information	n
Yes	1
No	1
Total	2

Similarly, the respondent in the baseline survey who had a My Health Record did not indicate whether he/she had used the functions within the My Health Record system. One respondent in the follow up survey indicated that they had viewed information about their current or past prescriptions.

Table 100: Number of respondents in the follow survey who had used the functions within the My Health Record system

Activity conducted when using the My Health Record system	Follow Up (n)
View documents completed by healthcare provider	0
View information about any of current or past prescriptions	1
Upload a document	0
Provide any information about current or past health	0
Other	0
None of the above	2
Prefer not to say	0

Note: Respondents were not limited to a single response.

The respondent in the baseline survey who had a My Health Record indicated that he/she was more informed about the healthcare received and was more aware about his/her health because of the My Health Record. Most respondents in the follow up survey indicated that they were more informed about the healthcare they had received and were more involved in making decision about their healthcare due to the My Health Record.

Table 101: Respondents' attitudes towards the My Health Record

Because of the My Health Record, they were:	Baseline	Follow up
	n	n
More informed about the health care received	1	7
More involved in making decisions about healthcare	0	7
More aware about own health	1	4
Actively attempting to improve own health	0	3
Other	0	2

Because of the My Health Record, they were:	Baseline	Follow up
	n	n
None of the above	0	3

Note: Respondents were not limited to a single response.

The respondent who had a My Health Record when the baseline survey was undertaken indicated that he/she did not know his/her intention to access the My Health Record in the next four months. Six respondents in the follow up survey reported that they were more likely to access their My Health Record in the next four months and another seven were unsure (Table 102).

Table 102: Respondents' intention to access the My Health Record

Respondents' intention in the next four months	Baseline	Follow up
	n	n
Increase the number of times accessing My Health Record	0	6
Decrease the number of times accessing My Health Record	0	0
Access My Health Record about the same number of times	0	0
Cancel My Health Record	0	0
Don't know	1	7
Total	1	13

Respondents in both baseline and follow up surveys were asked to rate their confidence in their abilities to use the My Health Record for a range of functions on a scale of (1 = "total lack of confidence" to 5 = "extremely confident").

The single respondent in the baseline survey who had a My Health Record was "Confident" in using the My Health Record to:

- change the privacy setting
- view documents
- upload documents or update details
- cancel the My Health Record

The respondent, however, was "somewhat confident" (i.e. 2) to use the My Health Record to discuss issues with his/her doctor or other healthcare providers.

Table 103 shows that overall, respondents in the follow up survey were "Somewhat Confident" (i.e. 2) to "Confident" (i.e. 3) in their ability to: change their privacy setting; view documents; and upload documents or update details in the My Health Record system. Respondents were also more likely to rate that they were "confident" (i.e. 3) to discuss their My Health Record with their doctors or other healthcare providers or to cancel their My Health Record if they chose.

Table 103: Respondents' level of confidence to use the My Health Record

Respondents' confidence in using My Health Record	Follow up			
	n			
	Total number of responses	Very confident and extremely confident	"Don't know"	Mean (SD)

Respondents' confidence in using My Health Record	Follow up			
	n			
Change privacy setting	14	5	2	2.25 (1.13)
View documents	12	4	2	2.10 (1.29)
Upload documents or update details	11	5	2	2.00 (1.32)
Discuss with doctors or other healthcare providers	11	8	1	2.80 (1.03)
Cancel My Health Record	11	7	3	3.25 (1.17)

Table 104 demonstrates respondents' indication in the follow up survey about whether they had observed that members of their healthcare provider team had worked better together because of the My Health Record from 1 = 'Not at all' to 5 = 'To a great extent'. On average, respondents indicated "very little" to "somewhat" about whether they had observed members of their healthcare provider team working better together because of the My Health Record.

Table 104: Respondents' indication of whether they had observed that having a My Health Record has meant that members of their healthcare provider team have worked better together

Observed that having a My Health Record has meant that members of their healthcare provider team have worked better together	Total respondents	'Somewhat' to 'A great extent'	Don't know"	Mean (SD)
	13	5	3	2.60 (1.65)

No one in the baseline survey reported any benefits from having a My Health Record. The following table presents benefits expressed in follow up survey.

Table 105: Frequency and responses expressed by respondents about the benefits from having a My Health Record at follow up

Benefits had from having a My Health Record:	n
No benefits	4
To have easy access of records for healthcare providers	2
To share information with others healthcare providers	1
All medical information is stored in one centralised location	1
Don't know the purpose/benefits	1

Respondents who indicated that they did not have a My Health Record (or unsure)

Of the 18 respondents in the follow up survey who indicated that they did not have a My Health Record or were unsure whether they had one, 13 indicated in the follow up survey that they had not received a letter informing them that a My Health Record was being created for them.

Table 106: Number and proportion of respondents in the follow up survey who did not have a My Health Record and did not receive a letter informing them that a My Health Record had been created for them

Did respondents receive a letter informing them that a My Health Record was being created for them?	n	%
Yes	4	23
No	13	77
Total	17	100

Most respondents in the baseline and follow up surveys had not attempted to register for a My Health Record (Table 107).

Table 107: Number and proportion of respondents who had attempted to register for a My Health Record

Baseline			Follow Up		
Attempted to register for a My Health Record	n	%	Attempted to register for a My Health Record	n	%
Yes	3	7	Yes	1	6
No	37	93	No	12	67
Don't know	0	0	Don't know	5	28
Total	40	100	Total	18	100

Only one respondent in the follow up survey opted out from having a My Health Record. He/she was asked to provide reasons for doing so, and indicated he/she did not see the purpose of having a My Health Record.

Table 108: Number and proportion of respondents who opted out from having a My Health Record at the follow up survey

Respondents who opted out from having a My Health Record	n	%
Yes	1	8
No	11	92
Total	12	100

Respondents in both the baseline and follow up surveys were asked to describe the benefits that they expected from having a My Health Record. Most respondents in the baseline survey indicated that the My Health Record would enable healthcare providers to provide high quality healthcare and have easy access to their health information. Respondents in the follow up survey also indicated the same benefits for healthcare providers (Table 109).

Table 109: Expected benefits from having a My Health Record expressed by respondents in the baseline and follow up survey

Baseline		Follow up	
Category	n	Category	n
To provide high quality healthcare	13	Have easy access of records for healthcare providers	4
Have easy access of records for healthcare providers	10	To share information between healthcare providers	3
Have one centralised medical record for individuals and healthcare providers	7	Don't know the benefits	3
For individuals to better monitor their own health	2	Have one centralised medical record for individuals and healthcare providers	2
For consumers to have control over the access/view and personalised records	1		
To have access to up-to-date and accurate information for individuals and healthcare providers	1		

Level of confidence in the security and confidentiality of the My Health Record system

All respondents in the follow up survey were asked to rate their level of confidence (1 = "total lack of confidence" to 5 = "extremely confident") regarding the security and confidentiality aspects of the My Health Record system (Table 110). On average, respondents were "somewhat confident".

Table 110: Means and standard deviations of respondent’s rating about their level of confidence in the confidentiality and security of the My Health Record

Respondents’ level of confidence in the confidentiality and security of the My Health Record	Follow up			
	n			Mean (SD)
	Total number of responses	“Confident” to “Very confident”	‘Don’t know’	
The ability of the My Health Record system to maintain your information as confidential and secure	31	6	6	2.52 (1.05)
That the My Health Record is secure from external threats (e.g., safe from hackers or online breaches)	30	8	10	2.48 (1.33)
The Government’s capacity to keep your personal information held in the My Health Record confidential	30	13	7	2.70 (1.11)

Respondents in the follow up survey were also asked to indicate their level of trust in the Government and others to treat their medical information appropriately (on a scale of 1 = ‘Not at all’ to 5 = ‘To a great extent’). On average, respondents “somewhat” trusted the Government and others to treat their My Health Records appropriately.

Table 111: Respondents’ level of trust in the Government/others to treat their medical information appropriately

Level of trust in the Government/others to treat their medical information appropriately	Follow up			
	n			Mean (SD)
	Total number of responses	Somewhat’ to ‘A great extent’	‘Don’t know’	
	31	18	2	3.00 (1.22)

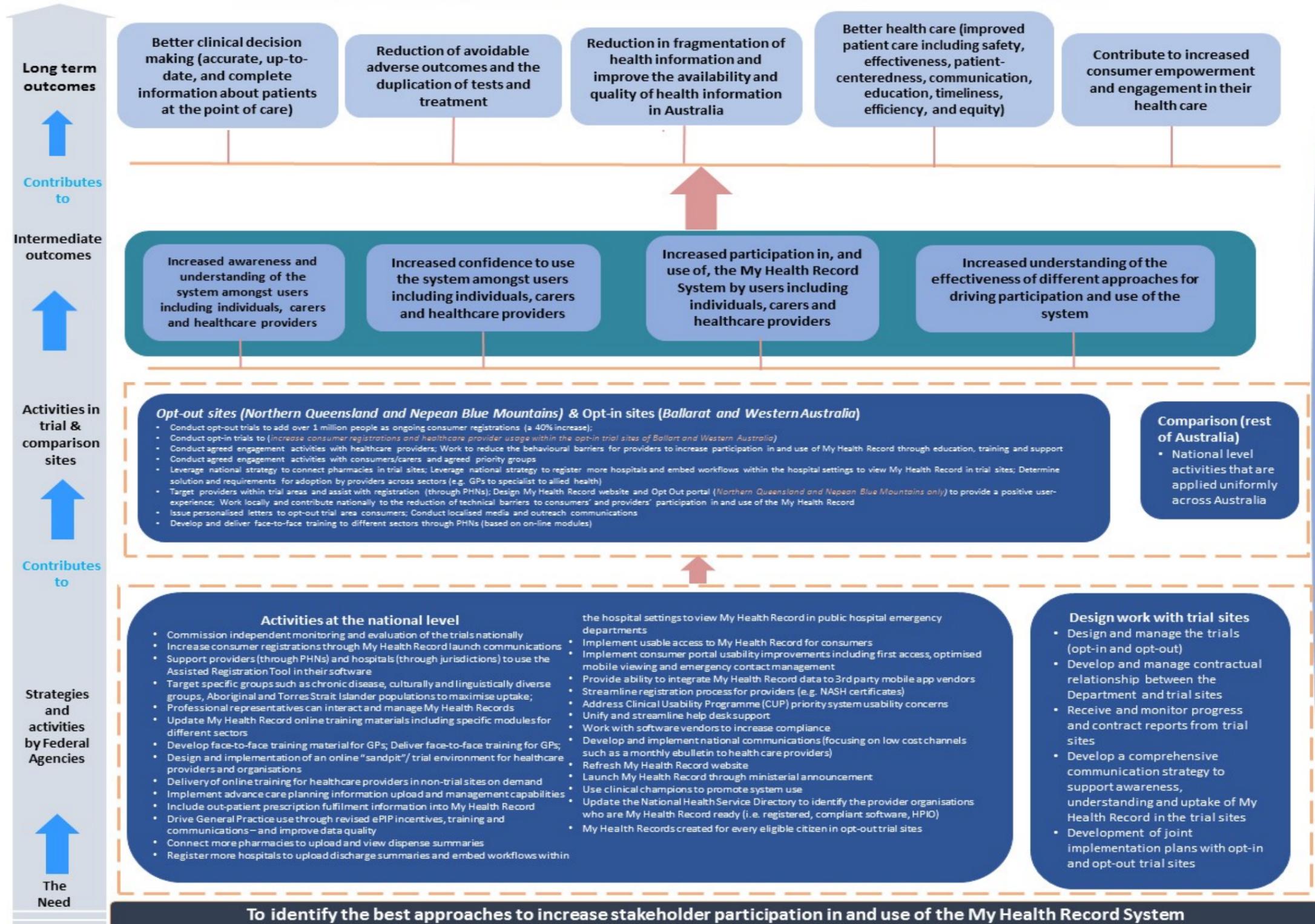
Most respondents in the baseline survey indicated that healthcare providers’ use of My Health Record system would increase the respondents’ likelihood of using the healthcare providers. In the follow up survey, responses were more evenly distributed.

Table 112: Respondents’ likelihood of visiting a healthcare provider who uses a My Health Record

Likelihood of visiting a healthcare provider who uses a My Health Record	Baseline		Follow up	
	n	%	n	%
Increase the likelihood of using them	32	78	11	36
Decrease the likelihood of using them	2	5	1	3
Does not affect decision to use My Health Record	2	5	7	23
Don’t know	5	12	12	39
Total	41	100	31	100

Appendix 15 National Program Logic

National program logic of the participation trials for the My Health Record system



External impacting factors:

Parallel national and state and territory initiatives (e.g. NDIS), editorial coverage of the trials not generated by trials themselves, election cycle, MBS Review, greater uptake at end of financial year due to MyGov Gateway use, Aged Care Gateway, implementation of competing mobile applications, level of satisfaction with the health system in the population, the extent of IT literacy in the citizenry, the level of trust in government in the population, the impact of previous state and territory and national efforts on the level and nature of word of mouth about electronic records, changes to e-health governance in Australia (establishment of the Australian Digital Health Agency), NeHTA work to promote e-health uptake and use

Long Term Outcomes	Better clinical decision making (accurate, up-to-date, and complete information about patients at the point of care)	Reduction of avoidable adverse outcomes and the duplication of tests and treatment	Reduction in fragmentation of health information and improve the availability of quality of health information in Australia	Better health care (improved patient care including safety, effectiveness, patient-centeredness, communication, education, timeliness, efficiency and equity)	Contribute to increased consumer empowerment and engagement in their healthcare
Intermediate Outcomes	Increased awareness and understanding of the system amongst users including individuals, carers and healthcare providers	Increased confidence to use the system amongst users including individuals, carers and healthcare providers	Increased participation in, and use of, the My Health Record system by users including individuals, carers and healthcare providers	Increased understanding of the effectiveness of different approaches for driving participation and use of the system	
Activities in trial and comparison sites	<p>Opt-out sites (Northern Queensland and Nepean Blue Mountains) & Opt-in sites (Ballarat and Western Australia)</p> <ul style="list-style-type: none"> - conduct opt-out trials to add over 1 million peoples as ongoing consumer registrations (a 40% increase) - conduct opt-in trials to increased consumer registrations and healthcare provider usage within the opt-in trial areas of Ballarat and Western Australia - Conduct agreed engagement activities with healthcare providers; work to reduce the behavioural barriers for providers to increase participation in and use of My Health Record through education, training and support - conduct agreed engagement activities with consumers/carers and agreed priority groups - leverage national strategy to connect pharmacies in trial sites; leverage national strategy to register more hospitals and embed workflows within the hospital settings to view My Health Records in trial sites; determine solution and requirements for adoption by providers across sectors (e.g. GPs to specialist to allied health) - target providers within trial areas and assist with registration (through PHNs); design My Health Record website and Opt-Out portal (Northern Queensland and Nepean Blue Mountains only) to provide a positive user-experience; work locally and contribute nationally to the reduction of technical barriers to consumers' and providers' participation in and use of the My Health Record - Issue personalised letters to opt-out trial area consumers; conduct localised media and outreach communications - develop and deliver face-to-face training to different sectors through PHNs (based on online modules) 				<p>Comparison (rest of Australia)</p> <ul style="list-style-type: none"> - national level activities that are applied uniformly across Australia
Strategies and activities by Federal Agencies	<p>Activities at the national level</p> <ul style="list-style-type: none"> - Commission independent monitoring and evaluation of the trials nationally - increase consumer registrations through My Health Record launch communications - support providers (through PHNs) and hospitals (through jurisdictions) to use the Assisted Registration Tool in their software - Target specific groups such as chronic disease, culturally and linguistically diverse groups, Aboriginal Torres Strait Islander populations to maximise uptake - Professional representatives can interact and manage My Health Records - Update My Health Record online training materials including specific modules for different sectors - develop face-to-face training material for GPS; deliver face-to-face training for GPs - design and implementation of an online 'sandpit'/trial environment for healthcare providers and organisations - delivery of online training for healthcare providers in non-trial sites on demand - implement advance care planning information upload and management capabilities - include out-patient prescription fulfilment information into My Health Record - drive General Practice use through revised ePIP, training and communications and improve data quality - connect more pharmacies to upload and view dispense summaries - register more hospitals to upload discharge summaries and embed workflows within the hospital settings to view My Health Record in public hospital emergency departments - implement usable access to My Health Record for consumers - implement consumer portal usability improvements including first access, optimised mobile viewing and emergency contact management - provide ability to integrate My Health Record with 3rd party mobile app vendors - streamline registration process for providers (e.g. NASH certificates) - Address Clinical Usability Programme (CUP) priority system usability concerns - unify and streamline help desk support - work with software vendors to increase compliance - develop and implement national communications (focusing on low cost channels such as a monthly ebulletin to healthcare providers) - refresh My Health Record website - launch My Health Record through ministerial announcement - use clinical champions to promote system use - update the National Health Service Directory to identify provider organisations who are My Health Record ready (i.e. registered, compliant software, HPIO) - My Health Records created for every eligible citizen in opt-out trial sites 			<p>Design work with trial sites</p> <ul style="list-style-type: none"> - design and manage the trials (opt-in and opt-out) - develop and manage contractual relationship between the Department and trial sites - receive and monitor progress and contract reports from trial sites - develop a comprehensive communication strategy to support awareness, understanding and uptake of My Health Record in the trial sites - Development of joint implementation plans with opt-in and opt-out trial sites 	
The Need	To identify the best approaches to increase stakeholder participation in and use of the My Health Record system				
External Impacting Factors	Parallel national and state and territory initiatives (e.g. NDIS), editorial coverage of the trials not generated by trials themselves, election cycle, MBS Review, greater uptake at end of financial year due to MyGov Gateway use, Aged Care Gateway, implementation of competing mobile applications, level of satisfaction with the health system in the population, the extent of IT literacy in the citizenry, the level of trust in government in the population, the impact of previous state and territory and national efforts on the level and nature of word of mouth about electronic records, changes to e-health governance in Australia (establishment of the Australian Digital Health Agency), NeHTA work to promote e-health uptake and use.				

