*A picture containing text

Description automatically generated* *A picture containing text, clipart

Description automatically generated*

**Participant Information Sheet**

**GP Advisory Group**

**Title:** Early intervention community-based multi-disciplinary model of care for adolescents with chronic pain

**Primary Investigator:** Dr Carolyn Berryman

Co-Investigators: Dr Simone De Morgan, Dr Nicki Ferencz, Dr Susie Lord, Prof Fiona Blyth, Ass Prof Anne Burke, Dr Dianne Wilson

# **What is the purpose of this research?**

The purpose of this research is to co-design an early intervention model of care based in the community to better manage chronic pain for adolescents. The care model will involve partnership with GPs and ensure connected and coordinated care across primary care and on to tertiary care (such as pain management units). This model of care will be co-designed with adolescents with chronic pain and their parents/carers as well as the research team and other experts in South Australia.

In addition to the two consumer advisory groups formed as part of this project – a Parent/Carer Advisory Group and a Youth Advisory Group and 15 interviews with adolescents with chronic pain - we wish to interview 5 GPs to provide the GP perspective on the model of care.

# **What does my participation involve?**

Participants will be asked to attend one 60 MINUTE meeting online on the platform Zoom or face to face.

You will be asked to discuss the impact and challenges of providing care to adolescents with chronic pain. You will also be asked about your perception of the gaps and needs in the local health system that relate to the management of adolescents living with chronic pain and what you think are the key elements of a better model of care. You will also be presented with a model of care co-created with consumers for comment on the feasibility and deliverability of such a model.

Participants will be presented with the semi-structured interview questions before being guided through the semi-structured interview with an interviewer (either Carolyn Berryman or Dianne Wilson). The interview will be recorded, transcribed and de-identified and stored on the password protected Research Data Storage platform managed by the University of South Australia.

The transcription will be emailed to the GP after it is completed so that the GP can check it for accuracy and comprehensiveness, at which point there is the opportunity to add any further thoughts. Feedback from the GP interviews will be integrated with those from the Youth Advisory Group, Parent/Carer Advisory Group and the interviews with 15 young people living with chronic pain, to develop a draft model of care for adolescents with chronic pain which will be presented to the Governance Committee for comment and return to consumer groups for further comment. At the end of the project (June 2024), a summary of the model of care will be distributed to you and plans for implementation will be discussed via email. The flow chart at the end of this document gives details of the project.

# **What are the possible benefits of taking part?**

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include better management in the community of adolescent chronic pain in the future.

# **What are the possible risks and disadvantages of taking part?**

It is not anticipated that there are any risks to participation in this study beyond those encountered in everyday life.

# **Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect any care, your relationship with professional and/or healthcare personnel, private healthcare practitioners, hospital staff or your relationship with the University of South Australia.

If you choose to withdraw from the study, you may also opt to have the information you have provided excluded from the study, however this has to be done within one month of the interview taking place.

# **What will happen to information about me?**

By providing consent, you consent to the research team collecting and using information about/from you for the research project*.* All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released unless required by law. However, the researcher cannot guarantee the confidentiality or anonymity of material transferred by email or the internet.

Information from interviews will be collated and each individual’s contribution will not be identifiable. *The de-identified interview recordings will be stored for 5 years on a secure UniSA Server.*

Data collected from this project may be used for another purpose by the researcher to establish a database/register publicly available through UniSA’s secure data repository (UniSA Data Access Portal) which may be used for future research projects (for which ethics approval will be sought). These data will be in deidentified form and shared on request from research teams who are interested to implement the model of care in their locality. The research team includes researchers from interstate (Sydney) and we may share the de-identified data with them in the process of analysis.

# **What if something goes wrong?**

If at any point you experience any significant distress during the study, you will be provided with resources to appropriate services who may help with your specific needs.

# **What happens when the research project ends?**

A summary of project results will be available upon completion and details of the model of care that is developed will be made available to you.

# **Who is organising and funding the research?**

This research project is being conducted by Dr Carolyn Berryman with support from her research team. The project is funded by the Cops for Kids scheme, a charity that donates money for research endorsed by the Australian Pain Society and funds are administered by the University of South Australia. The focus of the funding is to improve care for South Australian youth with chronic pain.

You will receive the amount agreed on for participation under the SA Health Guidelines for sitting fees for GPs:

([Sitting+Fees+and+Reimbursement+for+External+Individuals+Policy\_V2\_October+2021.pdf (sahealth.sa.gov.au)](https://protect-au.mimecast.com/s/rfNaCWLVNlFlApM0u6R4qU?domain=sahealth.sa.gov.au)$226.40 (1 hour) Prorated at 15 minute intervals • $56.60 (15 minutes) • $113.20 (30 minutes) • $169.80 (45 minutes))

You will need to invoice the University of South Australia for payment.

If knowledge acquired through this research leads to discoveries that are of commercial value to the University of South Australia or Australian Pain Society, there will be no further financial benefit to you or your family from these discoveries.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

# **Who has reviewed the research project?**

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the University of South Australia [205391] as required by the Australian government research requirements, specified in the National Statement on Ethical Conduct in Human Research (2007 - updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

# **Further information and who to contact**

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on:

**Research contact person**

|  |  |
| --- | --- |
| Name | Dr Carolyn Berryman |
| Position | Chief Investigator |
| Email | Carolyn.berryman@unisa.edu.au |

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, please contact:

|  |  |
| --- | --- |
| Reviewing HREC name | University of South Australia Human Research Ethics Committee |
| HREC Executive Officer | Human Ethics Officer |
| Telephone | +618 8302 6330 |
| Email | [humanethics@unisa.edu.au](mailto:humanethics@unisa.edu.au) |

