Evaluation of the Primary Care Enhancement Program

Participant Information Sheet and Consent Form

Support person

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This project is led by Fran Boyle from the Institute for Social Science Research, The University of Queensland (UQ).

Katie Brooker from the Queensland Centre of Excellence in Intellectual Disability and Autism Health is helping Fran do the project.

What is this form for?

You are being asked if you would like to participate in a research study because you support an individual with intellectual disability who has been to their GP clinic recently.

The study is being conducted at The University of Queensland's Institute for Social Science Research (ISSR) with the Queensland Centre of Excellence in Intellectual Disability and Autism Health.

This form explains the research study. It also tells you about any possible risks and benefits to you if you decide to participate. If you have any questions, please ask the researchers.

Participation in this research 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 stop at any time, and you would not need to give any explanation for your decision to stop participating.

What is this study about?

The Department of Health, Disability and Ageing has asked our team to work out if the Primary Care Enhancement Program (PCEP) is working. The activities in PCEP aim to improve primary health care professionals, like GPs and nurses, knowledge and skills in providing health care to people with intellectual disability. PCEP also aims to enhance care pathways and their usage and increase access to intellectual disability health resources for diverse people. PCEP is only available in the Wide Bay region in Queensland, central and eastern Sydney, Western Victoria and Tasmania.

As a person who has supported an individual with intellectual disability, we are keen to hear your experiences and perspectives about the PCEP activities. The information we gather will help us to understand the overall progress of the PCEP, what is working well and what might be done better.

Who can be in the study?

People who supported an individual with intellectual disability to access a GP clinic in one of the four areas PCEP is available (Wide Bay Queensland, central and eastern Sydney, western Victoria and Tasmania). You must be over the age of 18 years to take part in this study.

The person you supported with intellectual disability are also asked to participate.

What will happen if I decide to be in the study?

If you decide to take part in the study, you first need to sign the consent form and return it to us. You will be given a copy of this Participant Information Sheet and Consent Form to keep.

If you agree to participate, you will do an interview with one of the researchers, Katie. Katie might be joined by Ruby or Catrin, researchers with intellectual disability. The interview will go for about 1 hour.

We will ask you:

- personal questions like your age and how long you have supported the individual.
- questions about when you went to the GP clinic with the person you support. They will ask what you liked, what you didn't like and what you think needs to be changed about the visit.
- questions about yearly health checks or CHAP for the person you support.
- questions about the tools and resources developed as part of PCEP.

You can do the interview over the phone or on a video call. We will ask to record the interview; you can choose not to be recorded.

If you wish to add or change anything you can contact us afterwards to let us know.

What are the risks or side effects of being in this study?

We don't expect that participating in the study will have any risks. However, risks may include being asked personal questions, talking about an upsetting time when you visited a GP clinic and needing to meet with us. You are free to take a break or stop the interview at any time. Please also know that you can choose not to answer any question that you do not wish to answer.

What are the benefits to being in this study?

We cannot promise that you will receive any direct personal benefits from this research. However, taking part gives you an opportunity to provide feedback to the Department of Health and Aged Care about how PCEP is going and how it is being put into practice.

How will my data be kept private?

All information collected about you will remain confidential. All personal data will be de-identified, so that your name is not attached to any notes or summaries that are made. Findings will be reported so that individuals are not identifiable. Any information provided to the study team will be used for this study only, and not for any other purpose or future research. Electronic data (audio recordings of interviews, transcripts) will be stored on the securely using the University of Queensland's Research Data Manager (UQRDM) system, in accordance with the University's Research Data Management Policy.Data will be password protected and only accessible to the evaluation team. All data will be stored in UQ's database for 5 years from project completion and then secure destruction will take place according to UQ guidelines. Additionally, evidence of consent will be kept for 15 years from project completion.

The results of this evaluation will be included in a report that we prepare for the Department of Health, Disability and Ageing. Findings may also be published and/or presented for academic, health professional and consumer audiences. In any publication and/or presentation, information will not include any details that identify an individual or organisation without your permission.

Can I stop being in the study once I start?

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 stop being in the project at any stage. We will remove what you have shared with us from the project. You do not have to tell us why you want to stop.

Your decision whether to take part or not take part, or take part and then stop, will not affect your relationship with the researchers or the organisations they work with. If you decide to take part and then stop, you can tell the researchers if you would like them to keep your information in the project or if you would like them to remove it. It is your choice.

Who has reviewed this project?

This study has ethical approval and adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator

(07) 3365 3924	humanethics@research.uq.edu.au
(07) 3443 1656	

If you have any questions, concerns, or complaints at any time about this research study you can also contact the researchers:

Fran Boyle	(07) 336 56806	f.boyle@uq.edu.au
Katie Brooker	(07) 3163 1983	k.brooker1@uq.ed.au

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I agree to participate in the study and understand:

- I am 18 years of age or older
- I have read the Participant Information Sheet or someone has read it to me in a language that I understand.
- I understand what is involved, the purpose, and any potential benefits or risks of the research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I agree to participate in this research project as described and understand that I am free to withdraw at any time during the project.

Declaration by The University of Queensland team member

I have given a verbal explanation of the evaluation; its procedures and risks and I believe that the participant has understood that explanation and has agreed to participate.

Name of participant: ____

Name of evaluation team member: ____________________ Date: ______________