

My GP and Me
Participant Information Sheet and Consent Form
Person with Intellectual Disability

This project is being done by Lillian Forsyth. Lillian is a student at the University of Queensland (UQ). Lillian will use the project towards her Bachelor of Science (Honours) degree.

The other people working with Lillian are Katie Brooker, Ruby de Greef, and Catherine Franklin from Mater Research.

If you want to talk to Lillian about the project or have a question, you can call her on 07 3163 2412 or email l.donald@uq.edu.au.

What is this form for?

You are being asked if you would like to participate in a research project being conducted at Mater Research Institute and The University of Queensland.

This form will explain the research project, and will explain the possible risks and benefits to you if you decide to participate. If you have any questions, please ask the researchers.

What is this project about?

We want to explore the experiences of attending general practitioner (GP) practices from the perspectives of people with intellectual disability.

This means that we'll ask questions about what your experience in the practice, arranging appointments, and talking with your doctor. We also want to ask what being healthy means to you, as well as what changes you might like to see in your own health.

The findings from this project will help to support the development of resources for practice nurse education under a larger project. These resources are to improve health outcomes for people with intellectual disability.

We will either do an interview with you, or you can complete a survey. Your support people can be present in the interview if you like. Because we want feedback from people with intellectual disability on how we are interpreting this information, you can participate in up to three interviews or surveys.

Who can be in the project?

People with intellectual disability and their support people. You must be over the age of 18 years and living in Australia to take part in this project.

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

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, there are two steps to the project:

1. You will complete a short survey about yourself. It will include questions about you (like your age), about how often you visit your GP clinic, and about how you communicate.
You can do this survey online, over the phone, on a video call, or in person at the interview. This will take up to 15 minutes.
2. You will choose to do an interview with Lillian or an online survey. In either case, you will be asked questions about the environment of GP clinics and related administrative aspects, interacting with health professionals in the clinic, and your conceptions of health and health goals. You can talk about any aspects of your experiences that you feel are important.

If you choose to do the interview, you can do this in person, on a video call, over the phone, or in writing. Lillian can travel to you. She will ask to record the interview; you can choose not to be recorded. This will take between one and three hours.

If you choose to do the survey, this will be online. You can revisit it at any point within a month time span. This will take up to 50 minutes.

Because we want to receive insights and feedback from people with intellectual disability on how we analyse the data before we finalise our results, you can participate in up to three interviews or surveys. Each interview or survey will have a month in which it can be done.

These additional interviews and/or surveys are optional, and you can tick on the consent form if this is something you might be interested in. If you tick yes, Lillian will contact you within this year with more information.

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

We see minimal risks or side effects to participating in this research; however, risks may include being asked potentially personal questions about yourself and your health, talking about an upsetting time, and spending up to three hours on the interview/survey.

What are the benefits to being in this project?

Some people find it helpful to share what happened to them. But we cannot promise that you will receive any direct personal benefits from this research. This project will let us know how people with intellectual disability experience attending GP clinics in Australia. This may help us to develop resources to better educate practice nurses to better address people with intellectual disability's health needs.

How will my data be kept private?

We will store the data and personal information separate. This means we will not write your name or include any identifying material (e.g., your address or phone number) on these materials. All data will be kept secure in researcher offices in locked filing cabinets or password protected electronic files. When writing the results of this project, we will not include any material that allows you to be identified. Other people and students from the organisations on this project may examine this data in the future, in a de-identified way. They will not be able to work out which information is yours, or any of your personal information.

Will I be paid for taking part in this project?

Yes, you will be given a \$50 gift card for your time and effort, for each interview/survey that you participate in.

Can I stop being in the project 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. 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. You can complete a withdrawal form to stop being a part of the project, or you (or a substitute decision maker) can phone or email the research team.

Who has reviewed this project?

This project has been reviewed and approved by the Mater Misericordiae Ltd Human Research Ethics Committee (EC00332).

Should you wish to discuss the project in relation to your rights as a participant, or should you wish to make an independent complaint, you may contact the Coordinator or Chairperson, Human Research Ethics Committee:

Mater Misericordiae Ltd, (07) 3163 1585,
Level 2 Aubigny Place, research.ethics@mater.uq.edu.au
Raymond Terrace
South Brisbane 4101

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

Lillian Forsyth (07) 3163 2412 l.donald@uq.edu.au
Katie Brooker (07) 3163 1983 k.brooker1@uq.edu.au

My GP and Me
Consent Form for
Person with Intellectual Disability

My name is _____

- 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.
- I understand that I will be given a signed copy of this document to keep.

The researchers can contact me this year about having two more interviews or surveys (please tick one): Yes No

I agree that researchers can look again at my information from this study in the future (please tick one): Yes No

Signature _____ Date (DD/MM/YYYY) _____

Name of researcher _____

Signature _____ Date (DD/MM/YYYY) _____

Declaration by Substitute Decision-Maker

If the participant requires the consent of a Substitute Decision Maker, please also complete the following:

I, _____ confirm that I am the substitute decision-maker for
_____ (participant name)

I confirm that:

- 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 for the person named above to participate in this research project as described and understand that they are free to withdraw at any time during the project.
- I understand that I will be given a signed copy of this document to keep.

I agree that the researchers can contact us/me about having two more interviews or surveys this year. Yes No

I agree that researchers can look again at information from this study in the future. Yes No

Signature _____ Date (day, month, year) _____

Name of researcher _____

Signature _____ Date (day, month, year) _____