

Bridge to Better Health

Information sheet and consent form for young people with intellectual disability

This project is being completed by a team of researchers from the Mater Intellectual Disability and Autism Service (MIDAS) at Mater Research, University of Queensland, Griffith University, and Western Sydney University.

If you have any questions about the project, you can contact Katie Brooker on (07) 3163 1983 or email k.brooker1@uq.edu.au.

What is this form for?

You are being asked if you would like to participate in a research study because your general practice has chosen to participate in a study called *Bridge to Better Health*. The study aims to improve health for people with intellectual disability.

This form will explain the research study. It 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 study about?

We know people with intellectual disability don't have the same access to health care as people without disability. This study aims to try and make this better.

We have an idea on how we can make going to the GP better. This is our intervention called *Bridge to Better Health*. It is made for the nurses who work at your general practice. We want the practice nurses to be more involved in your care and in doing your annual health assessment. We will give them help and access to training and online resources.

The study will compare the Bridge to Better Health intervention to usual care. Usual care means the practice keeps working the way they normally would. Practices will be randomly put in the intervention group or in usual care group. You will not be able to pick what group your practice is put in.

We will look at this information for everyone in the study. We can compare the groups and find out if the intervention is helping.

We also want to talk to people to find out what they think about the study. We will ask you if you would like to talk to us after you have an annual health assessment and at the end of the study. You don't have to talk to us if you don't want to.

What is the intervention?

The intervention is called *Bridge to Better Health*. It is made for the nurses who work at your general practice. We want the practice nurses to be more involved in your care and in doing your annual health assessment. To help the practice nurses, we will give them:

- Support from a specialist intellectual disability nurse
- Training on intellectual disability health and health assessments
- Access to online resources and clinical tools

Who can be in the study?

People with intellectual disability who are over 15 years old.

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. Your parent or guardian must also sign a consent form because you are under 18 years old. You will be given a copy of this Participant Information Sheet and Consent Form to keep.

If you agree to participate, you will allow the researchers access to information about you to be able to find out if the intervention is helping. We will look at information for three years. We want to look at:

- Your medical record at the general practice
- Your annual health assessment
- Your medical records at hospital
- When you have had vaccinations, get scripts filled and use your Medicare card
- How you use NDIS and government payments

This will let us look at how you use the health system and if it changes.

If you agree to participate, you will do an interview with a research assistant from Mater Intellectual Disability and Support Service. They will ask you:

- personal questions like your age, about your health and experience
- questions about when you had a health assessment last
- questions about your experience doing the project

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

You will also have the option to repeat the interviews in about 1 year. This is optional and you can tick on the consent form if this something you might be interested in. If you tick yes, we will contact you next year with more information.

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

One risk to being in the research is how your medical record is shared with us. Data from your general practice will be sent using a secure fax machine and entered into a database called Redcap. This database will not have your name or other identifiable information. There is a small chance if there someone broke into the Mater IT system, they would be able to see your data or connect your name to your data. We call this re-identifiable data.

There are other minimal risks or side effects to participating in this research; you may include experiencing stress when sharing health care experiences, time constraints and confidentiality. We will do our best to make sure you feel comfortable.

There are other minimal risks or side effects to participating in this research; which may include experiencing stress when sharing health care experiences, time constraints and confidentiality. We will do our best to make sure you feel comfortable.

What are the benefits to being in this study?

We cannot promise that you will receive any direct personal benefits from this research. You may also help health services to improve the way their work with people with disability.

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 research offices in locked filing cabinets or password protected electronic files. There is a small risk if someone broke into the Mater IT system they would be able to see your data or connect your name to your data. When writing the results of this project, we will not include any material that allows you to be identified.

Medical and health data may need to be identifiable while we are gaining access to it. Once we have access it will be de-identified, and no identifiable information will be made public or shared. This information will be shared from your general practice or from Queensland Health and ABS data. This data will be stored for five years after the conclusion of the project, and then destroyed in-line with Mater Research and UQ data requirements.

The research team might look at the information from this study again in the future. We will not look at any information that identifies you.

Will I be paid for taking part in this study?

No. There are extra things to do in the project, like being interviewed about your experiences. If you do this, you will be given an \$50 gift card for your time and effort after the interview.

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

Should you wish to discuss the study 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 study, you can also contact the researchers:

Dr Katie Brooker (07) 3163 1983 k.brooker1@uq.edu.au
Dr Cathy Franklin (07) 3163 2412 midas@mater.org.au

Bridge to Better Health

Consent Form for

Person with intellectual disability under 18 years

My name is _____

- 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.
- I agree that researchers can look again at my information from this study in the future.
- I understand that my data being stored will be re-identifiable in the chance of an internet security breach, and that no published outcomes of the research will be identifiable.
- I agree that the researchers can contact me about having a follow-up interview:
After my health assessment Yes No
At the end of the study Yes No

Signature _____ Date (day, month, year) _____

Bridge to Better Health
Consent Form for
Substitute Decision-Maker

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 _____ (participant name) 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 researchers can look again at information from this study in the future.
- I agree that the researchers can contact me about having a follow-up interview:
After my health assessment Yes No
At the end of the study Yes No

Signature _____ Date (day, month, year) _____

Name of researcher _____

Signature _____ Date (day, month, year) _____