

Can you help?



Bridge to Better

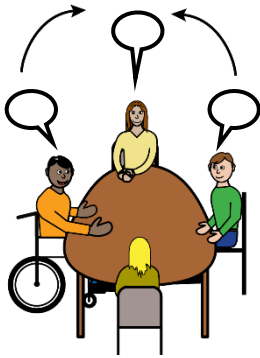
Health

Research Project



This is a research project about:

- getting health assessments
- going to see a doctor
- making health care better



We want to

- look at your health information
- ask you questions about your last health assessment

The people doing the project are:



Katie is from Mater Intellectual Disability and Autism Service.

- It is also called MIDAS.
- Katie looks after the project.



Sinead is from MIDAS.

- Sinead helps Katie do the project.
- Sinead can help answer questions.



Ruby is from MIDAS.

- Ruby helps with projects.
- Ruby has an intellectual disability.



This form will tell you about:



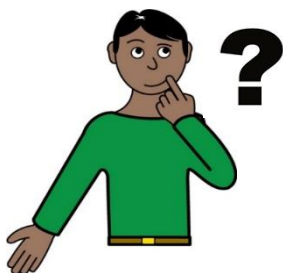
- what the project is about



- what happens if you take part in the project



- things you need to know about being in a project



- next steps if you want to be in the project



Are you interested in being in the project?



Yes – go to page 7

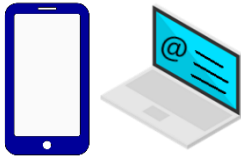


No – we have finished



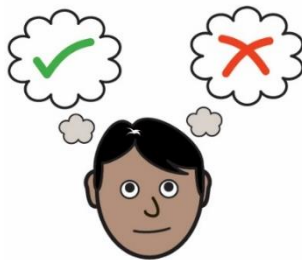
You can ask questions about the research project:

- You can ask a support person to do this for you



Our contact details are on page 25

Then you can choose if you want to be part of the research project. You can:



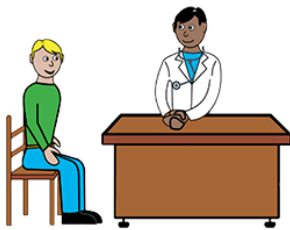
- choose to be part of this research project
- choose not to be part of this research project

It is up to you.

What is the project about?

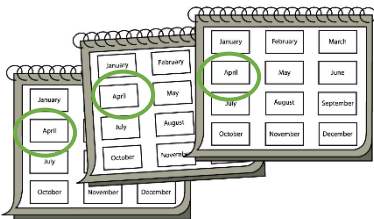


People with intellectual disability can have **yearly health checks.**



A yearly health check is when your GP checks your health.

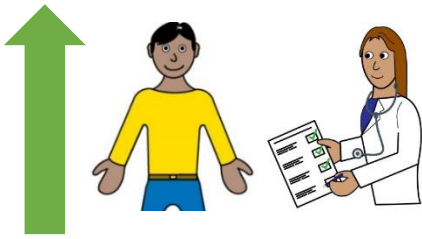
They are sometimes called annual health assessments or check-ups.



You should have a health check 1 time a year.

You should do this even if you feel well.

This is to check your health is good.



We want to help more people with intellectual disability have yearly health checks.



Our idea is to help nurses do the health checks.

We will give nurses

- Support from another nurse who knows about intellectual disability
- Training on disability
- Training on health checks

This is called our **intervention**.



An intervention is like a new way to do things. Or testing out a new idea.

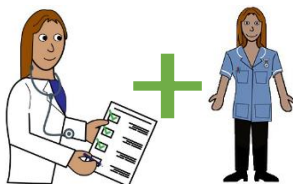


We want to find out if our new idea makes health checks better.



To do this we need to put people into two groups.

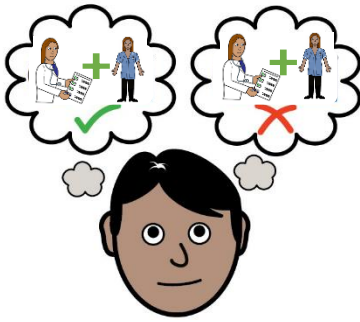
- Intervention group
- Regular group



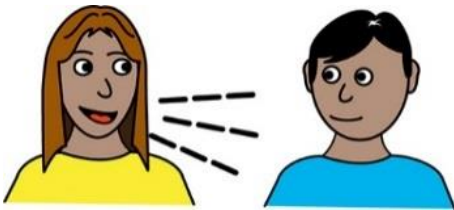
People in the **intervention group** will have their nurse help them do their health check



People in the **regular group** will have their health check the normal way.



We will look at people's health information in the two groups. We will be able to see if helping nurses made the health checks better.



We will also

- talk to nurses and ask if they thought it helped
- talk to people with intellectual disability and their support people. We will ask what they thought.



What happens if you take part in the project?

You will have to sign a consent form.



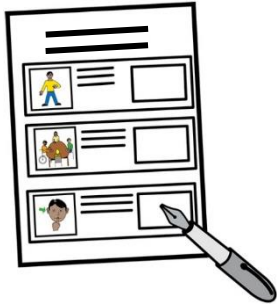
The form says you:

- understand what will happen in the research project
- agree to be part of the research project.



This is called giving consent.

- The form is on page 28 and page 29.



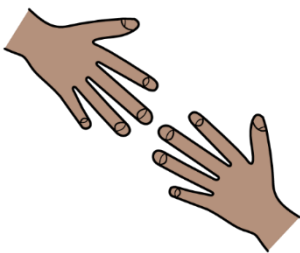
We will answer some questions like:

- your age
- your gender
- your postcode



You can answer the questions:

- in person
- over video call
- over the phone



You can have someone support you.

We will ask your GP to share your medical record with us.

We will look at your information for 3 years

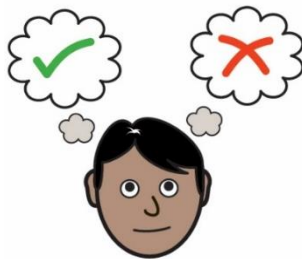
- 1 year before the project starts
- 1 year during the project
- 1 year after the project ends

We will ask the government to match your data to information from the hospitals, Medicare, Centrelink, Income and Queensland Health data.

This will help us work out if the intervention saves the government money.



After your health check we will ask if you want to talk to us.

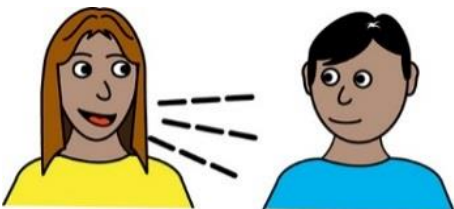


You can choose if you want to be in this part of the project. You can:

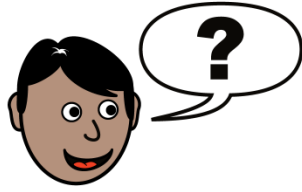
- choose to talk to us
- choose not to talk to us

It is up to you.

We will ask things about your health assessment:



- What happened
- How it made you feel
- What you didn't like
- What you did like or what went well
- What was different this time



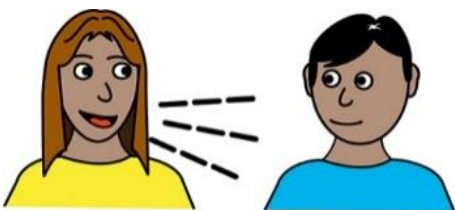
When the project ends we will ask if you want to talk to us again.



You can choose if you want in this part of the project. You can:

- choose to talk to us
- choose not to talk to us

It is up to you.



We will ask things about what it's been like going to your GP.

- What things have changed?
- Have things got better?
- What things can be done better?

These are things to know about the interviews



You can tell us:

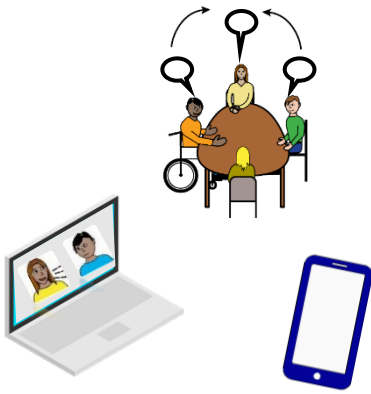
- what you think was good.
- what you think was bad.
- what you think can be done better.

What you tell us stays between us. We won't tell your GP practice.



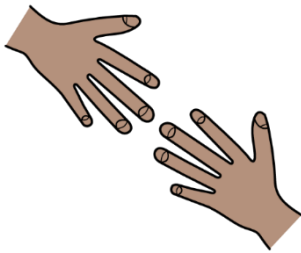
Katie, Sinead, or Ruby will be the person asking you the questions:

- It will depend on who is working on the day of your interview.



You can do the interview:

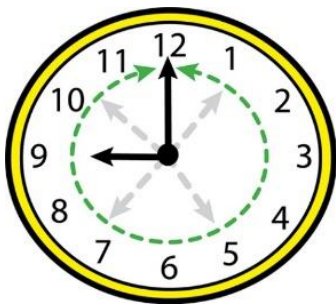
- in person. We can come visit you.
- on a video call
- on a phone call



You can choose who comes to your interview

- You can do the interview on your own
- Or have someone with you

You decide who comes to your interview

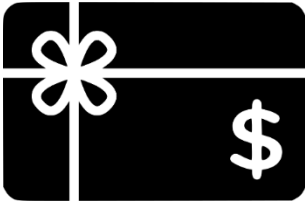


The interview will take about half an hour



You can:

- take a break when you want
- stop the interview when you want.

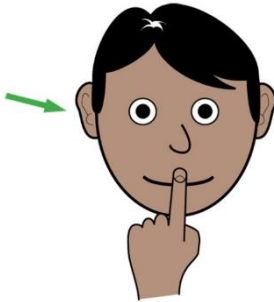


We will give you a \$50 gift card.

This is to thank you for your time.

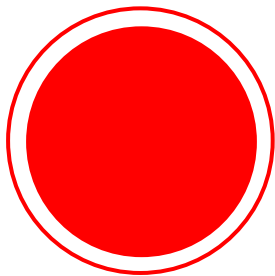


Things you need to know about being in a project



Katie, Sinead and Ruby will:

- keep your health information private
- keep what you say private
- not tell your doctors what you said
- not use your real name when they talk or write about the research project.

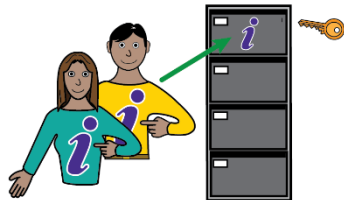


We will record the interview:

- You can tell us if you don't want to be recorded.
- That's ok.



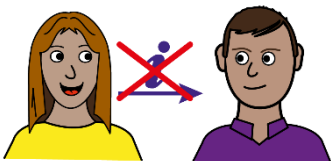
We will write things down.



We will keep the recording and things we write down safe:

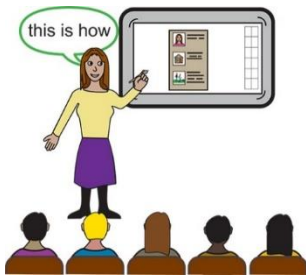
- Only the research team will know what information is yours.
- No one else will be able to work out which information is yours.

Other people and students may look at your information in the future. They will be from the organisations on this project.



They will not be able to:

- work out which information is yours
- work out your personal information
- find out your name



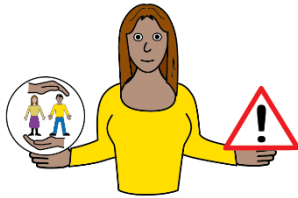
We will:

- talk at conferences and meetings about the research project
- write about the research project



We will send you a report of what we find:

- it might take a few years to do.



There are benefits and risks in research.



The benefits of this research project are:

- your story will help us learn how to make going to the GP better
- you might not have any benefit.



The main risk in this research project is keeping your information safe.

- We keep your name in one file.
- We keep your health information in another file.
- This is called re-identifiable data.



If someone broken into the Mater computer system. They might be able to match your name and health information.

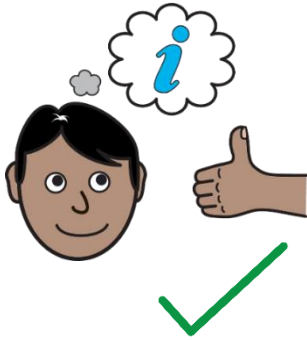
- This is a small risk.
- We do everything we can at Mater to keep your information safe.



The other risks of this research project are:

- you might be uncomfortable talking about yourself
- you might not like being asked questions
- talking about going to the GP might make you sad, upset or bring back bad memories
- but you can choose not to answer a question.

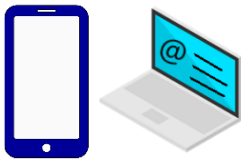
It is your choice.



There are people at Mater Hospital.

Their job is to make sure research projects are safe.

- They have checked this research project.
- They said it was okay to do.



You can talk to Mater Research Ethics if you are not happy with the way we are working.

- phone 07 3163 1585
- email research.ethics@mater.uq.edu.au

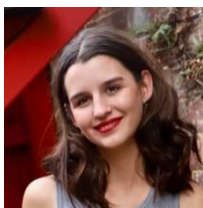
You can ask a support person to do this for you.

What are the next steps if you want to be in the project?

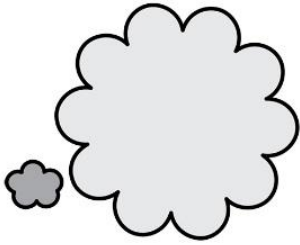


If you decide to take part you can tell Katie:

- phone 07 3163 1983
- email k.brooker1@uq.edu.au
- Katie works 9 am to 5 pm Monday to Friday
- You can ask a support person to do this for you.



- Or you can tell Sinead:
 - phone 07 3163 8267
 - email uqsgre14@uq.edu.au
 - Sinead works 9am to 5pm Monday to Friday
 - You can ask a support person to do this for you



Remember

You can:



- choose to be part of this research project
- choose not to be part of this research project

It is up to you.



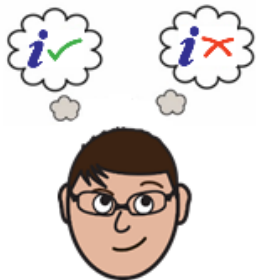
You can have someone support you.



You can decide to stop being part of the research project:

- It is ok to change your mind.

If you want to stop being part of the research project we:



- can keep what you told us in the research project
- can delete what you told us from the research project
- It is up to you



Consent form

My name is _____



- I am over 15 years old.



- I have read this information, or someone has read it to me. I understand it.



- I know someone can support me to take part in the research project.



- I am ok to share my medical record to be part of the project.



- I am ok to have my medical record linked to my Government, Centrelink, Income and Queensland Health data.



- Katie, Sinead and Ruby can ask me questions about myself.



- Katie, Sinead and Ruby can ask me questions about my health assessments.



- I know if someone broken into the Mater computer system. They might be able to match my name and health information.



- I know other people might look at my information in the future.



- I know I can stop being in the research project at any time.



Signature _____

Date (day, month, year) _____



Name of researcher _____

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 agree for _____ (participant name) medical record to be shared for the project.
- I agree for _____ (participant name) to have their medical data linked to administrative data sets.
- 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.

Signature _____ Date (day, month, year) _____

Name of researcher _____

Signature _____ Date (day, month, year) _____