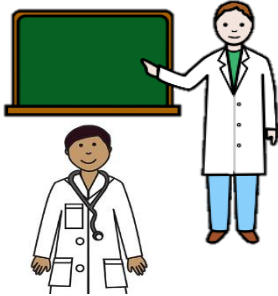


Help make seeing the doctor better.

For people with intellectual disability.



This research project is about going to the doctor.



We want your help because your doctor was part of a program to learn how to help people with intellectual disability.



This book will tell you about

- What you will do if you choose to help
- What to do if you want to help
- What you need to know about research



Fran Boyle from the University of Queensland is doing this research project.



Katie Brooker is helping Fran with this project.

She is from Queensland Centre of Excellence in Intellectual Disability and Autism Health.

We call this QCEIDAH.



Catrin and Ruby will also help Fran and Katie.

They are also from QCEIDAH. They have a disability.

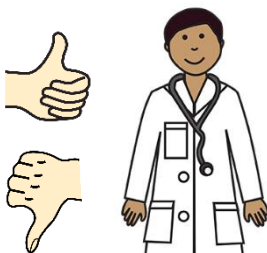


Katie, Catrin and Ruby want to talk to you. They call this an interview in research.



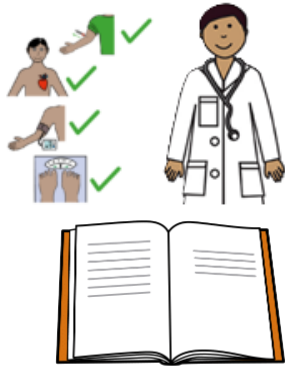
Before the interview they will ask you questions like:

- how old are you
- what is your gender
- how you want to talk to Katie, Catrin, and Ruby



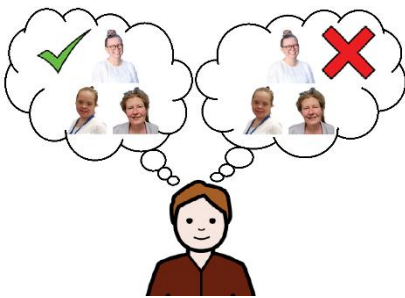
When they interview you, they will ask you questions about going to the doctor like

- What you liked about it
- What you didn't like about it
- What needs to be different about visiting



They will also ask you questions about:

- Yearly health checks
- Tools created for the program



Are you interested in talking with Katie, Catrin and Ruby?



Yes – go to page 6.



No – we have finished.



You can ask questions about the research project if
you would like to know more

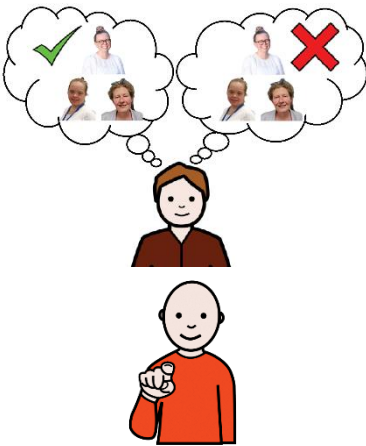
or



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



Katie's contact details are on page 17.



You can

- choose **to** help with this research project
- choose **not to** help with this research project

It is up to you.



What happens if you help



You will need to agree to the dot points on the consent form.

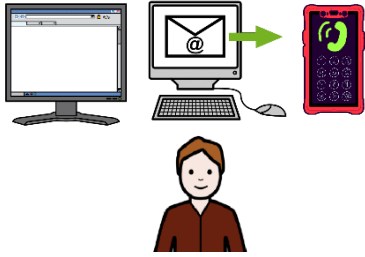
The form is on page 21 and page 22



The forms says that you

- know what will happen in the research project
- agree to help with this research project

This is called giving **consent**.



You can answer the questions before the interview

- on a website
- over the phone
- over email



You can also have someone support you.



The interview will be with Katie, Catrin and/or Ruby

But



you can ask family, friends or support join your interview.



The interview will take about 1 hour.



You can stop the interview at any time.



They also want to talk to your family and support workers.

You can say **no**.

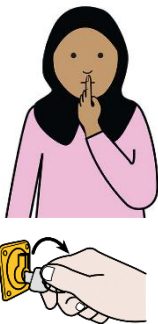
It is up to **you**.



We will give you a \$50 gift card.

This is to thank you for your time.

Things you need to know about helping us



Fran, Katie, Catrin and Ruby will

- 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



They will record the interview **and** write things down



You can tell them if you **do not** want to be recorded.

That is ok.



They will keep the recording and things they write down **safe**.

They use a special computer system called UQRDM to keep it safe. No one will be able to know which information is yours.



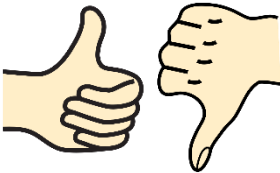
Other people and students from the businesses on this project may look at your information in the future. They **will not** be able to

- know which information is yours
- find out your personal information like your name

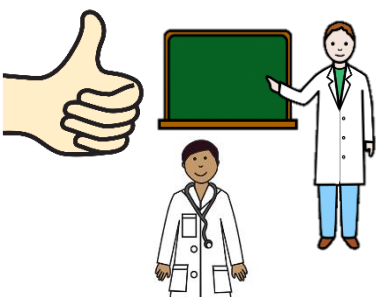
Fran, Katie, Catrin or Ruby may:

- talk to other people at meetings about the research project
- write about the research project

The people that they talk to **will not** know that the information is yours.



There are good things and bad things that could happen from helping with research projects.



The good things that could happen from helping are that you could help us to learn:

- if the program is good
- if there are things we need to change about the program

You **may not** find any good parts about helping with the research project.

We do not think that there any bad things will happen by helping us



The things that could be bad for you are:

- being asked questions about yourself
- talking about a time when you visited a GP clinic that was bad, made you sad or upset
- meeting with us



There are people at The University of Queensland.

It is their job to make sure research projects are safe.

They are called The University of Queensland Research Ethics.



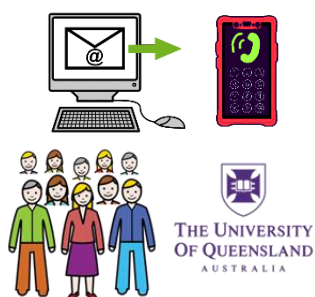
They check this project said it was okay to do.



You can talk to them if you are **not** happy with the way we are working.

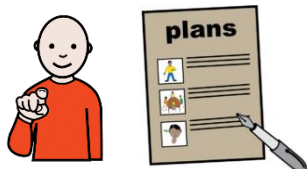


You can also ask support person to contact them.



These are their contact details

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



What to do if you want to help

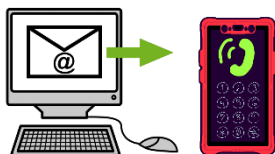


If you want to help you can tell Katie

Or



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



Her contact details are

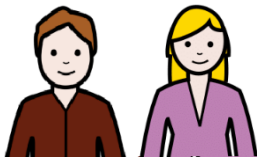
- Phone 07 3163 1983
- email k.brooker1@uq.edu.au



She works 9 am to 5 pm Monday to Friday



Remember



You can have someone support you.

You can:



- choose to help with this research project
- choose **not** to help with this research project

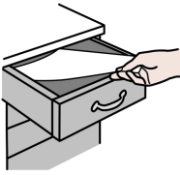
It is up to you.



You can choose to stop helping with this research project.

It is ok to change your mind.

If you want to stop helping with the research project they can:



- use what you told them in the research project

or



- take what you told them out of the research project



Consent form

You will need to agree to the dot points on the consent form.

This is called giving **consent**.



Katie will ask me if I agree to the dot points.



I am over 18 years old.



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



I know someone can support me to help with this research project.



Katie, Catrin or Ruby can ask me questions about myself.



Katie, Catrin or Ruby can ask questions about when I went to the GP clinic



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.

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: _____