



Can you help?

My GP and Me

Research project



This is a research project about

- going to the doctor's office
- seeing a general practitioner



This form will tell you about

- what happens if you take part
- things you need to know about research
- what to do if you want to take part.

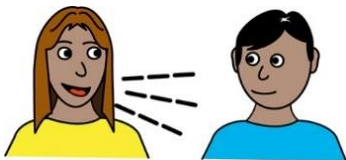


Lillian is from the University of Queensland.

- It is also called UQ.

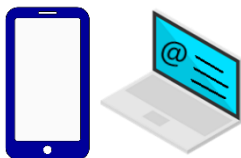


Katie is from Mater Research. She is Lillian's boss.



Lillian wants to ask you questions about what it's like when you go to the GP clinic.

- you can talk to Lillian. We call this an interview
- you can have your support people in the interview if you want to
- you can respond to a set of written questions. We call this a survey





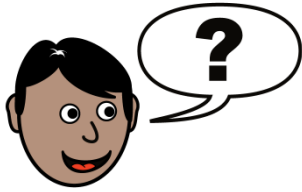
Are you interested in answering Lillian's questions?



Yes – go to page 4.

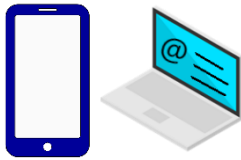


No – we have finished.



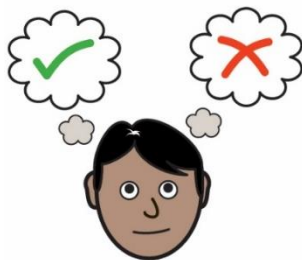
You can ask Lillian and Katie questions about the research project.

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



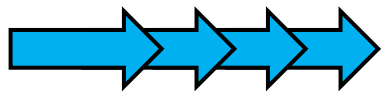
- Lillian's and Katie's contact details are on page 18.

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 happens if you take part

You will have to sign a consent form.



The forms says you

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



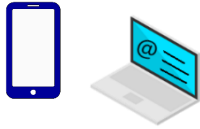
This is called giving consent.

The form is on page 21 and page 22

There are 2 ways to be part of this project.



- Talk to Lillian. We call this an interview
-



- Answer a survey



It is up to you. You can chose how you be part of the project.

When you chose to do the interview.

This is what will happen.



Before the interview you will answer some questions like

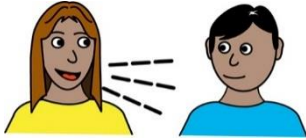
- your age
- your gender
- how you want to answer Lillian's questions



You can answer the questions

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

You can have someone support you.



You do the interview with Lillian

- You can decide if you want support people to come to your interview



Lillian will ask things about going to the doctor's office like

- what happens
- what the clinic is like
- what it is like talking with the doctor
- what you think about health



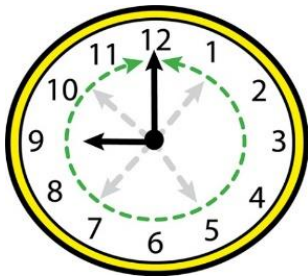
You can tell her

- how you feel.
- what you think is good.
- what you think is bad.
- what you think can be done better.

You can do the interview



- in person. Lillian can come visit you.
- on a video call
- on a phone call
- by writing what you think on paper or in an email.

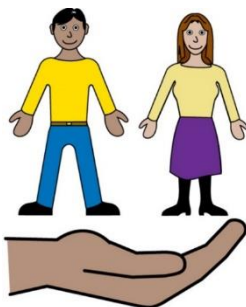


The interview will take 1 to 3 hours.



You can

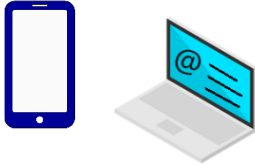
- take a break when you want
- stop the interview when you want.



You can have someone support you.

When you chose to do the survey.

This is what will happen.



Lillian will send you the survey. You can do it on a

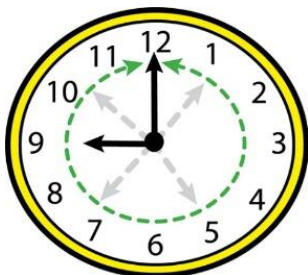
- smart phone
- computer

The survey will ask questions like your age and gender.



There will be questions about going to the doctor's office like

- what happens
- what the clinic is like
- what it is like talking with the doctor
- what you think about health

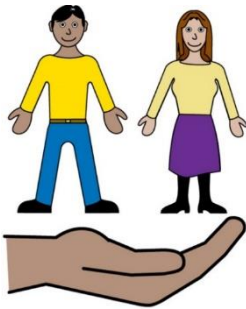


The survey will take up to 50 minutes.

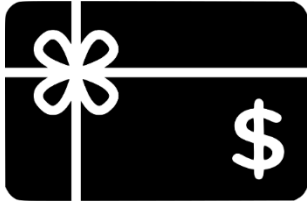


You can

- take a break when you want
- stop the survey when you want.
- come back to the survey later.



You can have someone support you.

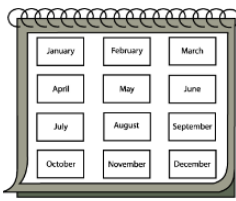


We will give you a \$50 gift card.

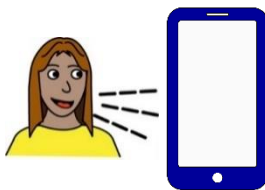
- This is to thank you for your time.



Later in the year Lillian wants to ask you more questions



- This will happen 2 times
- It will be about going to the doctor's office again.
- She will have more questions after she talks to other people with intellectual disability.

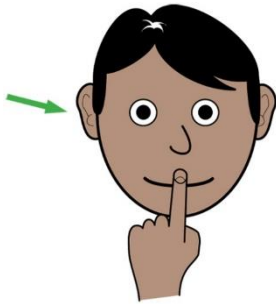


Is it ok for Lillian to call you later this year about another interview or survey like this one?

You can tell her yes or no on page 22.



Things you need to know about research



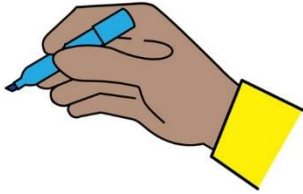
Lillian will

- keep what you say private
- not tell your doctors or the GP clinic about what you said
- not use your real name when she talks or writes about the research project



Lillian will record the interview

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

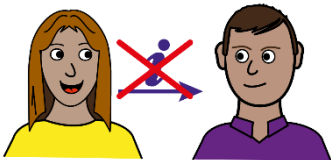


Lillian will write things down.



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

- No one will be able to work out which information is yours



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

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



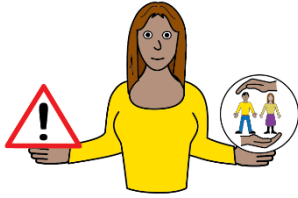
We will send you a report of what we found

- it will be done by the end of the year



We will

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



There are benefits and risks in research.



The benefits of this research project are

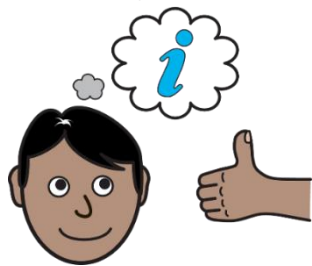
- your story will help us learn about how to make GP clinics better
- it might feel good to tell us what you think
- you might not have any benefit.



The 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 doctor's office might make you sad, upset or bring up bad memories
- but you can choose not to answer a question.

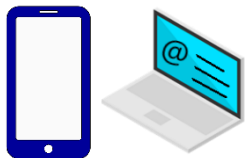
It is your choice.



There are people at Mater Hospital and The University of Queensland.

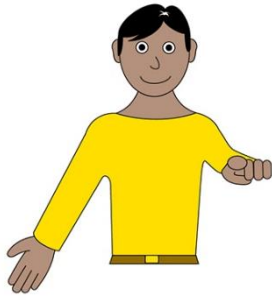
Their job is to make sure research projects are safe.

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



You can talk to the Mater Research Ethics people 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 to do if you want to take part



If you decide to take part you can tell Lillian.

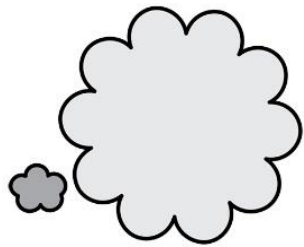
- email l.donald@uq.edu.au
- You can ask a support person to do this for you.



You can also talk to Katie. Katie is Lillian's boss

- phone 07 3163 1986
- email k.brooker1@uq.edu.au
- You can ask a support person to do this for you.

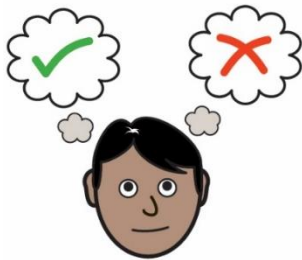




Remember



You can have a support person help you.



You can

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

It is up to you.



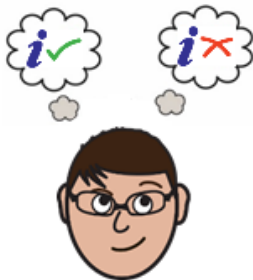
You can decide to stop being part of the research project.

- It is ok to change your mind.



To stop being part of the research project you:

- can call or email Lillian or Katie
- can fill out a form



If you want to stop being part of the research project Lillian

- can keep what you told her in the research project
- can delete what you told her from the research project

It is up to you



Consent form

My name is _____

Circle yes or no



• I am over 18 years.



• 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.



• Lillian can ask me questions about myself.



• Lillian can ask questions about when I go 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.



- Lillian can contact me this year about 2 more interviews or surveys.



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) _____

Thanks to  easy on the  for the use of their image bank © LYPFT
www.easyonthei.nhs.uk