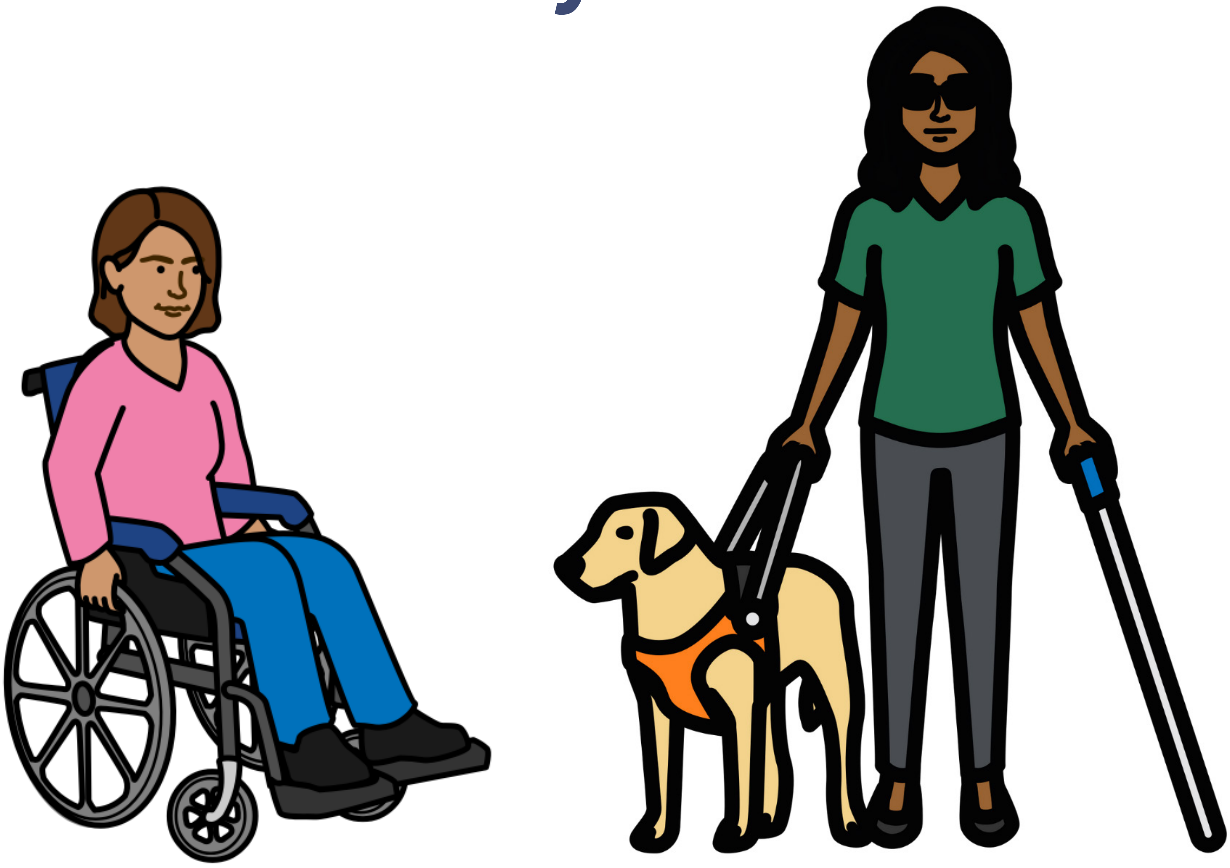
Easy Read

Participant Information Sheet

Workshops with people with disability

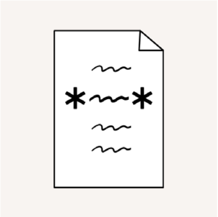


THE UNIVERSITY OF
MELBOURNE

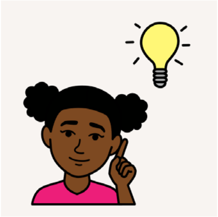
About Easy Read

This is an Easy Read form.

Easy Read uses pictures to explain ideas.

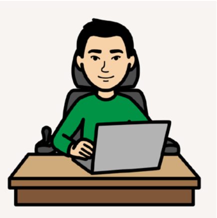


New words are ***bold with stars***.



We tell you what new words mean.

Easy Read includes key information.



All contact information is at the end of this form.

About this book

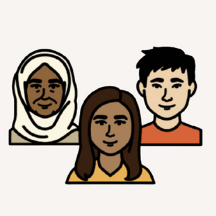
We call this book a ***Participant Information Sheet***.
Read this book before our consent form.

A Participant Information Sheet explains

- who is in the research team

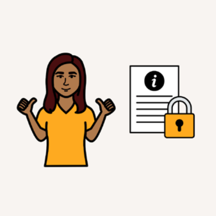
- what the project is about

- what the workshops are about



- who can be in the workshops

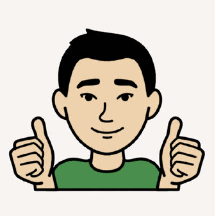
- what you will need to do and when.



This Participant Information Sheet also explains

- what we will do with your information

- who is paying for the project



- good things about the workshops

- hard things about the workshops

- who you can talk to if you have questions

- who you can talk to if you are worried or want to ***complain***.

Complain means you say you are **not** happy.

Who is in the research team?

The research team includes **women researchers** from the University of Melbourne.

The researchers are

- Tessa Saunders

- Claire Nightingale

- Jen Hargrave

- Madeleine Clarke.

The researchers also include

- Katja Hölttä-Otto

- Madhurima Das

- Jessie Cameron

- Julia Brotherton

- Kate Flynn.

Women with disabilities helping run workshops are

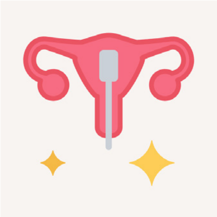
- Louise Bannister

- Karleen Plunkett.

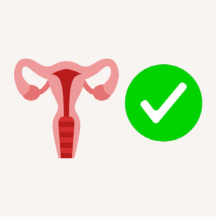
What is the project about?

The project is called
Making it a Real Choice: Improving accessibility of cervical screening self collection swabs for people with disability.

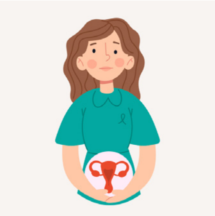
You can say **yes** or **no** to being in this research after you read this book.



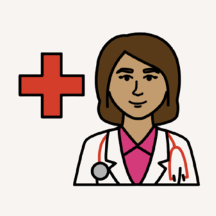
The project is about ***cervical screening***.



Cervical screening helps to stop cervical cancer by checking if the ***cervix*** is healthy.

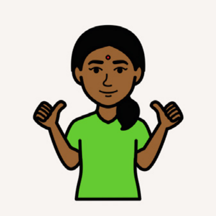


The cervix is inside the body at the top of the vagina.

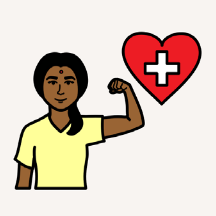


A cervical screening can be done by

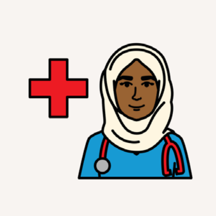
- a doctor or nurse



- you.



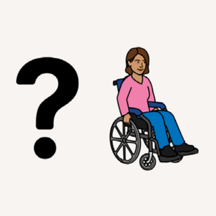
Self collection means **you** do the screening yourself.



You can ask the doctor or nurse to help you do it if you feel comfortable and give consent to do this.

Our project will help us learn

- what it is like for people with disabilities to do self collection



- how we can make self collection better for people with disabilities.

What are the workshops about?

Workshops are about self collection for people with

- physical disabilities

- sensory disabilities.

People might have other disabilities too.
For example, intellectual disabilities.

We will use what we learn in workshops to write

- a research report to share our findings

- a ***research grant***. A research grant is money given to someone to help them do research.

Who can be in workshops?

People can be in the workshops if they are

- a woman or person with a cervix

- aged between **24 and 74** years old

- living in Australia

- a person with a physical disability

- a person with a sensory disability.
  For example, someone Autistic or ***Deaf***.

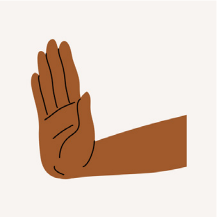
Deaf means you cannot hear or it is hard to hear.

What you will need to do and when

Before the workshops

A researcher will contact you and ask questions.

We will ask for your email and phone number.



We **cannot** include everyone in our research.

If we choose you for our research,
we will invite you to be in **2 workshops**.

We will ask about your accessibility needs. For example, help from an interpreter at the workshop.

At the workshops

Workshops include a group of 10 to 15 people.

Workshops can be

- online

- in person.

Online workshops go for **2 hours**.

In person workshops go for **3 hours**.

We will tell the group about different self collection tests and you can ask questions.

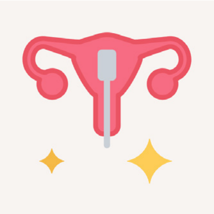
If you come to a workshop in person

You do **not** need experience with self collection if you come to the workshop in person in Melbourne.

We will give you a self collection kit
to look at and touch.

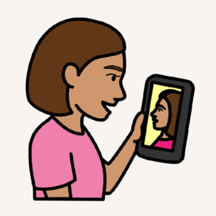
You do **not** have to do a self collection
test on yourself.

If you come to a workshop online



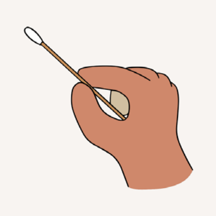
For online workshops, you must have ***tried*** a self collection kit before.

Tried means you had a go. It is OK if you did not do it properly or you found it hard.



You need some experience with the kits because

- you cannot touch the kits if you join online



- it is important to know how the kits look and feel.

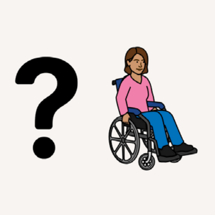
At workshop 1

In **workshop 1** we will ask

- What do you like about self collection?

- What do you **not** like about self collection?

- What do you think of the different tools for self collection we talked about?

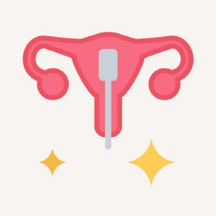


- Do you think people with physical or sensory disabilities would have problems with the kits?

At workshop 2

In **workshop 2** we will ask you how we could make self collection kits **better**.

Working in groups



You will work with 1 or 2 people to

- talk more about self collection

- share ideas about different self collection kits. For example, what you like or do **not** like.

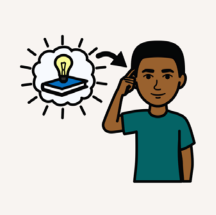
We will keep a record

In the workshops, we will

- record audio

- record video

- write down key points.



We save the information so we can remember important information later.

What we will do with your information

We will keep your information safe and private.

We mix your answers with answers from other people so we do not know who said what.

We will share research findings in lots of ways and we will **not** use names.

We have ***copyright*** over the research findings.

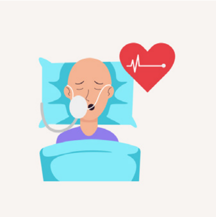
Copyright means we own and control how the information is used.

Who is paying for the project

Money to pay for this project comes from the Melbourne Disability Institute Seed Grant 2024.

Good things about the workshops

Your ideas will help us think of ways to help other people get a cervical screening test.



If more people get tested, we can help stop people from getting cervical cancer.

You also get a gift card when the workshops are finished.

You can choose a Visa card or a Coles card to be used only in Australia.

You can get your card

- by email

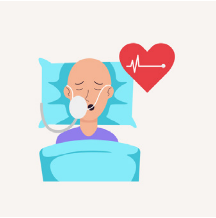
- by post.

If you do the **online** workshop, you get a gift card for $100.

If you go to the workshop **in person**, you get a gift card for $200.

Hard things about the workshops

Being in our workshops could make you upset.



We talk about cancer which can be a sad topic.

We talk about screening methods
which could be stressful.

Contact information is at the end of this book for places to get help if you feel sad or stressed.

Who you can talk to if you have questions

Our ***Chief Investigator*** is Tessa Saunders.

A Chief Investigator is the person who is in charge of the research.

Tessa can help if you need more information.

Email Tessa at tessa.saunders@unimelb.edu.au

Call Tessa on 03 903 539 72

If you are worried or want to complain

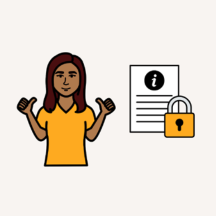
You can talk to Tessa if you are worried or want to complain.

If you do not want to talk to Tessa, talk to the Integrity Administrator at the University of Melbourne.

Call on 03 8344 1376

Email at research-integrity@unimelb.edu.au

If you have a complaint, you can also contact the ***Australian Information Commissioner***.



The Australian Information Commissioner is a government office that looks after your

- privacy

- rights.

Call on 1300 363 992

Post to GPO Box 5218
Sydney NSW 2001

All complaints are ***confidential***. This means nobody knows you made a complaint.

More help

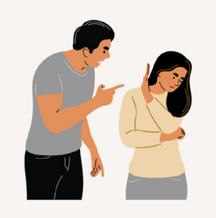
Call ***Lifeline*** on 13 11 14.

Lifeline gives free help to anyone who needs to talk.

Call ***13 YARN*** on 13 92 76

13 YARN is for Aboriginal and Torres Strait Islander peoples and run by Aboriginal and Torres Strait Islander peoples.

Call ***1800 Respect*** on 1800 737 732



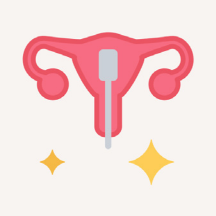
1800 Respect gives free support to people who face violence or abuse.

Call ***QLife*** on 1800 184 527

QLife gives free support to ***LGBTQIA+***
people in Australia.

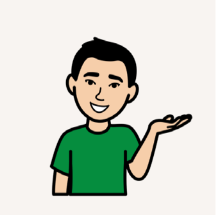
LGBTQIA+ includes lots of identities
and ways of loving people.

Learn more about cancer



To learn more about cancer or cervical screening
call the Cancer Council Helpline on 13 11 20.

Help to call



Anyone can use these **free** services in Australia.

Call 131 450 for the Translating and Interpreting Service if English is not your first language.

Call 1800 555 660 for the National Relay Service if you have communication support needs.

Call 1800 555 677 if you use a teletypewriter or TTY.

Embrace Access

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