



Co-producing cancer survivorship resources with and for people with intellectual disability

Stage 2 Co-Production Workshops

Participant Information and Consent Form



Flinders University Research Ethics Number: 8857



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The research team

We are **researchers** from Flinders University. Our job is to find out things. We do this by talking and writing things down.



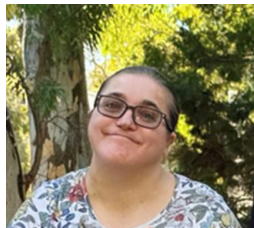
- Michelle Bellon



- Jennifer Baldock



- Irene Belperio



- Hannah Beinke



- Jala Burton



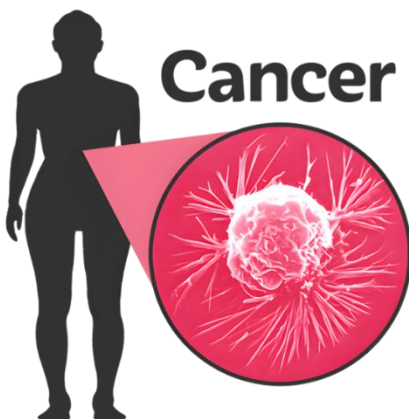
- Tim Cahalan

About this research



We want to know how to make **cancer** health care better for people with intellectual disability.

Cancer is a disease that



- can grow in any part of your body
- can spread from one part of your body to other parts
- can make you sick.



Cancer **survivorship** starts from the time when a person is told they have cancer (diagnosis).



Not many people with intellectual disability have been asked about cancer.



We will use what we learn in this research to make new **resources** about cancer survivorship with and for people with intellectual disability in Australia.



A **resource** is information like easy read booklets, videos, picture stories, and picture cards.



A short video about the project is here:

<https://youtu.be/7Jjv3MoG8Ng>



We got a grant from the Medical Research Future Fund to pay for this study. The grant number is 2040481.



We have a big team of people from all around Australia helping.

These people are from different organisations.



The aim



To work together in workshops to **co-produce** resources that help people with intellectual disability and cancer.

Co-production means people who will use the resources make the resources.

Can I be in this study?

You can be in this study if you are:



- over 18 years old and
- have an intellectual disability or
- family member or friend or
- disability service provider or
- health professional.



What will I do?

Take part in 5 workshops.



Each workshop will go for 2 hours with breaks.



The workshops will be between April and September 2026.



Each group will have 8 to 10 people.

Where will the workshops be?



You can join workshops online

or

in person at:

The logo for SACID, featuring the word "sacid" in a blue, lowercase, sans-serif font with a green dot above the 'i'.The logo for MiNDA, featuring the word "MiNDA" in a bold, green, uppercase, sans-serif font on a white background.The logo for Cancer Council, featuring a yellow stylized flower icon to the left of the words "Cancer Council" in a blue, sans-serif font.

- SACID, Prospect SA
- Minda Inc, Brighton SA
- Cancer Council SA, Eastwood SA



Tea, coffee and snacks are provided.

The logo for SACID, featuring the word "sacid" in a blue, lowercase, sans-serif font with a green dot above the 'i'.

SACID will help us do the workshops.



You can bring a friend or a support person.



We will ask to record what you say.



You will receive **\$100** for each workshop that you come to.

You only have to **take part if you want to**.



You can say No. It's your choice.

If you say no, then no one will be angry and the support you get will not change.



If you decide you want to take part, you can **change your mind at any time** and say no.

Once you say no, we will remove anything you said from our study records.

We will **not tell people your name or the names** of people you talk about.



We keep all your information safe at Flinders University for 5 years.

After then, we safely destroy it.

People to talk to about the study



You can use the phone numbers and email addresses to ask people or complain about this research.



If you have questions about the research, you can talk to **Jennifer Baldock** at Flinders University at:

Jennifer.Baldock@flinders.edu.au



If you want to complain about the research, talk with the Flinders University **Research Ethics Office**:

human.researchethics@flinders.edu.au

or 08 8201 2546.

Tell them this number: HREC-8857



We will make sure this research is safe for everyone.



If you feel sad or upset when talking to us, please tell us.

You can also call

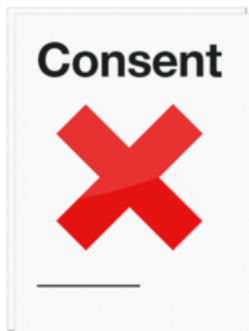
- **Beyond Blue Support Service** on 1300 224 636, or
- **Lifeline Australia** on 13 11 14 and they will talk with you.

If you want to take part in this study



If you want to take part, you need to sign your name on the form that says, 'I want to take part'.

That is on Page 16.



If you want to leave the study later, you can sign your name on the form that says '**I changed my mind** – I do not want to take part anymore' or tell someone who will contact us.

Your decision not to take part will not change the relationship you have with the services that support you.

That is on Page 18.

I want to take part in the study (giving consent)



- I am signing this form because **I want to take** part in the study.
- I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.
- I had the opportunity to ask questions and am happy with the answers you gave.
- I understand that you will record what we speak about; I agree to be recorded for this purpose.
- I understand that talking to you will not change the support I get.
- I freely agree to take part in this study and understand that **I am free to withdraw** (change my mind) at any time. Withdrawing will not affect my relationship with any of the named organisations or research team members.
- I would like to receive a copy of the summary via email or post, I have provided my details below and ask that they be used for this purpose only.

My Details

My name: _____

My signature: _____

Date I signed: _____

Witness Details

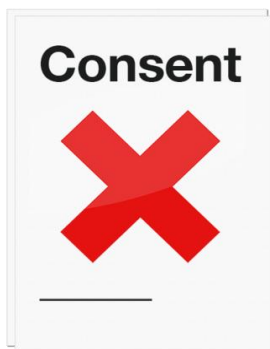
Name of the person who saw me sign:

Signature of the person who saw me sign:

How they know me:

I changed my mind – I do not want to take part anymore

Sign this form and send to: Michelle.Bellon@flinders.edu.au



- I am signing this form because I changed my mind.
- I do not want to take part in this study about.
- I do not want you to use what I said.

My Details

My name: _____

My signature: _____

Date I signed: _____



Thank you.