Participant Information and Consent Form

Improving palliative care for people with intellectual disability

This sheet has information about research that is looking at how to make palliative care better for people with intellectual disability.

Palliative care is special help for someone who is near the end of their life.

End of life means someone has an illness or a condition that means they will die.

Research means finding out what people think about things and using the information to help other people.

You can ask someone you trust to help you understand this sheet.

Who is doing the research?

My name is Julian Trollor. I am a researcher at the University of New South Wales. I am working with

Janelle Weise

and

Rachael Cvejic

and

Sara Elsie Walker

What is it about?

This research is about how to make palliative care better for people with intellectual disability.

We want to talk to people with intellectual disability about what they think.

Who can take part in the study?

People who:

- self-identify as having intellectual disability
- are aged 18 years old and over
- live in NSW
- have a life-limiting condition or complex health needs

What does taking part involve?

We will ask you to call us and answer some questions to check if you can take part in the study.

If you cannot take part, we will not keep any information about you.

If you can participate, you can choose to take part in

- **an interview or**
- **a group talk**

An interview involves answering questions by yourself or with a support person.

A group talk involves answering questions in a group.

There will be about 4 other people in the group.

If you want you can bring a support person with you.

In an interview or group talk we will ask you about:

- what you think a good end of life looks like
- What makes it hard and easy for people to have a good end of life
- How can we help people with ID to have good end of life

You can do the interview or group talk:

- in person or

- on the phone or

- via video conferencing (e.g. Zoom or Skype).

You can choose which questions to answer. You can say no if you do not want to answer a question.

We will ask to record what you say.

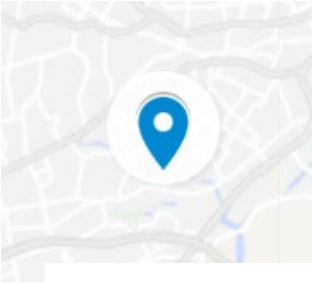
If you do an **interview** and do not want us to record, that is OK. We will take notes instead.

If you take part in a **group talk**, we must record it. There is no option to take notes instead.

If you use communication aids we will ask if we can take a photo of them.

We will use the photos to help us write down what you said.

The **interview** or **group talk** will take no more than 2 hours.



In person interviews and group talks will be held at:

- A private room at 3DN in Randwick
- A private room in the Sydney CBD.

You will get a $120 voucher to say thank you.

Do I have to take part?

You only have to take part if you want to.

You can say no. It is your choice. No one will be angry if you say no.

Even if you say yes, you can change your mind later and stop taking part.

What will happen to my information?

We will store your information at 3DN, UNSW Sydney on our computers.

The computers have a password.

Only the researchers will know the password.

We will keep the recordings of your interview or group talk in these computers as well.

We will keep your information for 5 years after we write reports about it.

We will keep your information private.
We will not tell anybody your name
or where you live.

No one will know it was you who took part.

We will write about what we find out.
If you want, we will send you a summary.

If you say it is OK, we may share what you said with other research teams so they can use it in their research.

This would only be if their research is similar to this research study.

Who can I get in touch with about the research?

If you have any questions, get in touch with:

Name: Sara Elsie Walker

Phone: **(02) 9065 7786**

Email:
IDPalliativeCare@unsw.edu.au

OR

Name: Dr Jessica Lee

Email:
jessica.lee1@health.nsw.gov.au

If you want to complain about the research, you can get in touch with the Human Research Ethics Coordinator. It is their job to listen to you and find out what happened.

Phone: **02 97675622**

Email: **SLHD-ConcordEthics@health.nsw.gov.au**

Tell them this number:
2022/STE00514

If you feel upset after taking part, you can talk to some who supports you or call one of these numbers.

Beyond Blue: 1300 224 636

Anyone can call this number any time of the day.

They have a website too. It is **www.beyondblue.org.au**

What if I am having a crisis?

A crisis is when you are very upset and need help straight away.

If you are in a crisis, you can call one of these numbers:

Suicide Call Back Service: **1300 659 467**

They have a website too. It is **www.suicidecallbackservice.org.au**

Lifeline: **13 11 14**

They have a website too. It is **www.lifeline.org.au**

Anyone can call these numbers any time of day.

If you have a hearing impairment you can call Lifeline through the National Relay service. Here is how:

For TTY phone 133 677 then ask for 13 11 14

For Speak and Listen phone 1300 555 727 then ask for 13 11 14

Where can I learn more about Palliative Care?

Click here to visit is a website with more information about palliative care.

I want to take part

Improving palliative care for people with intellectual disability

I am signing this form because I understand about the research, and I want to take part

☐ Tick this box if you have read the information about the study.
Or if someone has explained the study to you.

☐ Tick this box if you understand that you can change your mind later and not be in the study anymore.

☐ Tick this box if you want to bring a family member or support person with you.

☐ Tick this box if you agree we can share what you said with other researchers for their study.

☐ Tick this box if you want us to tell you what we find out from the research.

Please tick one of these boxes

☐ Tick this box if you want to be in an interview.

OR

☐ Tick this box if you want to be in a group talk.

My signature: _____

Date: _____

My phone number: _____

My address: _____

My email address: _____

I understand that you will only use my contact details for me to take part in the research and to tell me about the findings afterwards.

Witness signature (a witness is someone who saw you sign the form):
_____

Date: _____

I do not want to take part anymore

Improving palliative care for people with intellectual disability

I am signing this form because I changed my mind. I do not want to take part anymore and I do not want you to use what I said.

I understand that the information I gave in a focus group cannot be destroyed given the nature of the focus group.

My signature: _____

Date: _____

Witness signature (a witness is someone who saw you sign the form):
_____

Date: _____

Send this form to:

Prof Julian Trollor
3DN, UNSW
34 Botany Street
UNSW, NSW, 2052

Or email it to j.trollor@unsw.edu.au

You can also call us on the phone **(02) 9065 7786**

Thank you for reading.

This information sheet is for you to keep.