



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For a person with an intellectual disability

The Successful Ageing in Intellectual Disability Study (SAge-ID) – a nationwide study
Dr Liz Evans

Information about The Successful Ageing in ID study.

Hello!



This is Liz Evans.



This is Julian Trollor.



This is Rebecca Daly.

We are researchers.



We are doing a research study.

It is called The Successful Ageing in ID study – A nationwide study.

Or SAge-ID for short.

The study is about what it is like for people with an intellectual disability as they get older. This can help us see how people with an intellectual disability can stay healthy as the get older.



This letter is about whether you want to be in the study.



Can I be in this study?

You can be in this study if:

You are over 40 years old and you have an intellectual disability.

You have a person who knows you well who is happy to answer questions about you.



What will happen if I decide to be in the study?

Being in the study means that we send out a survey.

The survey asks questions about you.

There are 2 sections of the survey.



The 1st section is about your health and your experiences.



You can do the first section of the survey yourself.



Or you can ask someone to help you with it.



Or you can ask someone who knows you well to do it for you.



The 2nd section of the survey is about your thinking and behaviour.



This section should only be done by someone who knows you well.



You can choose who does this part of the survey about you.



There are other parts of the study too.

You can choose whether or not you do these parts as well.

It is up to you.



We might ask to speak on the phone to someone who knows you well.

We will ask about things like your memory.

It takes the person who knows you well about 50 minutes.

You can say yes or no to that part of the study.



We might ask you if you want to meet with us.

The meeting is with Liz or Rebecca.

Only some people in the study will be asked to do the meeting.

You can bring someone else with you if you want to.



At the meeting we will do different activities.

Like memory activities.

And checking how much you weigh.



And checking your blood pressure.



1 – 2 hours

The meeting goes for 1 to 2 hours.

But we have a break in the middle.



We will give you something to eat and drink in the break.



If we ask you to do the meeting, you can say yes or no.

It is your choice.

If you start the meeting but want to stop, you can ask to stop.

The meeting can be at our office in Randwick.

Or at your home. Or somewhere else that is easy for you to get to.



If you come to the meeting, we will pay you back for any money you spend getting there.



Like if you pay to catch the bus to the meeting.

Or a train or a taxi.



Or if you pay to park a car near our office.



We will give you back whatever you spend on getting to the meeting.

And whatever you spend on getting home again.

But the most that we can give you back is \$50.



Are there any risks from being in the study?

We don't think anything bad will happen from being in the study.

Most people who are in a study like this don't find it upsetting.



But sometimes people can get upset from questions about their health.

If this happens to you, you can tell us.



We can give you some phone numbers for you to talk about it.

We have listed these numbers at the bottom of this letter.

And we can give them to you again later if you need them.

What do I get out of being in the study?



We can't promise that you will get anything out of the study.

We hope that the information we collect will help other people with intellectual disability in the future.

Do I have to be in the study?



It's your choice.

You can say no.

Saying no won't change anything or make anyone upset.

You can choose which parts you do.

And you can choose which questions you answer.



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



If I say yes can I change my mind later?

Yes. There is a form called 'I changed my mind – I don't want to take part anymore'.

If you change your mind, write your name on it and send it to us.

Or you can call us, or ask someone else to call us.

If you change your mind, we won't contact you again and we won't collect any more information from you.

You can choose what happens to the information you already gave us.



We can keep it and use it for our research.
Or we can destroy it.

The choice will be yours.

What happens to my information if I am in the study?

We will store your survey in a locked filing cabinet in our office.

And it will be on our computers. The computers have a password.

No one except the study team can see your answers.

Your answers are kept private.

They won't have your name on them.





How do you use my answers?

We will use your answers to help our research.

We will look at answers from everyone together as a group.

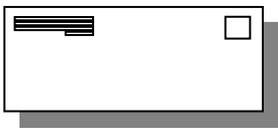
When we talk about your answers we won't say your name.



What happens after the study?

After the study finishes we will write a report about what we learned.

We can send you a copy if you want to see it.



After the study, we might send you a letter about your health.

Not everyone will get a letter about their health.

We only send it if your answers tell us something about your health that you might not know yet.



If you say it is OK we will also send a letter to your doctor.

What if I want to talk to someone about the study?

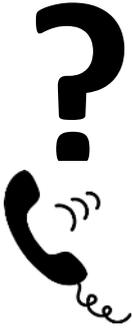
If you have questions about the study you can call:



Liz

on (02) 9931 9160.

Or you can email Liz on lizevans@unsw.edu.au.



What if I get upset from being in the study?

If you get upset from being in the study, you can call one of these numbers:

BeyondBlue: 1300 224 636

Anyone can call this number any time of day.

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

Here is a website with information about mental health:
www.mindspot.org.au

What if I am having a crisis?

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 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

For Internet relay connect to National Relay Service. Ask for 13 11 14

What if I want to complain about the study?

If you want to complain about the study, you can call:



the Human Research Ethics Coordinator at UNSW.

on (02) 9385 6222.



Or you can email them on humanethics@unsw.edu.au.

If you call or email them tell them it is study number HC17601.

Thank you for thinking about this study.

I want to take part in The Sage-ID Study

- Tick this box if you have read the information about the study. Or if someone has explained the project to you.
- Tick this box if you know that you can change your mind later and not take part anymore.
- Tick this box if you want to be in the Sage-ID study.

I want to do these parts of the study:

- Tick this box if you want us to do the phone call with someone who knows you well.
- Tick this box if you want to meet with us.

After the study is done:

- Tick this box if you want us to send you a report about what we find out.

If yes please write your address here:

Or write your email address here: _____

- Tick this box if you want us to write to you if we find out anything new about your health. Then please write your address here:

- Tick this box if it is OK for us to write to your doctor if we find out anything new about your health. Then please write your doctor's name and address here:

Tick this box if you want to hear about other research projects in the future.

If yes please write your address here: _____

Or write your email address here: _____

Your signature:

Sign on this line if you want to take part:

Write your name here:

Write the date you signed here:

This is our part to fill out.

Declaration by researcher:

I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

| | |
|--------------------------------------|--|
| Name of Researcher (please print) | |
| Signature of Researcher | |
| Date | |

I changed my mind – I don't want to take part anymore

Only fill in this page if you don't want to take part anymore.

I am signing this form because I changed my mind.

I don't want to take part anymore.

I know that changing my mind won't change anything.

It won't make anyone upset.

What should we do with the answers you already gave us?

Keep it and use it for your research. But don't ask me for any more.

OR

Destroy it. You can't use it for your research.

Sign on this line:

Write your name here:

Write the date you signed here:

Please return this form to

Liz Evans

3DN, 34 Botany St.,

University of New South Wales 2052.

Or email it to Liz: lizevans@unsw.edu.au

Or fax it to (02) 9931 9154.

You can also call us to tell us you don't want to take part anymore.

Our number is (02) 9931 9160.