

Plain Language Statement

Project: Understanding how carers share information with people with intellectual disability in emergencies

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Thank you for your interest in participating in this research project. Over the next few pages, you will find information about the research.

- This will help you decide if you want to participate.
- If you don't want to take part, you don't have to. Participation in this research is voluntary.
- Please read this information carefully. You can ask questions about anything you don't understand.

What is this research about?

- This research project aims to find out how carers and paid support workers (collectively known here as supporters) share information with people with intellectual disability in emergencies.
- An emergency can be something like a flood, bushfire, storm, or the COVID-19 pandemic.

We want to find out how people with intellectual disability get the information they need in emergencies. We have spoken to some of them and one of the ways they reported getting information about emergencies is through their supporters.

We are doing this research because we want to make sure people with intellectual disability can get the information they need in an emergency. We hope this can help them to make decisions for themselves and stay safe.

What will I be asked to do?

If you agree to take part in the research, you will be invited to take part in an interview where a researcher will talk to you about your experiences and ask you to share your ideas.

The researcher will ask you questions about:

- your experiences in emergencies, including how you access information
- how you support people with intellectual disability in emergencies, and how you share information with them.

We will tape-record the interview, and then write down the things you say. This will help us remember the important things you said. The interview can be done online or in person at a place where you feel comfortable, such as a quiet room at your local library or community centre.

How long will this take?

We anticipate the interview will take up to one hour.

What are the possible benefits?

There will be no direct benefits to you.

We hope to use your ideas to make sure people with intellectual disability can get the information they need in an emergency. After we have finished all the interviews, we will send you a summary of all the things people said.

Will I be reimbursed for my time?

If you decide to participate in an interview, you also will be given a \$50 gift card to reimburse you for your time. This is intended to cover the cost of travel, parking or lost income that you may experience taking part in the study.

The gift card is a VISA gift card. This will be emailed to you on the day of the interview. On request a physical gift card can also be provided.

What are there any risks to me if I take part?

There is some risk that talking about your experiences in emergencies might upset you. If this happens you can stop the interview at any time. You can skip questions you might find upsetting.

If you find anything about this research distressing there are services that can help:

- Lifeline: a free and confidential crisis support helpline that are open 24 hours a day, 7 days a week. To speak to someone call 13 11 14.
- Carer Gateway: provides free counselling to carers. To find out more visit carergateway.gov.au or call 1800 422 737 Monday to Friday, 8am to 5pm
- Employee Assistance Program: If you are employed to support people with disability you may have access to supports through your employer. Please consider this if anything about this research is distressing.

Do I have to take part?

No, you do not have to participate. If you start the interview you can stop at any time. You can choose to skip questions if you don't want to answer them. You don't have to explain why.

After the interview, you can choose to have your ideas removed from the research. If you decide you want your ideas removed, you need to let us know within 30 days of your interview. This is because we will be putting your ideas into a report and once we have written it we won't be able to take your ideas out.

What will happen to the information about me?

We will not use your real name in any reports or presentations. We will use a made-up name instead. We will not tell people you participated in the research.

We will not share your contact information with anyone outside of the research team unless required by law. Contact information means your name, phone number or address.

All the information you share with us, including the recording, will be stored on a computer. The information will be locked away with a password and only the researchers will be able to listen to it or read the notes. After 5 years we will destroy all the information.

Who is funding this project?

This research has been funded by the Melbourne Disability Institute as part of a PhD scholarship received by the researchers. Melbourne Disability Institute supports research which aims to ensure people with disability, their families and carers have equal rights and opportunities. To find out more about the Melbourne Disability Institute you can visit their [website <disability.unimelb.edu.au/>](http://disability.unimelb.edu.au/)

The funding amount is \$1000.

Where can I get further information?

If you would like more information about the project, please contact the researchers;

- Heidi Peart on 0420 719 852 or via email: hpeart@student.unimelb.edu.au
- Shanton Chang via email: shanton.chang@unimelb.edu.au

Who can I contact if I have any concerns about the project?

This project has 'human research ethics approval' from The University of Melbourne. This means there are rules about how we run this research project. Research participants should feel safe and respected.

You can make complaints about this research by:

- talking to the research team about your concerns; or
- contacting the Research Integrity Administrator on 03 8344 1376 or via email: research-integrity@unimelb.edu.au.

All complaints will be treated confidentially.

In any written feedback please include the name of the research team and/or the name or ethics ID number of the research project (34291)