



## **Participant Information Sheet – Group 2- Supporters/Family Members of Neurodivergent People**

**Project Title:** Neurodiversity Affirming Practices in Emergency Healthcare

### **Project Summary:**

You are invited to participate in a research study being conducted by Associate Professor Liz Thyer, Dr Caroline Mills and Emma Fleming from the School of Health Sciences, Associate Professor Lise Mogensen from the School of Medicine at Western Sydney University, Charlton Quitariano from the Department of Paramedicine at Monash University and Kitty Mach, a psychologist with lived experience of autism and ADHD.

The research aims to explore the perspectives of paramedicine practices and supports for people who identify as neurodivergent from multiple stakeholder perspectives.

### **How is the study being paid for?**

This study is being funded by Western Sydney University.

### **What will I be asked to do?**

You will be asked to participate in an interview where you chat with a researcher about your experiences of supporting a family member or loved one to receive a service from a paramedic at a time when that they were unwell.

This interview will take place online or in person at your convenience at a time that is agreed to between you and the researcher.

### **How much of my time will I need to give?**

You will be asked to give a maximum of 1 hour of your time, but the interview may range from 30 minutes to 1 hour.

### **What benefits will I, and/or the broader community, receive for participating?**

There is no direct benefit to you for your participation. However, your participation will contribute to establishing knowledge about supporting neurodivergent people in accessing community healthcare both now and in the future. Findings from this study will contribute to future research exploring how to improve access to emergency healthcare for neurodivergent people.

### **Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?**

It is possible that questions or discussion may cause some discomfort or distress for participants due to the potentially challenging nature of describing your experiences of supporting a family member or lived one in accessing paramedic services at a time that you may have been unwell. In case you experience any discomfort as a result of participation in the study, you can contact



the Mental Health Access Line: 1800 011 511 (offered by the NSW government, a 24-hour telephone service operating seven days a week across NSW) and can speak to a trained professional and gain information and referral to support. You may also wish to speak to your own health professional, such as your GP.

It is possible that you might disclose examples of professional misconduct by a healthcare worker, but we will not collect any identifying information about the healthcare professionals you discuss. If you do wish to follow up, you can contact the NSW Ambulance Complaints departments at: <https://www.ambulance.nsw.gov.au/about-us/contact-us/complaints>, or the NSW Health Care Complaints Commission at <https://www.hccc.nsw.gov.au/contact-us>

It's possible that taking the time to participate in interviews may be inconvenient. We recognise that you are busy, and your time is valuable. Data collection will be focused and directed on answering the research question to limit time commitments.

#### **How do you intend to publish or disseminate the results?**

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified, except with your permission. We will assign each participant a 'pseudonym' (fake name) so they are not identified. We will also not present stories in a way that would identify participants.

#### **Will the data and information that I have provided be disposed of?**

Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time. These include projects related to paramedicine practice or training for supporting neurodivergent people for the next 15 years.

#### **Can I withdraw from the study?**

Participation is entirely voluntary, and you are not obliged to be involved. If you do participate you can withdraw up until the point of data analysis. If you want to withdraw you can notify any of the research team by telling them or sending an email.

If you do choose to withdraw, interview data supplied can be removed from the study data set upon request up until the point of data analysis.

#### **Can I tell other people about the study?**

Yes, you can tell other people about the study by giving them the contact details of the researchers. You can tell them to contact Associate Professor Liz Thyer [E.thyer@westernsydney.edu.au](mailto:E.thyer@westernsydney.edu.au) or Dr Caroline Mills [caroline.mills@westernsydney.edu.au](mailto:caroline.mills@westernsydney.edu.au) to discuss their participation in the research project and obtain a copy of the information sheet.



### **What if I require further information?**

Please contact Associate Professor Liz Thyer [E.thyer@westernsydney.edu.au](mailto:E.thyer@westernsydney.edu.au) or Dr Caroline Mills [caroline.mills@westernsydney.edu.au](mailto:caroline.mills@westernsydney.edu.au) should you wish to discuss the research further before deciding whether to participate.

### **Privacy Notice**

Western Sydney University staff and students conduct research that may require the collection of personal and/or health information from research participants.

The University's Privacy Policy and Privacy Management Plan set out how the University collects, holds, uses and discloses personal or health information. Further details about the use and disclosure of this information can be found on the [Privacy at Western Sydney webpage](#).

### **What if I have a complaint?**

If you have any complaints or reservations about the ethical conduct of this research, you may email the Ethics Committee through Research Services: [humanethics@westernsydney.edu.au](mailto:humanethics@westernsydney.edu.au).

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep, and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H17060.

## **Explanation of Consent**

### **What will happen to my information if I agree to it being used in other projects?**

Thank you for considering being a participant in a university research project. The researchers are asking that you agree to supply your information (data) for use in this project and to also agree to allow the data to potentially be used in future research projects.

This request is in line with current University and government policy that encourages the re-use of data once it has been collected. Collecting information for research can be an inconvenience or burden for participants and has significant costs associated with it. Sharing your data with other researchers gives potential for others to reflect on the data and its findings, to re-use it with new insight, and increase understanding in this research area.

You have been asked to agree to Extended consent.

### **What does this mean?**

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When you agree to extended consent, it means that you agree that your data, as part of a larger dataset (the information collected for this project) can be re-used in projects that are

- an extension of this project
- closely related to this project
- in the same general area of this research.

The researchers will allow this data to be used by researchers in the field who are exploring paramedicine practice and support with neurodivergent or other vulnerable populations.

To enable this re-use, your data will be held at the University in its data repository and managed under a Data Management Plan. The stored data available for re-use will not have information in it that makes you identifiable. The re-use of the data will only be allowed after an ethics committee has agreed that the new use of the data meets the requirements of ethics review.

The researchers want to keep the data for 15 years for possible re-use. After this time the data will be securely destroyed.

You are welcome to discuss these issues further with the researchers before deciding if you agree. You can also find more information about the re-use of data in research in the [National Statement on Ethical Conduct in Human Research](#) – see Sections 2.2.14 - 2.2.18.

<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018>