



## Participant Information Sheet

### Emergency Ambulance Care in Out-Of-Hospital Deaths: Whānau Experience

**Lead Researcher:** Eillish Satchell

**Co-investigators:** Dr Natalie Anderson, Dr Tess Moeke-Maxwell, Professor Merryn Gott

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**Study Site:** The University of Auckland, School of Nursing,  
Auckland, New Zealand, 1023, Private Bag 92019.

Tēnā koe, thank you for your interest in this project. This participation information sheet contains information about our research project. Your participation in this research project is voluntary (your choice). Participation in this research project will not disadvantage you in any way. If you don't want to take part, you don't have to give a reason. If you do want to take part now, but change your mind later, you can pull out of the study at any time. If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 6 pages long. Please take some time to read and understand the following information before deciding to take part in this research project.

#### **What is the purpose of this study?**

This study will help us to find out more about the experience of families in Aotearoa New Zealand when a family member dies in the community where ambulance services respond. By understanding the experiences of families in these situations we will work with ambulance services to ensure that the best support and care is offered to families in future.

#### **Who is conducting the study?**

My name is Eillish Satchell (Ngāpuhi), and I am the lead researcher for this study. I am a nurse and am a PhD student currently completing my PhD exploring family experience in community emergencies at the University of Auckland. Other members of this research team are researchers from the University of Auckland Dr Natalie Anderson, Professor Merryn Gott, and Dr Tess Moeke-Maxwell (Ngāi Tai ki Tamaki; Ngāti Porou).

#### **Who can take part in the study?**

- We are looking for people who have experienced the death of a family member in the community where New Zealand ambulance services have responded.
- You can take part in this study as an individual or as a whānau/family group.
- You must be over 18 to take part in an individual interview.

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

If you agree to take part in this project, you will be asked to take part in one in-person interview with Eillish Satchell and share your story. The researcher will also ask you some questions about your experience. You will also be asked some questions about yourself and your loved one who has died. You will be asked to sign a consent form which shows you give permission to take part in this study. Your story will be kept confidential. We will not share any identifiable information, we will use a pseudonym (fake name) to refer to you and your information. You can choose what name to be called.

- Interviews will take place in person. You can choose where this interview takes place. You can choose to have a Zoom or telephone interview if you prefer.
- Family members can stay with you and may take part in the interview if they have also experienced the event.
- You may have any cultural supporters present whom you would like with you during the interview.
- We expect one hour to be enough time to talk if you are doing an individual interview. Family group interviews may take up to two hours. There will be time on the day for any questions, reading this information sheet, and any cultural practices you wish to engage in (karakia/prayer, whanaungatanga etc).
- Interviews will be audio-recorded; this is so we can accurately capture your story. This audio recording will be transcribed by either Eillish Satchell or a third-party transcription service, which will complete a confidential agreement.
- We will ask you for some basic information about you, such as your age and ethnicity, for reporting purposes.
- If applicable, the researcher may be accompanied by a kaumatua during your interview to provide cultural support. This will only happen with your consent and can be discussed with you when arranging your interview.

After the interview the researcher will create a 'story' based on what you share in the interview. We will give this story back to you and ask you to check if it is correct. You may make any changes or add any other information if you would like. Your story will include some important quotes (things you said) from your interview that the researchers may use in publications and presentations (any identifying names or content will be removed). You can choose whether these are included in the results. Checking your story is important because it helps the researchers know we have understood your experience correctly.

- You may choose not to receive a copy of this story if you only want to take part in the interview.
- You can expect to receive a copyback of your story within 4 weeks of your interview.
- You and your whānau can edit or choose to withdraw from the study if you no longer wish to participate within two weeks of receiving your story.

- If we don't hear back from you about your story in two weeks, we will assume your approval for the de-identified use of your story.

The researcher may also ask you if you or members of your whānau would be willing to give feedback on any resources the team develop to support families who experience community deaths. This is optional and you do not need to agree in order to take part in this study. If you are interested in taking part in this, we will contact you again in 2025 to arrange a time to meet with you to look at the information and resources.

### **What are the possible risks of participating in this study?**

There are no identified risks associated with participating in this study. However, we understand that interviews can sometimes be tiring, or the questions may seem too personal or emotionally painful. The interview may bring back memories of your experiences, and you may feel uncomfortable or distressed. If you start the interview but find the questions cause distress, you can ask the interviewer to stop at any time. The research team will be sensitive to the emotions associated with losing a loved one. If you have been upset by any aspects of the interview and want to talk to someone or need extra support please talk to the researcher or refer to the list of numbers at the end of this form.

### **Who is funding the study?**

The New Zealand Health Research Council has funded this study. They awarded Eillish Satchell and her team from the University of Auckland funding for three years.

### **Will any costs be reimbursed?**

We do not expect the study to cost you any money. To compensate you and your whānau for your time and to say 'thank you', we will provide each family/whānau with a \$50 voucher. This is yours to keep if you decide to withdraw from the project.

### **What are my rights as a Participant:**

#### *Participation is Voluntary*

Your participation in this research project is voluntary (your choice). Participation in this research project will not disadvantage you in any way. If you don't want to take part, you don't have to give a reason. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

#### *Withdrawal from participation and withdrawal of data:*

You may withdraw your consent for the collection of your information at any time by contacting Eillish Satchell. You do not have to give a reason and your decision will be confidential and will not affect your healthcare in any way.

- If you choose to participate individually you may choose to stop the interview and withdraw information at any time. You may choose to withdraw your data at any point up until two weeks post receiving your story, or, two weeks after the interview

if you choose not to receive a summary of the interview. After this period, information collected up until your withdrawal from the study will continue to be used and included in the study. This is to protect the quality of the study. Any information used will be de-identified so it cannot be linked back to you.

- If you wish to take part in a whānau/family interview, please note that withdrawal of your individual contribution to a whānau group interview is only possible up until the commencement of the group discussion. Once a group discussion starts we cannot withdraw your information as it is incorporated into the discussion with other members of your family. You may choose to leave the group discussion at any time and you do not have to answer any question you do not wish to
- A whānau/family group can withdraw for a period of two weeks following the interview provided that every individual who participated in the interview agrees.

#### *Confidentiality and de-identification of data:*

Researchers in this study will keep all identifiable information (any data that could identify you, e.g., your name, date of birth, or address) confidential. To make sure your personal information is kept confidential, identifiable information will not be included in any publicly available reports or results generated by the researcher. We will securely store this information at the study site, and only named researchers will have access to this information.

Researchers will de-identify your data for the purposes of sharing results and publications. This means we will remove or replace any data that could identify you. For example, we will not use your real name, instead, you will be identified by a pseudonym (fake name). Other data we may de-identify is the town/city where you live, age, and anything in your story that you or the researchers may feel is too recognisable. The researcher will keep a confidential list linking your de-identified data (e.g. your fake name) with your identifiable data (e.g. your real name) so that you can be identified by the researchers if needed. This will be kept confidential. The results of the study may be published or presented using your de-identified information, but not in a way that would reasonably be expected to identify you.

Very rarely, it may be necessary for the researcher to share your information with other people – for example, if there is a serious threat to public health or safety, or to the life or health of you or another person OR if the information is required in certain legal situations.

#### Confidentiality Risks

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. There is a risk that even with de-identifying your information, elements of your story could still be recognised. We will minimise this risk by de-identifying your information and any recognisable details about the event. You will also have the opportunity to review what details we include through the collaborative story process. Overall, the risk of people accessing and misusing your information is currently very small but may increase in the future as people find new ways of tracing information.

## **What will happen to my information after the study?**

### Rights to Access Your Information.

You will have the opportunity to receive back to you a collated story based on your interview. You also have the right to request access to the full interview (transcript) held by the research team. Both of these documents will be available to you within 4 weeks of completing the interview. You can request that any information you disagree with is corrected. You will have an opportunity to read, change, add or delete anything in your interview transcript that you wish to change within a two-week period following receiving your story.

### Can I find out results of the study?

Yes, you can choose if you would like to receive a summary of the results once the study is completed. You will be able to choose to receive this information on the consent form. Results are expected to be available in 2026.

### Storage and Security of Your Information

Your information will be stored securely at the University of Auckland during the study. Only the research team will have access to your identifiable data. After the study has finished your information will be transferred to a secure electronic archiving site facilitated by the University of Auckland and stored for a minimum period of 10 years before being destroyed in accordance with local data security guidelines. All data storage will comply with local and/or international data security guidelines at the University of Auckland.

### Future Research Using Your Information

Your information will be used by the research team for the purposes of this study, exploring New Zealand family experiences of community death where emergency ambulance services respond. This study is part of a larger research project in fulfilment of a Doctor of Philosophy.

Your information will not be used by the research team for any other purpose beyond this research project. We will not share your de-identified information with any other organisations for any reason. You can request reports or other information about any research that is done using your information.

### Māori Data Sovereignty.

*Māori data sovereignty* is about protecting information or knowledge that is about (or comes from) Māori people. We recognise the taonga of the data collected for this study. To help protect this taonga:

- We have consulted with the Te Ārai End of Life and Palliative Care Kāhui Kaumātua around the entire study design, methodology, analysis, dissemination of findings, development of assisted dying resources and the collection, ownership, and use of study data.
- We do NOT allow any individual or organisation to access de-identified study data, for any reason.

## Who should I contact for support or if I have questions/concerns?

This study has been designed with the Te Ārai End of Life and Palliative Care Kāhui Kaumātua to ensure cultural safety for all participants. If you require Māori cultural support, talk to your whānau in the first instance. You may also contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324, or contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 4868920 ext 3204 to discuss any questions or complaints about the study.

If you have any questions about our project, either now or in the future, please feel free to contact:

Eillish Satchell	Lead Researcher	<a href="mailto:Eillish.Satchell@auckland.ac.nz">Eillish.Satchell@auckland.ac.nz</a>
	Student Investigator	0800 191 016
Dr Natalie Anderson	Principle investigator/Supervisor	<a href="mailto:na.anderson@auckland.ac.nz">na.anderson@auckland.ac.nz</a>
Dr Tess Moeke-Maxwell	Co-Investigator	<a href="mailto:t.moeke-maxwell@auckland.ac.nz">t.moeke-maxwell@auckland.ac.nz</a>
Professor Merryn Gott	Co-Investigator	<a href="mailto:m.gott@auckland.ac.nz">m.gott@auckland.ac.nz</a>
Associate Professor Julia Slark	Head of School, The University of Auckland, School of Nursing.	<a href="mailto:J.Slark@auckland.ac.nz">J.Slark@auckland.ac.nz</a>

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at

Email: [ahrec@auckland.ac.nz](mailto:ahrec@auckland.ac.nz) Phone: 373 7599 x 83711,

Address: Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142."

The loss of a loved one is a difficult experience. If you would like access to grief support, you can access these free resources below. You can also let the researcher know who will provide you with further resources.

Phone: Free Call or Text 'Need to Talk' 1737

Website: <https://mentalhealth.org.nz/conditions/condition/grief-and-loss>

**Approved by the Auckland Health Research Ethics Committee on 03/04/24 for three years. Reference number AH27360.**