



**MEDICAL AND
HEALTH SCIENCES**
SCHOOL OF POPULATION HEALTH

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Participant Information Sheet – Adult SURVEY

Co-design of guidance for schools/kura, funerals/tangihanga and memorials for students

Project title:

Co-design of guidance for schools/kura, funerals/tangihanga and memorials for students

Research team:

- Associate Professor Sarah Fortune, University of Auckland
- Dr Tania Cargo
- Associate Professor Sarah Hetrick
- Mr Ben Simperingham
- Ms Linda Bowden
- Ms Brooke Brake

Sponsor: Ember Innovation. The funder has no influence on the design of the study, and will only see final outputs of the study.

This Participant Information Sheet will help you decide if you would like to take part in this study. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. Before you decide, you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, we will ask you to agree to consent electronically. You can download copies of both the Participant Information Sheet and the Consent Form to keep from REDCAP

This document is 7 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

What does the study involve?

We are conducting study **on the experiences of schools/kura, funerals/tangihanga and memorials for students**. We will be asking questions about planning and hosting these events that you may have experience of, and how these could be improved.

Whether or not you take part is your choice.

You are invited to take part in this study as a school staff member, whanau member or other members of the community with a perspective on planning and hosting funerals/tangi or commemorations for students aged 5-18 who have died.

You are able to take part in this study if you:

- Are aged ≥18 years
- Live in Aotearoa New Zealand
- Have experience of planning and hosting funerals/tangi or commemorations for students aged 5-18 years who have died or
- Are a bereaved parent/caregiver/whānau member of a child aged 5-18 years.

Your participation is voluntary (your choice). You do not have to take part. You are free to withdraw from the study at any time, up until the point when you complete the survey online, without giving a reason. If you do not wish to participate in the study you will not be disadvantaged in any way. You are encouraged to ask questions at any time during the study process.

Participating in the study will take some of your time. You will need to read this Participant Information Sheet and Consent form. Then you will be asked to complete the online survey, which will take approximately 15-20 minutes.

We will be recruiting as many people as possible.

Only members of the research team will have access to the study information. All information collected during the survey will be processed to remove identifying information.

Please be aware that we will be discussing a potentially sensitive topic. You would only respond to the questions you feel able to answer.

Benefits and Risks

This study will lead to the co-design of guidance for schools/kura for hosting funerals/tangi or commemorations for students aged 5-18 years who have died.

Talking about death and grief can be distressing. If you become distressed at any stage you can choose not to submit your answers. If you do become distressed you should talk to your usual support networks or you can call and talk to any of the help lines listed here:

- Text 1737 to speak with a qualified counsellor any time of the day or night
- Contact the PeerTalk phone line on 0800 234 432 (5pm - Midnight, seven days a week, who will connect them with a trained peer support worker who will listen to their experience and help you access further help if needed

Who pays for the study?

- Taking part in this study will not incur any costs to you
- This study is funded by a grant from Ember Innovation
- There is no reimbursement for taking part in this brief survey

Rights of the participant(s)

Participation is voluntary:

Your participation in this online survey is entirely up to you (your choice), and you will not be disadvantaged in anyway if you choose to participate or not to participate.

Withdrawal from participation and withdrawal of data:

You have the right to withdraw from the study at any time up until the moment you have completed and submitted the survey electronically. Once you have submitted your responses you can no longer withdraw your data as your responses will be de-identified (i.e. not be linked to your personal information). If you do decide to withdraw from the study, you will not be disadvantaged in any way.

Confidentiality and anonymity:

The survey is anonymous. However, we will invite you to share your contact information if you want to hear about the next phases of the study. If you share these details, responses will be de-identified by the lead researcher so we will not be able to link your responses to your personal details.

Once you have completed the survey you will be invited to participate in a further more in depth interview, in which you will need to identify your contact details. This information will be stored separately to your survey response. Again, this is entirely your decision as to whether you continue to participate or not.

Identifiable Information: Identifiable information is any data that could identify you (e.g., your name, physical address, email address). Only the researchers will have access to your identifiable information.

De-identified (Coded) Information: To make sure your personal information is kept confidential, information that identifies you will not be included in any report generated by the research team. The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

Future Research Using Your Information: Your coded information may be used for future related research. You will not be told when future research is undertaken using your information. Your information may be used for future research until it is destroyed (i.e. at least 10 years).

Security and Storage of Your Information

Your identifiable information is held at University of Auckland during the study. After the study it is transferred to a secure archiving site and stored for at least 10 years, then destroyed. All storage will comply with local data security guidelines.

Risks

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded and anonymised information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information (e.g. making it harder for you to get or keep a job or health insurance) is currently very small, but may increase in the future as people find new ways of tracing information.

This research includes basic information such as your ethnic group and geographic region. It is possible that this research could one day help people in the same groups as you. However, it is also possible that research findings could be used inappropriately to support negative stereotypes, stigmatize, or discriminate against members of the same groups as you.

What will happen after the study?

- All electronic data will be stored on the University of Auckland server
- All computer records will be password protected
- All future use of the information collected will be strictly controlled in accordance with the Privacy Act, 2000
- The information will be kept securely at The University of Auckland, for a period of at least 10 years
- If you wish, a summary of the study findings will be sent to you at the end of the study, and once the information has been analysed
- We expect a summary of the data to be available by late 2022

Contact details

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Associate Professor Sarah Fortune or Dr Tania Cargo
Social and Community Health,
The School of Population Health,
The University of Auckland
sarah.fortune@auckland.ac.nz Ph 09 923 6097 or

Professor Janine Wiles,
Head of Department, Social and Community Health,
The School of Population Health,
The University of Auckland
janine.wiles@auckland.ac.nz Ph 09 373 7599

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or 373 7599 ext 83711, or at the Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92 019, Auckland 1142.

**Approved by the Auckland Health Research Ethics Committee on 24 July 2025
for three years. Reference number AH29177.**



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Consent Form — Co-design of guidance for schools; funerals and memorials for students who have died by suicide

ONLINE SURVEY

THIS FORM WILL BE HELD FOR A PERIOD OF AT LEAST 6 YEARS

Project title:

**Co-design of guidance for schools; funerals and memorials for students who have died
by suicide**

Research team:

- Associate Professor Sarah Fortune, University of Auckland
- Dr Tania Cargo
- Associate Professor Sarah Hetrick
- Mr Ben Simperingham
- Ms Linda Bowden
- Ms Brooke Brake

Sponsor: Ember Innovation

I have read the Participant Information Sheet. I have been given sufficient time to consider whether or not to participate in this study and to ask questions, and was offered support from whānau/family or a friend to help me understand what the study involves. I am satisfied with the answers given to me, I understand the nature of the research and why I have been invited to participate.

I agree to take part in this research.

- I understand my participation is voluntary
- I understand that the time needed is around 15 minutes
- I understand I am free to withdraw any data until the time that I submit my survey responses electronically
- I understand that my participation in this study is confidential and that no material which could identify me personally will be used in any reports on this study
- I understand that data will be kept for at least 10 years and separate from the Consent Forms, after which they will be destroyed
- I understand my participant data may be used for future research, in de-identified form.
- I know who to contact if I have any questions about the study in general
- I consent to the research staff collecting and processing my information
- I agree that information collected about me up to the point when I withdraw may continue to be processed if I decide to withdraw from the study
- I wish to receive the summary of findings

Email/postal address: _____

- I agree to be contacted in the future about similar research

Name _____

Signature _____ Date _____

**Approved by the Auckland Health Research Ethics Committee on 24 July
2025 for three years. Reference number AH29177.**