

Participant Information Sheet

Exploring the early experiences of the assisted dying service in Aotearoa – assisted dying service users living with impairment, disability or are Deaf

Sponsor: Victoria University of Wellington

Lead: Dr Jessica Young

Study Site: Wellington

Contact phone number: +64 4 886 4513

Ethics committee ref.: 18493

You are invited to take part in a study on the views of disabled people about the accessibility of the assisted dying service. Whether or not you take part is your choice. 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 withdraw from the research up until the time data analysis begins.

Your decision to participate in this research or not will not impact on your assisted dying application.

This Participant Information Sheet will help you decide if you'd like to take part. 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 will happen after the study ends. Please feel free to talk about the study with other people and ask the research team any questions before deciding.

Please contact Aida Dekhoda if you have any questions on +64 4 887 3140 or assisteddyingresearch@vuw.ac.nz

If you agree to take part in this study, we will go through this information with you and answer any questions. 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 seven pages long, including the Consent Form. Please make sure you have read and understood all the pages.

VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THIS STUDY

Your participation is voluntary. You don't have to answer all questions if you don't want to. You can withdraw from the research up until the time data analysis begins, without any disadvantage to you.

If you decide to withdraw from the study, you can decide what happens to the information collected about you up to the point when you withdraw, for example, if you wish your interview transcript will be destroyed and won't be used in the research.

WHAT IS THE PURPOSE OF THE STUDY?

The End of Life Choice Act (2019) legalised assisted dying for people who are assessed as meeting all of the eligibility criteria. While providing new choices for people with a terminal illness, assisted dying also creates new challenges for individuals, health practitioners and the health system.

The purpose of the research is to gain insights into how the assisted dying service is working to inform the review of the assisted dying service to make sure it's safe, people-centred, mana enhancing, accessible, and available equitably to all eligible people. We think it's important to learn more about your perspectives on this.

The findings of the study will help us make recommendations for service users, health professionals and the health system.

HOW IS THE STUDY DESIGNED?

We want to talk to 15 people with a variety of impairments about how the assisted dying service can ensure their needs are being considered adequately.

We will conduct the interview via Zoom. There will be two interviewers, Pip Patston and Kate Diesfeld. If you would like Kate to be with you during the interview (Auckland only), just let us know. **Please let us know how we can meet any accessibility or other needs you have so that you can comfortably participate.** The interview will last up to 90 minutes. If you feel tired or distressed, you can take a break or finish the interview another time.

WHO CAN TAKE PART IN THE STUDY?

You are eligible to participate if

1. you identify as having an impairment or disability or are Deaf AND
2. have capacity to participate in the research AND
3. you have been assessed as eligible for assisted dying under the Act OR
4. applied for the assisted dying services but were told you were ineligible.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

If you choose to participate, we will contact you to arrange an interview at a time that suits you. Interviews will be audio-recorded. In the interview, Pip Patston and Kate Diesfeld will ask about your thoughts on assisted dying. We will ask you questions like, 'Can you please tell us about your experiences so far of seeking assisted dying? How would an assisted dying provider take your needs into account? What does an ideal assisted dying service look like from your perspective?'

You are welcome to have a support person and a cultural advisor during the interview. We are happy to find a cultural advisor if you would like us to. We will have New Zealand Sign Language interpreters available via NZ Relay.

If you would like to have a Māori interviewer with Pip and Kate, we will invite one of our Māori team members. We will ask you about what cultural needs we should be aware of and discuss a plan about how to meet those.

WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

People's views on assisted dying vary widely and can be challenging to talk about. You do not have to answer any questions that you find uncomfortable. We will ensure the confidentiality of your participation in the study and the information we collect about you, except where a participant discloses something that causes the researcher to be concerned about a risk of harm to yourself or others. You will not be identified in any publication, and we will remove your name from the interview transcripts by using another name of your choice. No participant's identity will be revealed to anyone other than the researchers. We will ensure the story you share with us is treated respectfully.

You might find some of the questions difficult to answer, or they may cause you discomfort. At any point during the interview, you can ask to pause or stop or for the recording to be turned off.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

You may find this a valuable opportunity to share your experiences, and your contribution to the study may benefit others. There has been no research with disabled people about assisted dying. Your experiences going through the process of requesting assisted dying are important to learn about. This study will add to the research on assisted dying in Aotearoa.

This information may improve disabled people's experiences of assisted dying services. The research might inform the delivery of assisted dying services. For example, we may make recommendations for educating health professionals about how to talk about disabled people's preferences, as well as how they want their family/whānau involved. The study may also educate health professionals about how to make accommodations for disabled people who request assisted dying services.

WILL ANY COSTS BE REIMBURSED?

You will receive a \$50 voucher to acknowledge your contribution to the research.

WHAT IF SOMETHING GOES WRONG?

The day after your interview, Pip or Kate will contact you to check how you are. If you become seriously distressed because of participating in the study, the expenses for a professional counselling session or a GP appointment will be covered by the study.

WHAT WILL HAPPEN TO MY INFORMATION?

The data collected (e.g., your contact details and digital audio recordings) will be securely stored (with password access only) on secure university servers. The interview will be recorded to the Zoom-managed cloud and transcribed using their built-in automated service and then checked by a research team member. We will delete any recordings from the cloud once they are transcribed.

If you would like to review and revise your interview transcript, please check the box on the consent form. We ask that you send any revisions back to us within two weeks.

Any personal information held about you (such as contact details and the interview audio recording) will be deleted at the completion of the research. You can ask for a copy of any of your information and can correct any information about you. The interview transcripts that have all identifying information removed, such as names and places will be kept for much longer and may be used in other research on this topic. De-identified data will be retained for at least 10 years in secure storage. Only the research team will have access to the data.

The project results will be published in media articles, conference presentations and research articles, and reports will be written for health professionals and educators.

CAN I FIND OUT THE RESULTS OF THE STUDY?

A summary of the results will be sent to you if you wish at the end of the study.

WHO IS RUNNING AND FUNDING THE STUDY?

Dr Jessica Young is leading the research. Kate Diesfeld and Pip Patston are leading this study on disability. Dr Young and the research team have made a substantial contribution to the growing field of assisted dying research in New Zealand. Some of the team are members of the government-appointed Support and Consultation for End of Life NZ (SCENZ) Group, although this research is independent of that group.

The Health Research Council funded this study. The research team are affiliated with Victoria University of Wellington, Auckland University of Technology, Otago University, University of Canterbury, University of Auckland and Queensland University of Technology.

WHO HAS APPROVED THE STUDY?

The ethical aspects of this study have been approved by an independent group of people called the Health and Disability Ethics Committee (HDEC). It checks that studies meet ethical standards. The Northern A Health and Disability Ethics Committee has approved this study through the full review pathway [ref 2023 EXP 18493].

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

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

Dr Jessica Young, Lead Investigator
+64 4 886 4513
jessica.young@vuw.ac.nz

Professor Kate Diesfeld, Co-Investigator
+64 9 921 9999 x 7837
kate.diesfeld@aut.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@advocacy.org.nz
Website: <https://www.advocacy.org.nz/>

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHIC
Email: hdecs@health.govt.nz

LIST OF SUPPORTS

All the following services are free and available 24/7.

Te Whatu Ora: "Assisted dying is a sensitive topic and may be difficult for some people. If reading this information raises distressing feelings for you, there is support available. You can call or text **1737** (<https://1737.org.nz>) for free to speak to a trained counsellor at any time." Further information on assisted dying for the public is available on the MoH website: <https://www.health.govt.nz/our-work/life-stages/assisted-dying-service/assisted-dying-information-public>

Grief resources: <https://www.griefcentre.org.nz/resources/>

Lifeline: Phone 0800 543 354 (0800 LIFELINE) | www.lifeline.org.nz. Lifeline provides free, private telephone counselling 24 hours a day, 7 days a week.

Suicide Crisis line: Phone 0508828865 | <https://www.lifeline.org.nz/services/suicide-crisis-helpline/>

Consent form – Exploring the assisted dying service

Please tick to indicate your consent to the following

1. I have read and understood the Participant Information Sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
2. I have been given enough time to consider whether to participate in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
3. I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
4. I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
5. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
6. I understand that I can withdraw my information up until the start of data analysis and that the information collected about me up to that point may continue to be used.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
7. 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.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
8. I understand my responsibilities as a study participant.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
9. I agree to the interview being audio-recorded.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
10. I would like Kate to attend in person (Auckland only)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
11. I wish to review a copy of the interview transcript. I understand that if I want to make changes to the transcript, I will need to send that back within two weeks.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
12. I wish to receive a summary of the results from the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Email: _____

Declaration by participant: By writing or typing my name in the Signature box, I hereby consent to take part in this study.

Participant's name: _____

Signature: _____ Date: _____

Declaration by agent of participant: I assisted the above participant to complete the consent form.

Agent's name: _____ Relationship: _____

Signature: _____ Date: _____

Declaration by a research team member: I have given a verbal explanation of the project to the participant and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____ Date: _____