

# Exploring the early experiences of the assisted dying service in Aotearoa

# UPDATE

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*"The fact that you are asking the questions and talking to participants of all sides. You know, not just people like us but the providers and so on. I think that's probably a good way of starting the [review] process"*

– Eligible for Assisted Dying Participant

## Our 10 Key Recommendations Submitted for the Review of the Act

As you may the End of Life Choice Act was recently reviewed. We used the data collected to inform our 10k word submission which contained 77 recommendations. We're pleased to share the top ten here.

1. Permit health practitioners to raise assisted dying (AD) with patients in the context of a discussion about available end-of-life options;
2. Provide follow-up care to families whose relatives sought or as a minimum died by AD and for ineligible applicants;
3. Revise the statutory roles of the Registrar AD, AD Review Committee, and Support and Consultation for End of Life in New Zealand (SCENZ) Group;
4. Improve data collection and reporting processes about ethnicity and other factors;
5. Provide further mandatory training and optional support and develop cultural guidelines, competency standards and practice assessment processes for all ADPs;
6. Develop mandatory training for all relevant health professionals regarding AD law and policy including their roles under the Act and AD referral process, and handling AD requests;
7. Improve the communication with the AD service, in particular the accessibility for people with impairments, the clarity of the call-back service, and the usability and discoverability of the website;
8. Establish rules within the Act, or in policy, regarding institutional objection. We broadly favour the approach to regulating institutional objection in the Queensland Voluntary Assisted Dying Act;
9. Utilise attending nurse practitioners as an AD provider workforce and as team members for administering AD removing the requirement that NPs work "under the instruction" of an AMP in the AD process;
10. Create a best practice model that promotes the integration of AD into the health care system.

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## Recruitment Concludes

The research team has concluded recruitment and commenced analysis. We were very fortunate to speak with 96 people over the past year who are involved across the assisted dying pathway and in the community. It is clear over the course of this project that within the service there is great care and aroha.

It was a serious undertaking, and the research team would like to give the biggest thanks to members of community across the motu who helped achieve collating these diverse experiences.

### Upcoming: Stage 2 – Creating Resources

Please keep an eye out for information about the next stage of the research. We are going to turn what we have learned into resources that will help support service users and providers. We will seek your feedback on the draft resources in online hui later next year.

## Study Protocol Published

We have had our [first publication](#) in the *BMJ Open*. It is free to access. Highlights include:

- This research is a large-scale qualitative study that incorporates a broad range of people who are involved in New Zealand's assisted dying service.
- The diversity of the research team and the advisory groups provide robust review and specialised guidance to develop a sensitively designed protocol.
- A pragmatic sampling method is proving necessary due to low response numbers in AD service user cohorts and the small potential participant population size.
- Some healthcare, patient support and disability advocacy organisations have not circulated recruitment flyers limiting the diversity of the sample to date.

Jess and Ben contributed to a [BMJ editorial](#), discussing balancing access and safety. Copy available on request.

For more information about the project, please visit:

[tinyurl.com/assisted-dying-research](https://tinyurl.com/assisted-dying-research)