



# Epilepsy New Zealand **Papātai** **Oranga Wellbeing Survey FAQ**

## **Why is Epilepsy New Zealand undertaking this study?**

At Epilepsy New Zealand their mission is to improve the quality of lives of people living with epilepsy and unexplained seizures in Aotearoa New Zealand. So that Epilepsy New Zealand can better understand the impact of their services and are able to design and deliver services in the future that best meet your needs, they are conducting a survey.

## **Do I have to take this survey?**

No, you do not have to participate if you do not wish to. The survey is completely voluntary, and you can skip any questions that you don't feel like answering. Participation will not affect your access to any Epilepsy New Zealand, or any other in any way, but you will be helping Epilepsy New Zealand to understand how to better serve its community, so your participation is extremely valued.

## **What will this survey ask me?**

This survey will ask respondents how they feel about their life and circumstances at this moment.

There are four types of questions in this survey:

- **Personal questions about life:** these are more personal questions about what you think and feel about your life. Previous feedback has shown that participation in this survey may encourage further self-reflection on one's life and circumstances; should you wish to talk to someone about your experience or thoughts, contact information for support lines is provided throughout the survey.
- **Open Feedback:** There is an opportunity to give anonymous feedback and tell us about your experiences.
- **Engagement with the Epilepsy New Zealand:** these help us to understand your current level of engagement with Epilepsy New Zealand. This will help us to understand what level of engagement survey participants feel they have. You do not need to have any engagement with Epilepsy New Zealand to complete the survey.
- **Demographic questions:** these help us to understand the type of person who is filling out the survey. They will ask about things like your age, what region you live in, and whether or not you have a diagnosis of epilepsy.

## **Do I have to answer all the questions?**

All questions are voluntary; you may skip any question that you do not wish to answer.

## **What happens to my data?**

- When you complete the survey online, your answers will automatically be stored in Huber Social's online survey platform database.
- Once all data has been entered, it will be downloaded to Huber Social's secure server and deleted from the online survey platform; all data is held within Australia.
- The surveys are de-identified. A respondent's answers will never be connected to their name.
- Results will only be considered at a group level; no individual data will ever be reported.
- Huber Social and Epilepsy New Zealand will not disclose any respondent's answers to other parties without consent, except in response to legal requirements.

For more information, you can review Huber Social's Data Privacy Policy at [hubersocial.com.au](https://hubersocial.com.au)



### How do I complete the survey?

Instructions for how to complete the survey are in the introduction of the survey itself.

In summary:

- The survey should take around 15-20 minutes to complete.
- For the first few sections, you will be given a statement or question, and asked to think about your answer based on a seven-point scale.
  - This scale will either be about agreement (do you 'strongly disagree' or 'strongly agree' to the statement) or frequency (doing or feeling something 'all of the time' or 'none of the time').
- There will be some open-ended and demographic questions; please feel free to write as much or as little as you would like.
- At the end you will be asked to answer a few questions about your level of engagement with Epilepsy New Zealand.

Please note: **For those completing the survey online, it must be answered in one go.** If you close the web browser, you must start the survey again as it will not save.

### Can someone else help me take this survey?

Yes, if needed you may ask someone else to help you take this survey, such as a family member, friend, or other support person. However, the goal of this survey is to understand how you feel about your life, and while there are no right or wrong answers, we do ask that you answer each question honestly based on how you yourself are feeling. **The person who is helping you to complete the survey cannot advise you on how to answer a question.**

### Why does the survey ask such personal questions?

Epilepsy New Zealand is aiming to support people as best we can, and to better understand any inequities in our service delivery. So, in order to better understand what an individual and community needs, we ask questions about many different aspects of life. The range of questions are important to gain a whole of life understanding; however, if you do not wish to answer a question, you may skip it.

### If I can't take the survey, how can else can I provide feedback?

If you have specific feedback about your service, you can also contact Ross McLeod from Epilepsy New Zealand, on 0800 37 45 37. We always value your thoughts and will continue to provide opportunities to give this kind of feedback in the future.

### How do I access the survey?

You can access the survey using the link below:

<https://survey.alchemer.com/s3/7319787/Epilepsy-NZ-2023>