

Migraine in Aotearoa New Zealand Survey 2022: Methodology Report

Background

Migraine is a chronic neurological condition that affects an estimated 642,000 people in Aotearoa New Zealand (NZ), and is a leading cause of years lived with disability worldwide. Despite this, there is very little known about the prevalence, burden and impact of migraine in NZ, how it is treated and what could be done to improve outcomes for people with migraine.

Migraine Foundation Aotearoa New Zealand (MFANZ) is a charity established in 2022 with the mission to raise awareness of the impact of migraine disease and support people living with migraine in NZ. Recognising this dearth of information as a significant research gap and a major barrier to effective advocacy, MFANZ undertook an online survey on migraine in NZ in 2022.

Aims

To collect data about:

- Chronic migraine
- Medication overuse
- Types of acute and preventive medications used
- Non-medication acute and preventive treatments used
- Disability from migraine
- Impact of migraine on work
- Use of, access to and experience of health services
- Experiences of stigma
- What could be improved for people with migraine.

The purpose of the survey was to use the data collected to promote better access to effective treatments, increase awareness and understanding about the impact of migraine disease among Government agencies, health professionals, workplaces and the public, and provoke actions to improve the experiences of people with migraine in employment and education settings, health and disability services and society in general.

Survey development and data collection

The survey was developed using existing questions where possible (e.g. the Migraine Identification test (ID-Migraine testTM),¹⁻³ the Migraine Disability Assessment Scale (MIDAS),⁴⁻⁶ demographic questions as used by Stats NZ and the Ministry of Health) and qualitative questions. The survey was put online using SurveyMonkey and piloted tested by six people, most of whom had migraine disease, one of whom was an analyst.

The online survey started on 22 August 2022 and ended on 7 Oct 2022. The survey was promoted through MFANZ social media and networks, including Health Navigator, Neurological Foundation, New Zealand Pain Society, a large engineering firm (through a staff newsletter). A link to the survey was placed on the MFANZ website landing page and media articles to draw people to this webpage included a primary care electronic newsletter, an article by an AUT journalist, and a Scoop press release.

The survey questionnaire is available online.

Ethics

Ethics approval for this survey was not obtained as this was low risk research and did not meet the requirement for approval by the Health and Disability Ethics Committee. The project was not affiliated with a university and did not have access to university Ethics Committee review.

All identifiable information (e.g. email addresses for contacting participants) was removed from the final analysis dataset.

Dataset creation and data processing

There were 579 responses to the survey. Responses were downloaded from SurveyMonkey into Excel for processing and analysis.

Four duplicates were removed (identified by having the same IP address and same responses but one response was incomplete; the incomplete response was removed).

An additional 33 responses were removed as they answered only three of the remaining 51 questions (<6% of the survey), hence did not contribute to the substantive research questions or provide sociodemographic information to understand who they were.

There were an additional four people who had a MigraineID score of 0 and 25 people who had a MigraineID test score of one (a positive test is a score of 2 or 3). Of these, 17 reported being diagnosed with migraine by a health professional, eleven were not diagnosed and one had a missing response to this question. Those twelve people without a formal diagnosis and MigraineID test score of 0-1 were also excluded from the analysis, leaving 530 responses in the final survey dataset.

Therefore, this analysis includes all people (n=530) with a positive MigraineID test score OR a migraine diagnosis by a health professional. The MigraineID test has a sensitivity of 84% and specificity of 76%, so some people with a negative test will actually have migraine disease, hence it is appropriate to also include those with a migraine diagnosis, even if the MigraineID score is not positive.

A data dictionary containing a description of all variables in the final analysis dataset is available from MFANZ on request, including the creation of derived variables, such as acute medication overuse and current use of any preventive medication (which were created from answers to a series of individual questions) and prioritized ethnicity.

Limitations of the survey

This is not a representative sample of people with migraine in NZ but a self-selected, opportunistic sample recruited largely through social media and online channels. A response rate cannot be calculated. The sample will under-represent people who are not active online. The survey also relied on people being aware of a migraine diagnosis, or likely diagnosis, and will miss people who have not been diagnosed or are not aware of their diagnosis. There was no age limit specified for who could complete the survey, but children and young people were not actively recruited. Hence, weighting was not appropriate to apply to survey responses.

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