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Request to include questions on migraine disease in the New Zealand Health Survey

Introduction

This submission provides the rationale and justification for including a small set of questions on migraine disease in the New Zealand Health Survey (NZHS). The questions are a mix of new questions from validated questionnaires and previously used questions to allow comparison of results over time.

The submission starts with discussing how migraine disease, and the questions we wish to include, align against the Ministry of Health's NZHS content criteria and the NZHS objectives, then the questions are presented in the context of measurability.

Migraine disease questions and New Zealand Health Survey content criteria

Degree of burden / potential benefit

Affects a large percentage of the population

Migraine disease is a complex neurological condition that affects an estimated 624,000 people in Aotearoa New Zealand.[1] This estimate is from the Global Burden of Disease (GBD) study, that measures the impact of diseases on death rates and disability around the world. In 2018, the GBD found that migraine caused the second highest number of years of healthy life lost due to disability (YLD) worldwide. In 2018 in New Zealand, migraine ranked fourth – below low back pain and anxiety and with a similar disability impact to major depressive disorder.

Although there have been no studies in Aotearoa on the economic costs of migraine, a publication from Australia in 2018 found that the yearly cost of chronic migraine per person was AU$21,706; and AU$6,137 for episodic migraine.[1] This included health system costs, such as paying to see health professionals and for medications, and productivity costs from the reduced ability to work and having to take time off work. If these estimates are similar for Aotearoa, that would equate to around NZ$5 billion a year.

The most severe and debilitating form of migraine is chronic migraine, which has a population prevalence of 1-2%.[2–4] In chronic migraine, headache occurs on 15 days or more each month (episodic migraine is when headache occurs 14 days a month or less). Those with chronic migraine experience the highest levels of impaired functioning, reduced quality of life and worse socioeconomic position (especially higher rates of poverty and unemployment).[2,5,6] We estimate that around 50,000 people in Aotearoa are likely to have chronic migraine, based on US data that 7.69% of people with migraine disease have chronic migraine[7], but a more robust estimate for Aotearoa is needed.

Studies on the burden of disease from the Ministry of Health have consistently shown that migraine is within the top 20 conditions that contribute to the greatest health loss in Aotearoa (migraine was calculated to cause 1.4% of loss of Disability Adjusted Life Years or DALYs in 2006 amongst the whole

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[1] Based on Global Burden of Disease data (http://ghdx.healthdata.org/gbd-results-tool, accessed February 2022)

population[8]; 2.4% of loss of DALYs among women and 3.4% of loss of DALYs among those aged 25-44 years in 2013[8]). DALYs are not the best indicator to measure the health and disability impact of migraine disease since it combines YLD with years of life lost due to premature mortality (YLL), and migraine is not a fatal disease. A better measure is YLD. The latest Ministry of Health report on burden of disease does measure YLD,[9] but unfortunately combines migraine disease into a classification of 'headache disorder', which includes other types of headache. However, estimates for the YLD due to migraine in Aotearoa can be sourced from the GBD online webtool, as referenced above.

Endurability

The information need is enduring and is likely to be important for the health sector in the future

Given the known burden of migraine disease, it is important that we have accurate data on who is most affected, whether they are accessing services and treatment appropriately and what gaps in treatment are occurring. However, our current best estimate of the prevalence of migraine in Aotearoa is based on a question that will significantly under-estimate the actual prevalence. This comes from the 2006/07 NZHS which found an overall migraine prevalence of 9.4% (95% confidence interval: 8.8-10.2); 12.9% (11.8-14.0) for women and 5.5% (4.7-6.3) for men.[10]

The most recent estimate of the prevalence of migraine in high income countries, based on a narrative review of prevalence studies, is around 14%[11]; the 2019 estimate from the GBD for high income countries was slightly higher at 17%. Estimates from US surveys sit at around 16%.[6] The estimate for Aotearoa of 9.5% looks to be a significant underestimate, as there is no compelling reason to think that rates here would be lower than comparable international countries.

The prevalence estimate for Aotearoa (which also inform the results in the GBD study) is based on this question in the long-term health conditions module of the NZHS:

> Have you ever been told by a doctor that you have …. migraine?

This was repeated in 2013/14, with an additional question about current treatment for migraine; results from the 2013/14 questions do not appear in the online NZHS webtool or in other publications from the Ministry of Health. Although these results would be useful, they would not provide a robust updated estimate for migraine prevalence. This is because the prevalence of doctor-diagnosed migraine is well known to underestimate the actual prevalence of migraine. There is a substantial undiagnosed burden of disease and doctor-diagnosed migraine will miss many people who do not realise they have migraine disease. Even amongst patients who have been assessed by a doctor, many may not be aware of their migraine diagnosis. In a study of over 1000 patients diagnosed with migraine at headache centres, only 28% knew they had migraine disease.[12]

The need for more accurate prevalence data is ongoing and will help the health sector to become more aware of the burden of migraine disease and identify unmet needs of patients who suffer from migraine.

Relevance

Aligns with Ministry of Health targets and priorities

Two of the Ministry of Health's health targets are a 'strong and equitable public health system' and 'better primary health care'. Both of these are relevant to improving the knowledge about and management of migraine disease in Aotearoa. The health system and primary health in particular are not providing equitable, quality and effective care when people with a disabling disease that has established treatments are not being diagnosed or treated according to the evidence.

Underdiagnosis is a significant problem for people with migraine disease. In the US, around a third of people who have migraine disease (according to the ICHD 3rd edition) do not report receiving a diagnosis of migraine from a doctor.[13] This can be due to patients either not seeking help for migraine symptoms from a health professional and/or receiving an incorrect diagnosis.

Lack of attendance or access to health care is extremely common in those with migraine disease. In the US, half or less of people with headache symptoms and disability saw a health professional for these symptoms in the past year.[13–15] This can be due to many reasons, including cost, difficulty getting an appointment, and stigma around migraine being seen as a women's problem and 'just a headache'. In Aotearoa in 2020/21, 28% of people had an unmet need for health care (were unable to see a doctor because of lack of availability, transport or cost) in the past 12 months, even higher for Māori (35%) and Pacific (33%).[2] The likelihood of underdiagnosis of migraine disease due to lack of attendance at a health centre is very high, especially for Māori and Pacific people.

There is also the issue of mis-diagnosis. When people with migraine disease do consult with a health professional for their symptoms, many receive an incorrect diagnosis. Estimates vary widely, depending on context and setting – one study found that only 25% of patients with migraine consulting a doctor received an accurate diagnosis;[15] another found that 87% of consulters received a correct diagnosis;[16] another that only 76% of those with episodic migraine and 33% of those with chronic migraine received a correct diagnosis;[14] another that 25% of those with migraine were not diagnosed correctly.[17] Migraine is commonly misdiagnosed as sinus headache or tension headache,[18,19] when symptoms that assist in the diagnosis of migraine disease such as photosensitivity, phonosensitivity and nausea are not asked about, and symptoms that overlap with other headache type, such as nasal congestion, facial pain or triggering with stress, are misattributed to another diagnosis. We do not have data on the extent of misdiagnosis of migraine in Aotearoa and these survey questions provide an opportunity to investigate this problem.

Comparability

Has coherence with other data sources, could be easily compared

There are no other data collections with comparable questions on migraine disease, which is why we need this data source to include them. However, the ID-Migraine test questions can be used in many healthcare settings to screen for migraine disease and more widespread adoption of these into practice would not only increase the accuracy of diagnosis of migraine disease but also allow comparison of rates across services, particularly primary and secondary health care. Once we have an updated prevalence of migraine using the ID-Migraine test, this can serve as a basis of greater advocacy and awareness raising about the importance of using standardised and validated screening tests in these settings.

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[2] From https://minhealthnz.shinyapps.io/nz-health-survey-2020-21-annual-data-explorer/_w_237f0ccb/#!/explore-indicators, accessed 11/05/2022

Opportunity to highlight inequities

Would provide information that could be used to reduce inequities

Migraine disease is two or three times more common in women than men,[11] at least after puberty (rates of migraine in male and female children before puberty are roughly equal, suggesting a significant hormonal influence on disease manifestation).

Migraine disease is also more common among those of working age, and affects people's ability to work, study, engage in social activities and family life.[6,11,13]

Research from the United States has found that the highest prevalence of migraine was in indigenous people.[20] From the 2006/07 NZHS, overall prevalence of migraine for Māori was 8.6% (7.3-9.9); 11.4% (9.3 - 13.5) for Māori women and 5.4% (3.8 - 7.0) for Māori men.[3] However, given the issues outlined with asking about doctor-diagnosed migraine, these estimates are likely to be significantly underestimated, especially with the additional difficulties in accessing healthcare that Māori experience.

From the 2006/07 NHZS, overall prevalence of migraine for Pacific people was 6.7% (4.6 - 8.8); 9.5% (5.9 - 13.0) for Pacific women and 3.7% (2.2 - 5.8) for Pacific men.[4] This lower prevalence may be due to imprecise results, or for the same issues with the question and access to care outlined above. Research from South Auckland also confirmed that Pacific people are less likely to be diagnosed with migraine, despite having migraine symptoms.[5]

Hence, including these new questions on migraine disease may bring to light inequalities that have previously been obscured, by age, sex, ethnicity, deprivation and measures of socioeconomic status.

Responsibility

The NZHS is the most appropriate vehicle for collecting this data

A national, household survey among a representative sample of the population such as the NZHS provides the ideal mechanism for delivering these questions. Online surveys and other methods are at high risk of bias as are data collections from patient populations.

We could not obtain an accurate estimate of prevalence from a health service setting or administrative data, due under-diagnosis (from lack of access or attendance to health care providers) and misdiagnosis from health providers. Prescription data has extremely limited usefulness not only because of the issue of under-treatment, but because there are very few migraine-specific treatments. The majority of medication used in both the prevention and acute treatment of migraine disease are primarily indicated for other conditions (e.g. NSAIDs, anti-hypertensives, anti-convulsants, anti-depressants).

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[3] From online data tables https://www.health.govt.nz/publication/portrait-health-online-data-tables-2006-07-new-zealand-health-survey-results

[4] From online data tables https://www.health.govt.nz/publication/portrait-health-online-data-tables-2006-07-new-zealand-health-survey-results

[5] Thomson, AN., White, GE., & West, R. (1993). The prevalence of bad headaches including migraine in a multiethnic community. *New Zealand Medical Journal*, *106*(967), 477–480.

Migraine disease questions and the objectives of the New Zealand Health Survey

Objective of the New Zealand Health Survey	**How the questions on migraine disease align to the objective**
Provide an evidence base to inform health system funding, policy, programmes and advocacy with a focus on long-term priorities	We need a more valid estimate of the extent of the disease in order to raise awareness, reduce the burden of disease, increase the amount of research into migraine disease, advocate for better care and treatment, and tackle the stigma associated with migraine disease.[21] Underdiagnosis and undertreatment of migraine disease are widespread issues internationally but we have no data from Aotearoa. This is needed to improve the quality and effectiveness of primary and secondary care services involved in the management of migraine disease.
Monitor and research population health status and the prevalence of key health behaviours and risk factors	The current best estimate of migraine prevalence in Aotearoa is based on a flawed question. These questions will provide a more robust estimate of prevalence.
Monitor barriers to access and use of healthcare services including health service user experience	These questions will provide a greater understanding of how migraine disease is distributed across sub-groups with varying levels of access to heath care. We will also be able to detect differential rates of migraine diagnosis and treatment.
Provide ability to carry out robust statistical analysis and enable linkage to other data collections to address wider information needs	Including questions on migraine disease in the NZHS will allow us to investigate co-morbidities in people with migraine disease and link to other datasets, such as the pharmaceutical data. For example, we could explore how many/which people are being dispensed triptans for migraine disease.[22]

Migraine disease questions and the measurability criteria

We are proposing a set of eight questions, four to provide a more robust estimate of the prevalence of migraine disease and chronic migraine; one to provide additional information on the burden of migraine disease; and two to allow comparison to previous questions in the NZHS and estimate the extent of underdiagnosis (due to misdiagnosis and poor access to health care) and the extent of undertreatment (quality of health care). The list of proposed questions and their sequencing is appended.

Questions to identify people likely to have migraine and chronic migraine (prevalence)

The most important questions to include are those that can more accurately identify people likely to have migraine disease (rather than those who have a doctor-diagnosis of migraine). We propose using the ID-Migraine test™, which consists of a set of three questions that have been internationally validated in multiple countries, settings and languages, tested against a gold standard of migraine diagnosis (a semi-structured diagnostic interviews and examination by a headache specialist with diagnosis consistent with the International Classification of Headache Disorders (ICHD)).[23,24,25,26]

Answering yes to two or more of these questions is a positive test, with a sensitivity of 84% and specificity of 76%.[27]

1. Has a headache limited your activities* for a day or more in the last three months? Yes/No
2. Are you nauseated or sick to your stomach when you have a headache? Yes/No
3. Does light bother you when you have a headache? Yes/No

*Activities refers to work, study, play or other things you needed to do in the day

Since we have no existing data on the prevalence of chronic migraine, and this is the most disabling and costly form of migraine disease, we want to include a question that will allow us to estimate chronic migraine prevalence. This question is used when assessing the burden of migraine disease:[28]

> On average, on how many days a month do you have a headache?
> - 0-7 days per month
> - 8-14 days per month
> - 15-23 days per month
> - >/=24 days per month
> - Continuous/nearly continuous (essentially no headache-free time)
> - Don't know/refused

Questions to quantify the burden of migraine

We want to estimate the burden of migraine in a way that can be used to quantify at least part of the economic and societal cost of reduced productivity because of migraine. We propose using the first question from the Migraine Disability Assessment (MIDAS) test, which has been tested for reliability against daily dairy records:[28,29]

> On how many days in the last 3 months did you miss work or school because of your headaches?
> a. 0-93
> b. Don't know/refused

Questions to allow comparison with previous surveys and estimate access to medical care

We would like to repeat the same questions that were asked in the 2013/14 NZHS, to allow comparison with results in 2013/14 (and 2006/07, for the question on doctor-diagnosed migraine). Not only will this identify underdiagnosis (and undertreatment) but sex, age and ethnic differences in underdiagnosis/undertreatment, and how this is correlated with other measures of access in the NZHS. The questions are:

> Have you ever been told by a doctor that you have migraines?
> What treatment do you now have for migraines?

Measurability

Questions on migraine have been successfully implemented in previous rounds of the NZHS. The additional questions we propose are widely used in research, clinical practice and for screening purposes in a range of settings to provide effective estimates of migraine prevalence and burden. The ID-Migraine™ test has been shown to be valid and reliable in international studies.[23,27]

Core or module content

These questions would fit within the long-term conditions module, as they have in the past. This is because they do not need to be monitored continuously. A once-off data collection is sufficient and could be collected in a 1 year timeframe to gather robust prevalence estimates across age, sex and ethnic groups. We would not expect prevalence to change significantly over time unless there were large demographic shifts in the population. A review of international headache prevalence studies has highlighted the need for validated diagnostic questions, a large enough sample size to distinguish differences in prevalence by age and gender and a neutral screening question.[30]

This topic is relevant to the general population due to the large number of people affected by migraine disease, which affects not only the individual, but family members, employers, schools and social contacts.

Answering the migraine questions would only take a few minutes, as it is not an extensive or long survey instrument. We acknowledge that any additional questions create respondent burden, hence we would like to identify the questions on migraine prevalence (questions 1-4) to be essential to provide more robust estimates, and the question on chronic migraine (question 5) is essential to fill an existing data gap, given we have no estimates at all on the prevalence of chronic migraine in Aotearoa. Question 6 would fill another existing data gap, as we also have no estimates of the economic and social burden of migraine disease in Aotearoa, but is dependent on having the questions on prevalence. The questions to allow comparison to previous NZHS data (questions 7-8) would be extremely useful but are not essential for the purpose of establishing a more robust migraine prevalence estimate.

Although these might be considered ‘new’ questions, they could also be considered as questions to replace the previous questions on migraine in 2006/07 and 2013/14, which were removed for reasons we are not clear on, but need to be revised and updated to provide better quality data.

Support for this submission

Migraine Foundation Aotearoa New Zealand (https://www.migrainefoundation.org.nz/) drafted this submission (contact fiona@migrainefoundation.org.nz). The submission has been reviewed and is supported by:

- Dr Calvin Chan, Headache Specialist and Consultant Neurologist, Department of Neurology, Palmerston North Hospital, Midcentral District Health Board
- Professor Debbie Hay, Department of Pharmacology & Toxicology, University of Otago
- Associate Professor David Rice, Associate Head of Research, School of Clinical Sciences, AUT; Waitemata Pain Service, Dept of Anaesthesiology and Perioperative Medicine, Waitemata District Health Board, President of the New Zealand Pain Society

Appendix: Proposed questions

1. Have you had a headache in the last 3 months?
    a. Yes – go to question 2
    b. No/Don't know/refused – go to question 7
2. Has a headache limited your activities* for a day or more in the last three months?
    a. Yes/No/Don't know/refused – go to question 3

   *Activities refers to work, study, play or other things you need to do in the day
3. Are you nauseated or sick to your stomach when you have a headache?
    a. Yes/No/Don't know/refused – go to question 4
4. Does light bother you when you have a headache?
    a. Yes/No/Don't know/refused – go to question 5
5. On average, on how many days a month do you have a headache?
    a. 0-7 days per month
    b. 8-14 days per month
    c. 15-23 days per month
    d. >/=24 days per month
    e. Continuous/nearly continuous (essentially no headache-free time)
    f. Don't know/refused

Go to question 6

6. On how many days in the last 3 months did you miss work or school because of your headaches?
    a. 0-93
    b. Don't know/refused

Go to question 7

7. Have you ever been told by a doctor that you have migraines?
    a. Yes – go to question 8
    b. No/Don't know/refused – go to next section
8. What treatment do you now have for migraines? (multiple responses possible)
    a. No treatment
    b. Medicines, tablets, pills or injections
    c. Diet
    d. Counselling
    e. Exercise or physiotherapy
    f. Other (specify)
    g. Don't know
    h. Refused

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