WHĀNAU VOICE

Whānau Māori experiences of stroke and gout across the Wellington rohe

Pōneke | Pōrirua | Kāpiti | Te Awakairangi

A collaboration between Āti Awa Toa Hauora Partnership Board, Stroke Aotearoa and Arthritis NZ (Mateponapona Aotearoa)

July 2026

Acknowledgements

First and foremost, we extend our heartfelt thanks to the whānau who generously shared their time, lived experiences, and whakaaro as part of this kaupapa. Your willingness to speak openly about the realities of living with stroke and gout has made this report possible. Your voices are at the heart of this work and provide invaluable insights that will strengthen advocacy for more equitable, culturally responsive health services and systems that better reflect the needs and aspirations of whānau Māori.

We also acknowledge and sincerely thank our colleagues and partners who contributed their expertise and guidance throughout the development of the survey. Your input helped shape the design and delivery of this research, ensuring it was meaningful and relevant to the communities it was intended to serve.

Finally, we are deeply grateful to the many health providers, community organisations, marae, libraries, and other community spaces across the motu that supported this kaupapa by promoting the survey within your networks and communities. Whether you shared the survey directly with whānau or displayed a poster in your organisation, your support helped amplify Māori voices and contributed to the success of this project.

Ngā mihi nui ki a koutou katoa.

Citation: Āti Awa Toa Hauora Partnership Board, Stroke Aotearoa, & Arthritis NZ Mateponapona Aotearoa (2026). Whānau Māori experiences of stroke and gout across the Wellington rohe. Wellington, Aotearoa New Zealand.

Published in July 2026 by Āti Awa Toa Hauora Partnership Board, Stroke Aotearoa, & Arthritis NZ Mateponapona Aotearoa.

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Executive Summary

This report presents the findings of a whānau voice study exploring Māori experiences of stroke and gout across the Wellington rohe, conducted in partnership between the Āti Awa Toa Hauora Partnership Board, Stroke Aotearoa, and Arthritis New Zealand. Drawing on 58 survey responses from stroke survivors, people living with gout, individuals who have experienced both conditions, and their whānau, the report identifies key challenges and opportunities to strengthen prevention, care delivery, recovery, and long-term management of two highly prevalent and preventable conditions.

Findings highlight:

- Persistent gaps in the understanding of both stroke prevention and gout management, indicating a need for clearer, more accessible education across the care continuum.
- Unmet needs for accessible information, follow-up support, and coordinated long-term care.
- Whānau reported a greater level of perceived impact and unmet need than individuals often reported for themselves, reinforcing the importance of whānau-inclusive assessment and care planning.
- The need for tailored, condition-specific support as stroke can significantly limit physical activity due to functional impairment, while gout flares and fear of pain can also reduce participation in exercise.
- A reported lack of support and professional understanding of the broader impacts of both conditions, specifically their impact on mental health and wellbeing.

Stroke: Summary of Insights

Findings indicate that there is a generally positive baseline of care for people who experience strokes, however there are inconsistencies in how the system supports prevention and recovery pathways. While individuals often recognise the importance of exercise, physical and functional barriers limit participation, especially where tailored rehabilitation support is lacking.

A recurring theme is the disconnect between patient and whānau perspectives, with whānau identifying greater limitations and unmet need. This suggests current assessment and service models may not fully capture the lived reality of recovery. Mental health impacts are significant and enduring, yet support pathways are not always visible, accessible, or trusted.

There is a clear need for improved follow-up care, better coordination across services, and communication approaches that are proactive, culturally appropriate, and accessible (including visual formats).

Gout: Summary of Insights

Gout continues to be experienced as a chronic, irregular condition that is often poorly controlled, despite the availability of effective treatment. Findings typically indicate limited understanding of gout as a long-term condition that requires daily consideration. Inconsistent use of medication (i.e. not taken every day) can result in people experiencing flares and other adverse symptoms (e.g., mobility issues and pain).

Key barriers include limited access to care, cost, stigma, and a lack of education. Whānau play an important role in supporting gout management, but they are not always included in education or care planning. As with stroke, gaps in communication and follow-up can lead to disengagement and poorer outcomes.

Report Structure

The report is structured to prioritise key insights and action. Following this summary, five overarching system-level recommendations and aligned recommendations for funders, providers, and whānau are presented up front. A concluding section summarises the key themes and opportunities for change. Detailed quantitative and qualitative findings for stroke and gout, along with methodology, demographics, and supporting analysis, are provided in the appendices to enable deeper exploration while keeping the main report focused on what matters most for decision-making. This report presents survey findings comparing self-completed and whānau-completed responses to allow for both lived experience and whānau perspectives to be reflected.

Five overarching recommendations

These recommendations reflect the system-level priorities identified across both conditions and outline our proposed actions to strengthen prevention, treatment, and long-term care for whānau.

1. Embed whānau-centred, culturally safe care

A key overarching recommendation is to embed whānau-centred, culturally safe care as the standard model across both stroke and gout services. Across both stroke and gout surveys, whānau consistently reported unmet needs, low confidence in services, and valuable measures and support systems that are often overlooked (e.g. peer support, whānau involvement in care, need for whānau advocacy). The findings show that health conditions are experienced collectively, with impacts extending beyond the individual to affect whānau wellbeing through caregiving responsibilities and support for whānau to recover. Embedding whānau-centred and culturally safe approaches is critical to improving engagement, trust, and long-term outcomes.

> *“ I think we need "whanau approaches" earlier. When you are a family that has a history of stroke, gout, heart failure, kidney disease, cancer and other related diseases, it’s very difficult because the system only deals with individuals not really whānau.” 55-64, wāhine Māori, whānau member of stroke survivor*

“Resources and information developed by people with lived experience here in our rohe.” 55-64 wāhine Māori, gout consumer

2. Strengthen clear, culturally grounded communication and health literacy

Across both conditions, whānau reported significant gaps in understanding, particularly where information was complex, inconsistent, or delivered only once. There was strong demand for plain language, visual resources, culturally appropriate information, and opportunities to revisit information over time. Improving communication and health literacy is essential to supporting informed decision-making and self-management.

“.... information available is not clear, poorly written, disease and [is] deficit focused, and punitive not positive.” 55-64 wāhine Māori, gout consumer

“More knowledge [is needed] out there, a lot of things as Māori are chalked up to [being] gout but not enough on what it actually is, we need more awareness.” 25-34 wāhine Māori, whānau member of gout consumer

3. Establish proactive, long-term, well-coordinated care pathways

A consistent theme across stroke and gout is that support tends to reduce significantly after the acute phase or initial diagnosis. This creates fragmentation and leaves whānau without clear ongoing support. There is a need for structured, long-term follow-up pathways that extend well beyond initial treatment, alongside stronger coordination between hospital, primary care, and community services. The inclusion of a named contact person or navigator would provide continuity and ensure whānau know who to reach when needs change.

“Post-stroke support is not as good as it could be, in my view... You are virtually left alone as time goes by. I think that creates loneliness.” 55-64, wāhine Māori, stroke survivor

“I've had to work out myself what works best for me. Medical and health professionals have not been helpful.” 45-54 tāne Māori, gout consumer

4. Improve equitable access to holistic, affordable, community-based supports

Both conditions highlight major barriers to accessing rehabilitation and wellbeing support, including cost, availability, transport, and confidence. Improving equity requires expanding access to community-based and home-based services such as rehabilitation, dietetics, and exercise programmes, while ensuring these are affordable and culturally safe. Services also need to recognise that fear, anxiety, and reduced confidence can be as limiting as physical impairment, particularly for younger people who often feel current services do not meet their needs.

> *“I would like some support in getting active, I am really keen to get some help but am finding proper support that does not cost an arm and a leg. I am a uni student so getting active is important for me and finding a new sense of self after the stroke is also important for me.”* *18-24, wāhine Māori, stroke survivor*

> *“I manage ok but others within my whanau could use more support in terms of eating better with their flare ups.”* *45-54, wāhine Māori, gout consumer*

5. Integrate mental health, peer support, and lived-experience leadership into care

Emotional wellbeing challenges such as anxiety, depression, fear, and stress were consistently reported across both conditions, yet are not always systematically addressed. There is a clear need to integrate mental health screening into routine care for both patients and whānau, alongside improved access to counselling and culturally grounded support. Peer support and lived-experience leadership should also be embedded within services to ensure that shared experience and community knowledge are recognised as central to recovery and long-term self-management.

> *“I think we need "whanau approaches" earlier. When you are a family that has a history of stroke, gout, heart failure, kidney disease, cancer and other related diseases, it’s very difficult because the system only deals with individuals not really whānau.”* *55-64, wāhine Māori, whānau member of stroke survivor*

> *“Attending men’s groups. Talking with other people that have had gout.”* *55-63, wāhine Māori, whānau member of gout consumer*

Five Recommendations to Funders, Providers and Whānau

Key recommendation	Funders	Providers	Whānau
Embed whānau-centred and culturally safe care	Invest in Māori-led and whānau-centred models of care and workforce cultural capability.	Embed whānau-centred, culturally safe practice and involve whānau in care planning and decision-making.	Participate in care planning, ask questions, and advocate for whānau needs.
Communication and health literacy	Fund co-designed health education resources and health literacy initiatives.	Use clear, culturally appropriate communication and provide accessible education for patients and whānau.	Build knowledge of prevention, management, and available supports.
Long-term follow-up and care coordination	Resource integrated care pathways and navigation services that support continuity of care.	Provide structured follow-up, coordinated care, and access to navigators or care coordinators.	Stay connected with follow-up care and seek support when needs change.
Access to holistic support	Fund affordable and accessible rehabilitation, lifestyle, and wellbeing programmes.	Improve access to rehabilitation, allied health, exercise, nutrition, and community-based services.	Engage in rehabilitation, healthy lifestyle activities, and available support services (e.g. Rongoā Māori Services)
Mental health and peer support	Invest in mental health services, peer-led initiatives, and lived-experience leadership.	Integrate mental health screening, wellbeing support, and peer support into routine care.	Prioritise mental wellbeing, seek support when needed, and connect with peer networks.

> ***"My dad had Alzheimer's and it took some time to hear from drs he had gout. Even though he had a large lump on the top of his foot and he was getting pain behind his knee. We were not told about precautionary measures. what it is."*** *55-64, wāhine Māori, gout consumer*

Conclusion

One in four New Zealanders live with multiple long-term conditions, including diseases such as gout and stroke, often alongside other chronic illnesses like diabetes, cancer, cardiovascular disease, and mental health or addiction challenges. These conditions are responsible for around 80% of all deaths and health problems from long-term conditions.

In 2019, the Health Quality & Safety Commission New Zealand reported that 2,713 Māori living in the Wellington region were living with gout, accounting for approximately 15% of all Māori with gout in Aotearoa New Zealand. These figures are likely to have increased over time; however, there is currently no up-to-date, statistically robust regional-level data—such as an updated Atlas of Healthcare Variation—to confirm more recent trends.

There is also no available regional-level data on Māori stroke prevalence. However, it is well established that Māori and Pacific peoples experience stroke around 15 years earlier than European New Zealanders and have poorer post-stroke outcomes. This is largely driven by systemic inequities that limit access to timely and appropriate healthcare, as well as effective stroke education and support. As a result, around 60% of strokes among Māori and Pacific peoples occur during working age (15–64 years), compared with approximately 20% among other ethnic groups.

Up to 90% of strokes are linked to ten modifiable risk factors, including high blood pressure, physical inactivity, poor diet, and smoking. These same risk factors are also strongly associated with gout, meaning they carry a shared and equally important burden across both conditions.

This report explores the lived experiences of whānau Māori in the Wellington rohe who are affected by one or both of these conditions, either directly or through supporting whānau members. The findings are based on the voices of 58 whānau Māori living in Wellington and examine their perspectives on how these conditions impact quality of life, their understanding of risk factors and prevention, and their experiences with health professionals they trust and feel meet their needs to live well. The report also considers broader health indicators, including current health status, mental health impacts, and access to appropriate advice, information, and planning support.

In summary findings from both the stroke and gout datasets point to consistent gaps between what services currently provide and what individuals and their whānau need to effectively prevent, manage, and live well with these conditions. Across both, understanding is often partial, and care is experienced as irregular rather than continuous, contributing to preventable negative impacts on health, wellbeing, and quality of life.

A clear theme is the importance of adopting more holistic, whānau-centred models of care. Whānau member supporting their loved ones reveal additional layers of unmet need, particularly in understanding, support, and day-to-day management. Strengthening communication, ensuring it is culturally appropriate and accessible, and embedding whānau involvement in care planning are critical to improving both engagement and health outcomes.

Overall, there is a strong opportunity to shift towards more proactive, coordinated models of care that prioritise follow-up, continuity, and practical support. By addressing system gaps in education, service integration, and responsiveness to lived experience, stroke and gout services can better support individuals and their whānau in managing these conditions effectively and improving their long-term wellbeing.

Appendices

Appendix 1: Background

One in four New Zealanders lives with multiple chronic health conditions (also referred to as long-term conditions). These conditions are often preventable and experienced by several generations in the same whānau. The greatest burden of long-term conditions is experienced by Māori and Pacific people, who experience these conditions 10-20 years earlier, on average, than non-Māori and non-Pacific.[1]

Because long-term conditions account for the majority of ill-health in Aotearoa, focusing on the voices of whānau who live with these conditions will strengthen our ability to support, advocate for, and resource the people most affected. For this mahi, we have centred our efforts on stroke and gout — two preventable, long-term conditions with some of the highest prevalence rates and most significant inequities in Aotearoa.

Informed by insights from its earlier engagements with whānau Māori, Āti Awa Toa Hauora Partnership Board identified prevention and better management of preventable long-term conditions as one of its top 10 priorities for action in its rohe.[2] Stroke Aotearoa has also gathered whānau voice across multiple rohe, identifying barriers to stroke prevention and recovery. Arthritis NZ places consumer voice at the centre of its work, systematically collecting and responding to the experiences of people living with arthritis and their whānau across Aotearoa to support living well with arthritis and related long-term conditions.

Underpinning this partnership between Āti Awa Toa Hauora Partnership Board, Stroke Aotearoa, and Arthritis NZ is a shared commitment to improving prevention, care, and research for people living with long-term conditions.

The impacts of stroke

In Aotearoa, 89,000 people are currently living with the effects of stroke, and every year, it's estimated there are over 9,000 strokes and an unknown number of transient ischaemic attacks. A transient ischaemic attack (TIA) is like a stroke except the signs last for no longer than 24 hours and show no damage on brain imaging. Stroke is the second largest cause of death in Aotearoa, and the leading cause of adult disability. Stroke isn't limited to older people: up to 30% of strokes happen to people under the age of 65.

Not everyone has the same risk of stroke, and not all stroke survivors have the same outcomes. Stroke occurs more often, with more severity, and around 15 years earlier, on average, in Māori and Pacific communities. This means if they survive their stroke, they live longer with the effects of stroke on their lives, and there is likely to be a greater impact on their whānau. These communities also experience the highest recurrent stroke rates, are more likely to be diagnosed with high blood pressure than non-

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[1] Te Whatu Ora. *About long term conditions – Chronic health conditions. In: Long-Term Conditions – Diseases and Conditions*. Te Whatu Ora. Accessed 8 December 2025.

[2] Āti Awa Toa Hauora Partnership Board. (2025, June 1). *Community Health Plan*. Retrieved 8 December 2025, from https://atiawatoaimpb.nz/2025/06/01/community-health-plan/

Māori and non-Pacific adults and have higher prevalence of Atrial Fibrillation (AF) at a younger age than NZ Europeans. Māori are also more likely to die of stroke than non-Māori.

The disparities in stroke rates and outcomes in these communities are largely driven by systemic inequities that create barriers to accessing relevant healthcare and stroke education and perpetuate cultural misalignment within healthcare settings.

Up to 90% of strokes are preventable. A healthy blood pressure is the best defence against stroke, other than being smokefree. Time and cost barriers, and a lack of awareness, mean that many New Zealanders don't regularly check their blood pressure. Stroke Aotearoa offers free blood pressure and pulse checks to identify AF in communities throughout Aotearoa, helping thousands of people every year to better understand their risk of stroke.[3]

The impacts of gout arthritis

The overall prevalence of gout in Aotearoa in 2019 was 5.7% for people aged 20 years and over. Māori and Pacific people experience higher rates of gout than non-Māori/Pacific people in Aotearoa New Zealand. Most notably, approximately 35.4% of Māori men and 49.6% of Pacific men over the age of 65 are estimated to have gout, compared to 17.5% of non-Māori/Pacific men. The average age of onset is also lower for Māori and Pacific people.

Gout is a type of arthritis. It is a long-term condition that requires long-term treatment and is caused when there is too much uric acid in your blood. Gout flares occur due to fluctuations in blood uric acid levels that cause crystals to form, cause joint pain and gradually dissolve.

Without treatment, flares become more frequent and lead to irreversible bone and joint damage, chronic pain, disability, or even amputation in the worst-case scenarios. The illness is also linked to various comorbidities such as chronic kidney disease, cardiovascular disease, metabolic syndrome, and depression, which all add to the burden of care associated with gout.[4][5]

This inequity was thoroughly explored in the Health Quality and Safety Commission's (2019) Atlas of Healthcare Variation report.[6] Although Māori and Pacific people with gout were more likely to receive urate-lowering therapy (ULT) (60% vs. 56% for non-Māori/Pacific), they were also less likely to receive it regularly (39%, 36% and 43% for Māori, Pacific people, and non-Māori/Pacific respectively). This means that, because ULT is less frequently accessed by Māori and Pacific patients throughout the year, they are more susceptible to flares and therefore hospitalisation.

The report also found that in 2019 non-Māori/Pacific gout consumers had a non-steroidal anti-inflammatory drug (NSAID) dispensing rate of 35%, compared to 41% for Māori and 46% for Pacific people. Using NSAID to manage gout-related pain is inappropriate in the long-term as it can speed up the development of renal dysfunction or exacerbate existing issues relating to various

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[3] Stroke Aotearoa New Zealand. *Statistics & data; What is a stroke?* Retrieved 8 December 2025, from https://www.stroke.org.nz

[4] Dehlin M, Jacobsson L, Roddy E, et al. Global epidemiology of gout: prevalence, incidence, treatment patterns and risk factors. Nat Rev Rheumatol. 2020 Jul;16(7):380–90.

[5] Howren A, Bowie D, Choi HK, et al. Epidemiology of depression and anxiety in gout: a systematic review and meta analysis. J Rheumatol. 2021 Jan;1;48(1):129-37

[6] Health Quality & Safety Commission New Zealand. *Atlas of healthcare variation: gout* [Internet]. HQSC [updated 2021 March 19; cited 2021 September 15]. Available from: www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/gout.

comorbidities. In line with these findings, the rates of gout-related hospitalisation for Māori and Pacific people, respectively, were approximately *five* and *nine* times higher than for non-Māori/Pacific.

The relationship between gout arthritis and stroke

Research shows that gout is also linked to an increased risk of stroke and other heart-related problems. High uric acid can contribute to inflammation and damage in the blood vessels, which may lead to stroke. People with gout often have other health conditions that raise stroke risk, such as high blood pressure, diabetes, kidney disease, high cholesterol, obesity, and heart disease.[7]

Recent studies suggest that the risk of stroke or heart attack can be particularly high in the weeks following a gout flare. The inflammation and stress on the body during a flare may trigger cardiovascular problems. Because of these risks, gout is not just a joint disease, it is also a sign that cardiovascular health needs attention. Managing gout, controlling other health conditions, and adopting a healthy lifestyle can all help reduce the risk of stroke and heart problems.

Conducting this survey

The survey was designed to capture both individual and whānau perspectives on prevention, care, management, and overall wellbeing, recognising that these conditions are experienced collectively as well as individually. An online, whānau-centred survey approach was used to enable broad participation across the Wellington rohe (Pōneke, Porirua, Kāpiti, and Te Awa Kairangi), with targeted promotion through community networks, health providers, and partner organisations. The survey was open for six weeks and included a mix of quantitative and qualitative questions to capture both measurable trends and in-depth lived experiences. Responses were analysed using a combination of descriptive and thematic approaches to identify key patterns, insights, and priorities to inform future service planning, advocacy, and whānau-centred health responses.

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[7] Cipolletta E, Tata LJ, Nakafero G, Avery AJ, Mamas MA, Abhishek A. Association Between Gout Flare and Subsequent Cardiovascular Events Among Patients With Gout. JAMA. 2022;328(5):440–450. doi:10.1001/jama.2022.11390

Appendix 2: Stroke Survey Quantitative Data Findings

Time since stroke experienced

Participants were asked when stroke occurred, with responses grouped into standard time bands from recent (last 12 months) to over 10 years.

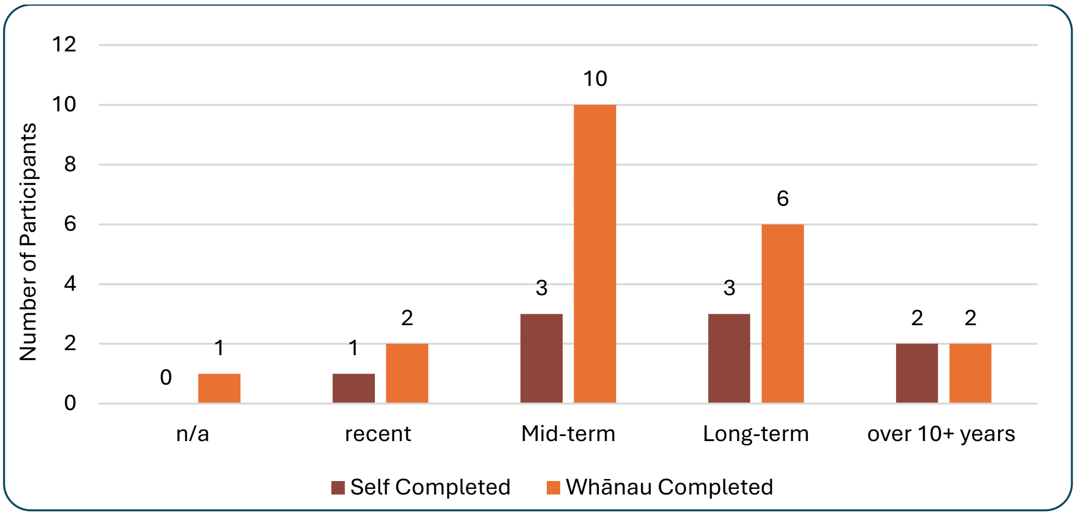


Figure 1. Time since stroke was experienced by participants or their whānau members

Number of stroke events experienced

Overall, the most common response in both groups, was participants reporting on the experience of one stroke or Transient Ischaemic Attacks (TIA) in their lifetime (self=8; whānau=12).

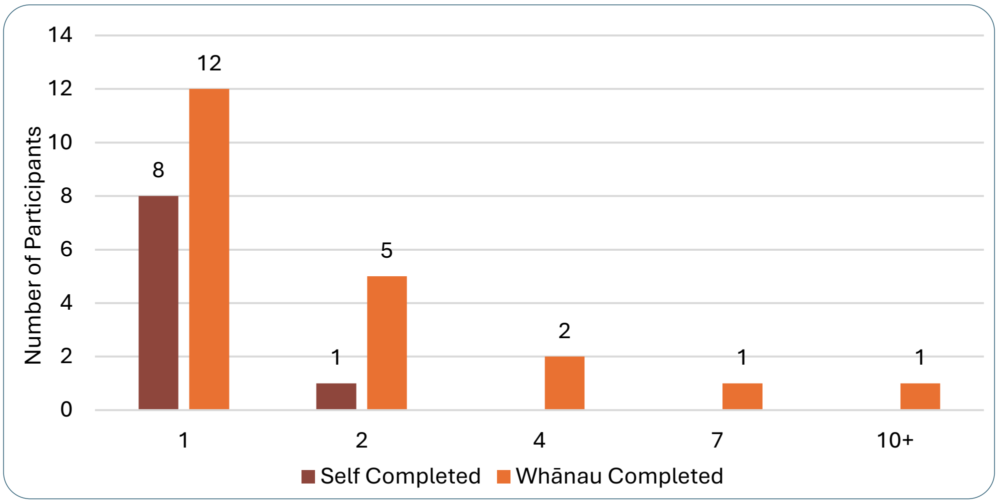


Figure 2. Number of strokes experienced, including TIAs, reported by stroke survivors and whānau

Current health status

Most participants rated health as good or fair, with stroke survivors generally reporting slightly more positive health (4 good, 1 very good), while whānau prospection leaned more toward fair (n=9) and poor health.

Figure 3. Current health status

Ability to exercise

Self-reported exercise ability was generally higher, with six participants reporting some capacity and none were unable to exercise, while whānau responses indicated greater limitation, with most reporting their loved one could exercise only with effort (n=8) or not at all (n=7).

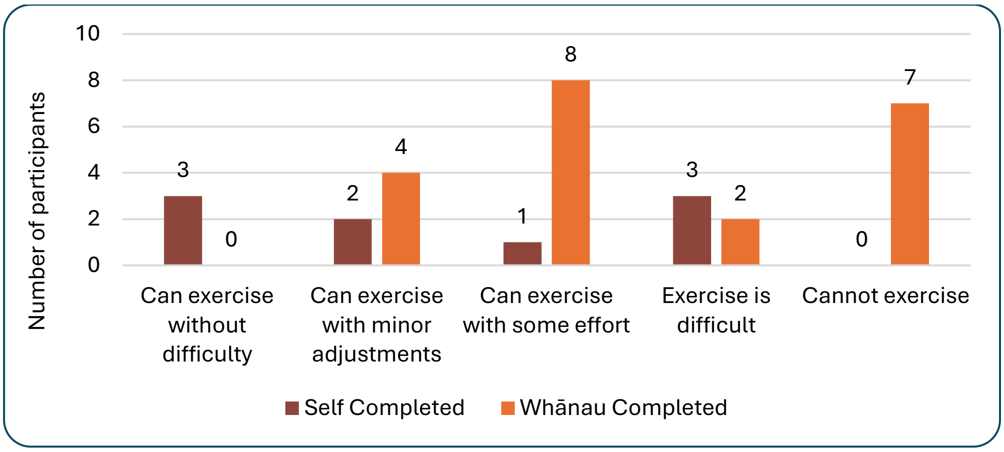


Figure 4. Current exercise ability level

Awareness of support services/resources

Self-completing participants showed a spread across awareness levels (slightly aware n=3; somewhat aware n=2; very aware n=3). Whānau participants were more concentrated in lower-to-mid awareness levels, mainly somewhat aware (n=10) and slightly aware (n=6), with fewer reporting high awareness.

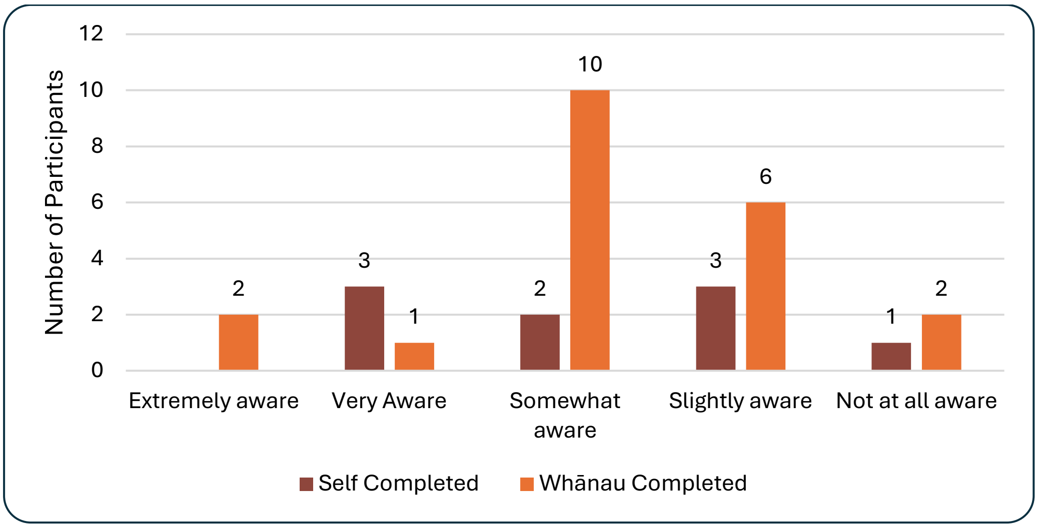


Figure 5. Participant-reported levels of awareness of support services and resources

Levels of understanding, met needs, trust, and mental health and wellbeing

Participants were asked to indicate their level of agreement with a set of statements using a six-point response scale: strongly agree, agree, neutral, disagree, strongly disagree, or don't know. The results are detailed below.

Understanding of stroke risk factors and prevention

Understanding was generally positive, with half of participants agreeing or strongly agreeing (self = 5; whānau = 10), but a large number of neutral responses (self = 4; whānau = 9) suggests variable confidence and gaps in applied understanding, particularly among whānau.

Available resources met needs

Perceptions of whether resources met needs were mixed, with many neutral responses (self = 4; whānau = 7) and more negative views among whānau (n=6 disagreed), indicating uncertainty and limited confidence that current supports fully meet needs.

Health professionals understand my needs

Views were moderately positive but varied, with some agreement among both groups (self = 3; whānau = 8), alongside a high number of neutral responses (self = 3; whānau = 10), suggesting inconsistent experiences of being understood.

Levels of trust in health professionals

Trust was generally positive, especially among stroke survivors (n=6 agree/strongly agree), while whānau responses were more mixed (n=11 agree/neutral; small numbers strongly disagree), indicating variability in trust across experiences.

Mental health impacts

There was strong recognition of the negative impact of stroke on mental health, particularly among whānau (n=20 agree/strongly agree), while most stroke survivors also reported impact (n=5 agree/strongly agree), highlighting the significant ongoing emotional burden.

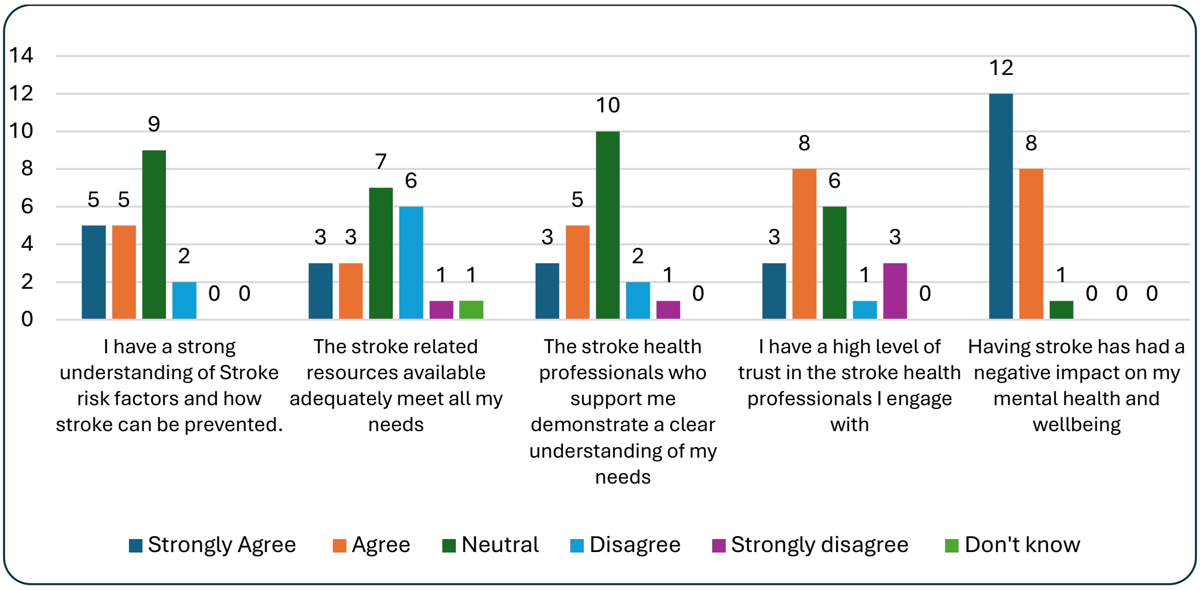


Figure 6. Whānau completed survey responses to levels of understanding, met needs, trust, and mental health and wellbeing.

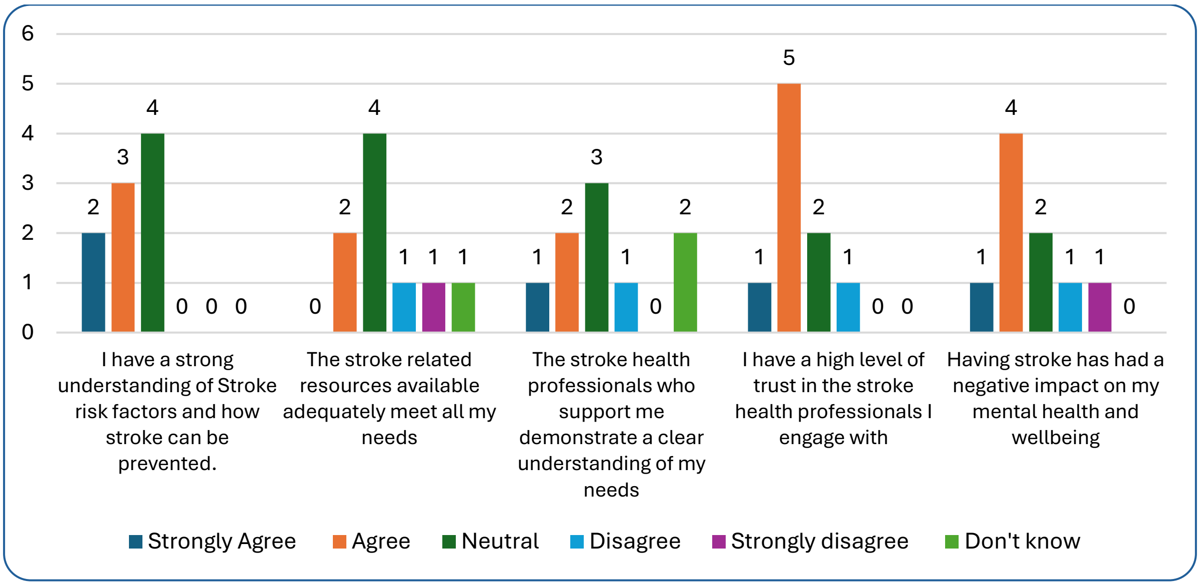


Figure 7. Self-completed survey responses to levels of understanding, met needs, trust, and mental health and wellbeing

Accessible stroke advice and planning

Participants reported mixed understanding of stroke and prevention planning, with some clear understanding (stroke survivors n=2; whānau n=6 completely) but many indicating only partial understanding.

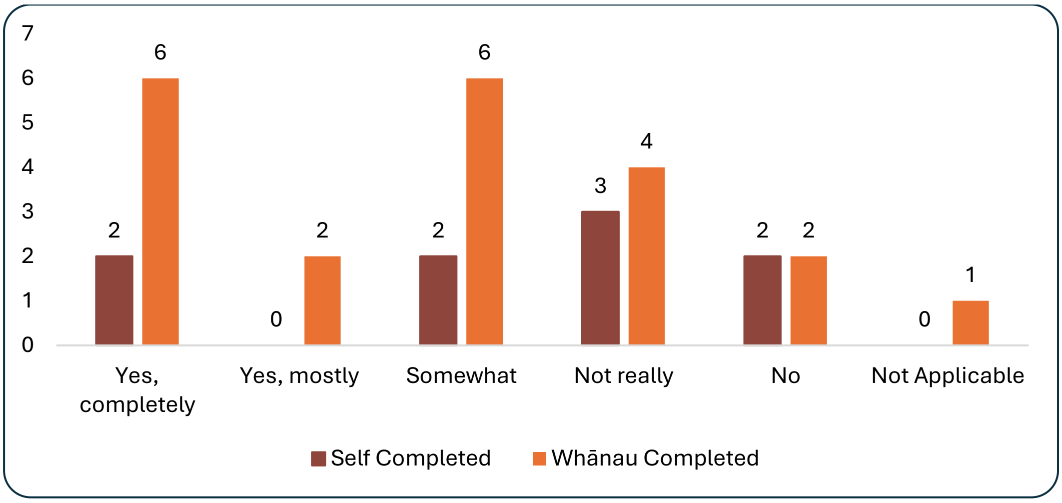


Figure 8. Participant views on how clearly stroke and stroke prevention plans were explained to them and their whānau by doctors or pharmacists

Things to improve understanding

Participants most often identified follow-up support (n=14), visual information (n=10), and culturally appropriate communication (n=10) as the most helpful resources for understanding and preventing stroke.

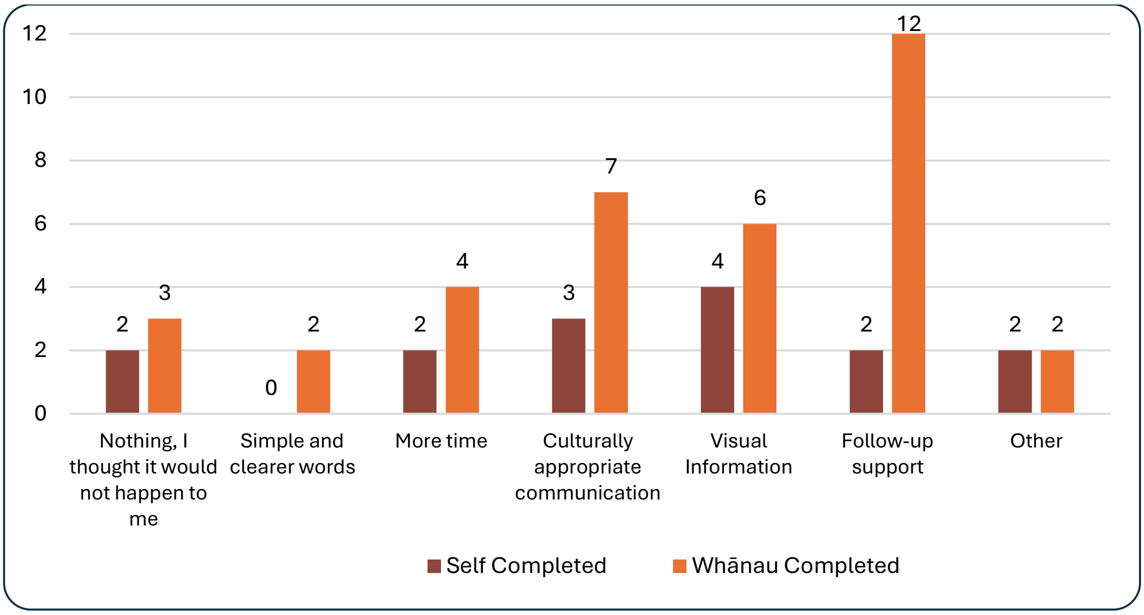


Figure 9. The level to which survey participants' doctors/pharmacist explained the condition/offered a prevention plan

The "other" option invited participants to comment and share their thoughts. Here, participants highlighted breakdowns in continuity of care between the hospital and primary care.

> *"The reason the stroke occurred was because she was taken off her blood thinner medication, hospital and GP not talking." 55-64 wāhine Māori, whānau member*

Another highlighted a lack of age-appropriate information, particularly for young people affected by stroke.

> *"More information for younger people." 18-24 wāhine Māori, stroke survivor*

Understanding of co-morbidities and stroke

Stroke survivors generally reported limited understanding of links between stroke and other conditions, with only two indicating high understanding. Whānau participants more often reported moderate understanding, with most indicating they understood these connections somewhat (n=11) and fewer very well (n=4).

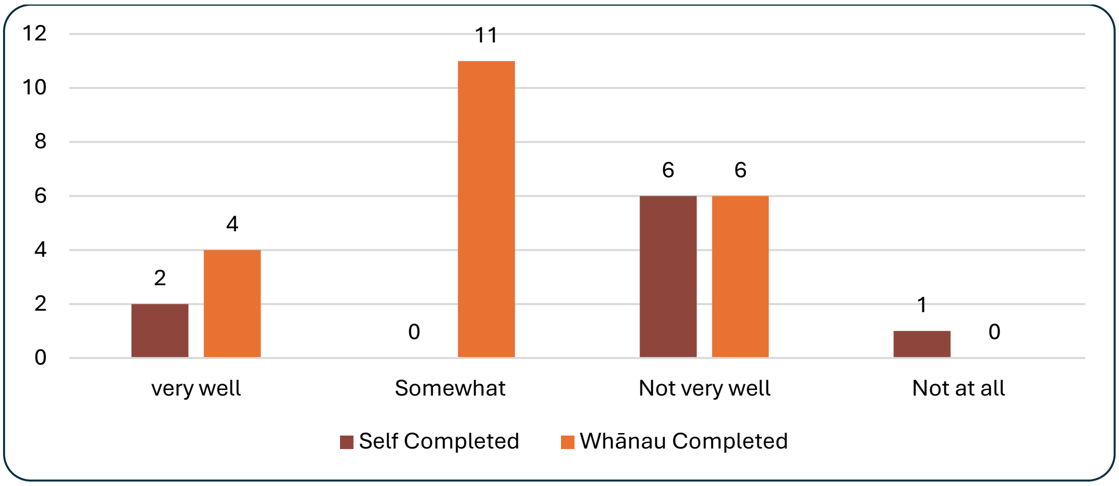


Figure 10. Participants' understanding of stroke and other comorbidities

Appendix 3: Stroke Survey Qualitative Data Findings

Participants were asked five open-ended questions to provide deeper insights into stroke experiences, with responses analysed separately for participants and whānau, highlighting key themes for each group and supported by direct quotes.

Stroke survivor and whānau stroke prevention strategies

What kind of things do you or your whānau member do to prevent stroke from happening again?

Stroke survivors described a proactive, holistic approach to preventing another stroke, centred on maintaining regular physical activity as a core, everyday practice that supports recovery and ongoing health. This is closely combined with healthy eating and broader lifestyle changes, such as reducing salt and alcohol intake, reflecting an understanding that prevention requires sustained behaviour change rather than a single action. Many survivors also emphasised the importance of adhering to prescribed medication and following clinical advice, including listening to their bodies and monitoring their wellbeing. Alongside this, managing weight and maintaining awareness of ongoing stroke risk were highlighted as key motivators, reinforcing a strong sense of personal responsibility and vigilance in reducing the likelihood of recurrence. This was reflected in the following responses:

"Awareness of the risk, knowing that there are no guarantees that I won't have another one. Try to keep fit, watch what I eat and try to keep my weight down." 65-74, wāhine Māori, stroke survivor

"Eat well, restrict salt consumption, try to limit alcohol consumption, exercise is really important." 45-54, tāne Māori, stroke survivor

"The relationship between certain medications that could lead to stroke. The better expectations on elderly experiencing strokes - it came as a surprise with our healthy but elderly father." 35-44, wāhine Māori, whānau member

Whānau members described a collective and supportive approach to preventing another stroke, with a strong focus on ensuring medication is taken correctly and maintaining regular clinical monitoring through GP visits and check-ups. Alongside this, they recognised the importance of physical activity and healthy eating, often actively encouraging their loved ones to exercise regularly, adopt healthier diets, and reduce risk behaviours such as smoking and alcohol use. These responses reflect both practical actions within daily life and broader lifestyle changes influenced by lived experience. Importantly, whānau highlighted their role in motivating, supporting, and advocating for stroke survivors, demonstrating that stroke prevention is approached as a shared responsibility grounded in care, encouragement, and ongoing engagement.

"Have had a clinician properly monitor and administer blood thinning medication." 45-54, wāhine Māori, whānau member

"My mama gave up smoking after her first one. She passed in 2020 from a major stroke. Three out of her four kids don't smoke or drink to try and prevent ourselves from having a stroke." *35-44, wāhine Māori, whānau member*

"Encouraging each other to eat healthy and exercise regularly." *25-34, tāne Māori, whānau member*

Barriers to living well with stroke

What gets in the way of you or your whānau member living well with stroke?

Stroke survivors described a range of interconnected barriers that make it difficult to live well after stroke, with emotional impacts such as fear, anxiety, and uncertainty about the future emerging as significant challenges. Many expressed an ongoing fear of falling, reinjury, or experiencing another stroke, which can limit confidence and participation in daily life. These emotional barriers are compounded by persistent physical impairments such as weakness, balance issues, and communication difficulties, which subsequently restrict independence and everyday functioning. Survivors also highlighted structural challenges, including difficulty accessing timely and affordable healthcare, financial strain, and housing issues, all of which add stress and hinder recovery. In addition, life disruptions such as work pressures, time constraints, and relationship changes further interfere with their ability to prioritise their health, reinforcing the complex and multifaceted nature of living well after stroke.

"Not knowing where to start with health, I am finding it daunting to [go] outside and am unbalanced since stroke. Very scared of falling and injuring myself again." *18 – 24, wāhine Māori, stroke survivor*

" Medical bills that occur occasionally. Waiting in the public sector ie wait list. Unable to get medical insurance due to the stroke and the issues that they found (heart). *55-64, tāne Māori, stroke survivor*

Whānau members described multiple, compounding barriers to living well after stroke, with financial strain emerging as the most significant challenge. This included loss of income, costs of care, and the need to make substantial financial sacrifices to support their loved one. They also highlighted ongoing difficulties accessing appropriate services, particularly rehabilitation and specialist support, with many expressing frustrations at gaps in aftercare and perceived inequities in the health system. Increased dependency following stroke placed considerable pressure on whānau, requiring them to balance caregiving responsibilities with work, travel, and family commitments, often over extended periods. Alongside these practical challenges, whānau emphasised the emotional and mental health impacts of stroke, including depression, grief, loss of confidence, and the enduring sense of change or "lost years", reflecting the profound and long-term effects on both survivors and their wider whānau.

"The dependency now since my dad had his stroke. We had to remortgage our houses to support him adequately - being prepared financially." *35-44, wāhine Māori, whānau member*

"Initially we were just told what it was and that mum couldn't drive. But because my pāpā had a stroke also back in 2006 we kind of knew what could happen. No information was given to the wider whānau to help (with) prevention for themselves or support around how to do this." *35-44, wāhine Māori, whānau member*

Examples of "great care" (or an absence of care)

What is an example of great care you and your whānau received during your stroke journey?

Stroke survivors described "great care" as being a combination of compassionate, person-centred treatment and clear, supportive communication throughout their stroke journey. Positive experiences were strongly linked to healthcare staff who showed kindness, reassurance, and professionalism, helping to ease fear and make survivors feel valued as individuals rather than just patients. Clear explanations about their condition, medications, and recovery process were also vital, enabling survivors to better understand and manage their health with confidence. Ongoing rehabilitation and allied health support, such as speech therapy or occupational therapy, were seen as essential parts of high-quality care, helping survivors regain function and being able to readapt to daily life. Alongside clinical care, the support of whānau played a vital role, providing emotional stability, practical help, and a sense of teamwork, particularly during the early and most uncertain stages of recovery.

"The Hutt Valley Hospital team have been outstanding. From the moment I was diagnosed through to the ongoing follow-up care, the professionalism and support have been excellent." 55-64, tane Māori, stroke survivor

"The nurses at Wellington Hospital were amazing, made me feel comfortable the whole time and treated me like a person rather than a patient. They knew how scared I was as I am young and helped me calm myself and realise I was okay." 18-24, wāhine Māori, stroke survivor

Whānau members described "great care" as beginning with strong, responsive acute and emergency clinical support. This in turn provided reassurance and a critical foundation for recovery for both the patient and their wider whānau. They also highlighted the value of well-coordinated, wrap-around services following hospital discharge, particularly when rehabilitation and community-based support led to visible improvements in function, confidence, and participation in everyday life. Beyond formal services, whānau emphasised the importance of family, friends, and community networks as essential sources of practical and emotional support, with shared learning across whānau playing a key role. However, many also noted gaps in rehabilitation pathways, where limited formal support meant whānau often had to take on significant responsibility for coordinating care and driving recovery themselves, sometimes adding to the overall burden *despite* positive outcomes.

"The fabulous team on release (from) the hospital which we received for 6 - 7 weeks. The 1:1 daily or 2-day visits, included outings to encourage to get back in the community." 55-64, wāhine, whānau member

"We joined a local community of stroke and dementia whānau and patients which we learnt about through other whānau who practiced trial and error." 35-44, wāhine Māori, whānau member

Examples of what didn't go so well

What is an example of something that didn't go so well?

Stroke survivors described negative experiences as being largely driven by gaps in ongoing support and systemic barriers, particularly after the initial recovery phase. Many felt that post-stroke care diminished over time, leaving them isolated and required to self-advocate for limited rehabilitation services such as speech or occupational therapy. Delays and gaps in emergency responses were also noted in some cases, particularly where frontline staff lacked knowledge of less common stroke presentations. Survivors further highlighted the lasting impact of physical impairments on safety and independence, affecting everyday activities such as mobility in the community. These challenges were compounded by broader external pressures, including COVID-19 disruptions and caregiving responsibilities, which further limited access to timely and appropriate care. Overall, survivors' responses reflect frustration with fragmented, delayed, and insufficient long-term support to meet their complex recovery needs, as demonstrated below:

> *"Post-stroke support is not as good as it could be, in my view. I think support for stroke victims peters off over time. You are virtually left alone as time goes by. I think that creates loneliness. Perhaps we need more support groups in our communities." 55-64, wāhine Māori, stroke survivor*

> *"Covid and lockdowns really took its toll. Living with a mother who had Alzheimer's and the relentless pursuit of trying to get help, real help I mean not pamphlets but SLTs [speech and language therapy] (particularly for me) and others like OTs [occupational therapist], massage therapists, and I finally got to see a neurologist 6 years after the fact." 45-54, tāne Māori, stroke survivor*

Whānau members described negative experiences as being driven by serious concerns about the quality and safety of care, including misdiagnosis, medication errors, inadequate supervision, and unsafe caregiving practices that placed their loved ones at risk of harm and undermined trust. A major issue was the lack of access to sustained rehabilitation, with whānau often needing to repeatedly advocate for therapies such as speech and physical therapy, with limited success. They also highlighted broader clinical and system-level failures, including poor care coordination, inappropriate transfer decisions, and the absence of clear rehabilitation plans, all of which impacted recovery outcomes. In addition, whānau reported a lack of clear information and guidance around prevention and recovery, leaving them uncertain about how best to support their loved one. In some cases, this contributed to further health deterioration. Overall, these experiences reflect frustration with inconsistent care, limited support, and gaps in both clinical practice and system design.

> *"Mum had a fall, broke her arm. This wasn't immediately diagnosed and we weren't informed. Later on we realised she also had a stroke." 55-64, tāne Māori, whānau member*

> *"Mum had aphasia, couldn't walk and had no use of the whole right side of her body. I had requested several times for a speech therapist and physical therapist to provide assistance for her, but no such luck!" 45-54, wāhine Māori, whānau member*

Services and supports that would help stroke survivors/whānau live well with stroke

What other services and supports would allow you and your whānau to live well after stroke?

Stroke survivors highlighted the need for more accessible, ongoing, and responsive support to help them live well after stroke, with a strong emphasis on regular rehabilitation services such as speech therapy, neurology, and home-based care that fit into their daily lives. They also identified the importance of affordable opportunities to stay physically active, recognising exercise as both a key prevention strategy and a source of physical and mental wellbeing. In addition, survivors valued practical, tailored education for both them and their whānau to better understand stroke, recovery, and how to provide effective support in everyday settings. Alongside these needs, they emphasised the importance of practical supports (for example, affordable or subsidised services, meals, and suitable housing) which help reduce barriers and enable greater independence throughout their recovery journey.

> *“Specialists like those mentioned before in this survey particularly speech language therapists and neurologist, therapists.” 45-54, tāne Māori, stroke survivor*

> *“I would like some support in getting active, I am really keen to get some help but am finding proper support that does not cost an arm and a leg. I am a uni student so getting active is important for me and finding a new sense of self after the stroke is also important for me.” 18-24, wāhine Māori, stroke survivor*

Whānau members emphasised the need for more accessible, ongoing, and practical rehabilitation services that are better tailored to the needs and confidence of stroke survivors, including supported physical activities and improved access to clinical care. They also highlighted the importance of clearer communication, regular follow-up, and flexible, whānau-friendly information, such as resources they can access in their own time and opportunities to ask questions, so they feel better equipped to support recovery. In addition, whānau identified a range of practical supports to ease everyday challenges, including assistance with transport, meals, caregiving, and affordable or subsidised services. Importantly, they also called for more culturally grounded support, including kaupapa Māori resources and iwi-based support, reflecting the need for care that is both accessible *and* culturally meaningful for whānau.

> *“I think my brother and sister could benefit from pool activity. However, my brother is quite [self] conscious as well as would need help while in the water. I'm not sure there is a service that helps [like] this.” 55-64, wāhine Māori, whānau member*

> *“More te reo Māori resources.” 45-54, wāhine Māori, whānau member*

Additional Comments

At the conclusion of each survey, participants were invited to share any final reflections or thoughts in response to the question: *"Is there anything else you'd like to share with us?"*

The responses provided valuable insight into the lived experiences of stroke survivors and their whānau. These comments have been included as a closing section to this segment, offering readers the opportunity to reflect on the voices and experiences shared throughout the survey findings. The comments highlight a range of emotions, perspectives, and priorities, allowing readers to draw their own conclusions and identify the themes and insights most relevant to their reading and understanding.

"Stroke sucks" 45-54, wāhine Māori, whānau member

"I think we need "whanau approaches" earlier. When you are a family that has a history of stroke, gout, heart failure, kidney disease, cancer and other related diseases, it's very difficult because the system only deals with individuals not really whānau." 55-64, wāhine Māori, whānau member

"I would like to offer my services to a strategic planning forum to do with the stroke." 45-54, tāne Māori, stroke survivor

Appendix 4: Gout Survey Findings Quantitative Data

Number of gout flares experienced (lifetime)

Gout flare frequency was high, with many gout consumers reporting 10 or more flares (self n=9; whānau n=4) and a combined total of at least 193 flares across 28 participants. Overall, this reflects a significant burden of gout with substantial impacts on quality of life for participants and their whānau.

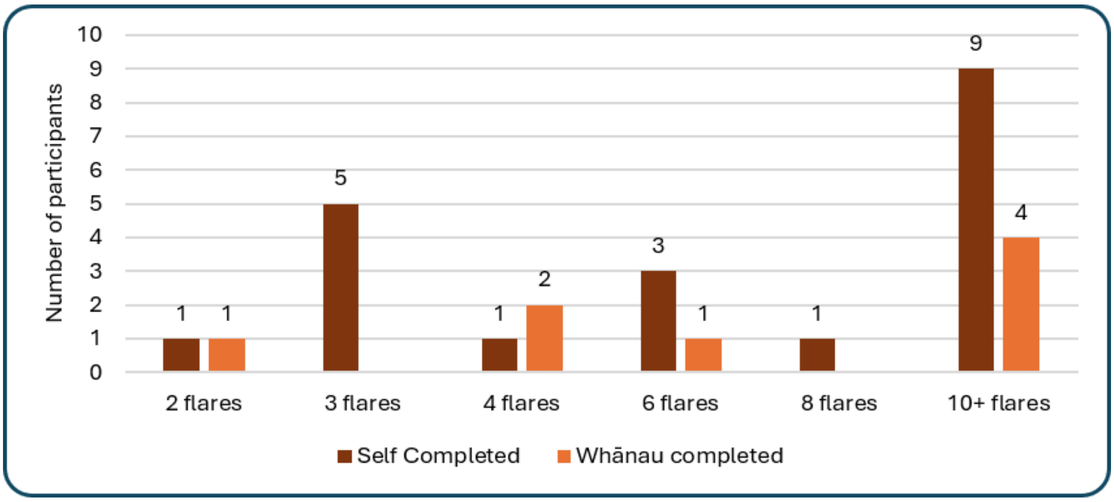


Figure 11: Number of gout flares experienced (over lifetime) by gout participants

Year gout flares started

Most participants reported first experiencing gout flares in recent years (from 2021 onwards, n=9), although experiences spanned a wide time range from the 1980s to present. Whānau-reported experiences were more recent overall (mostly post-2012), highlighting a pattern of increasing recent onset alongside some variability and a small number of unclear responses.

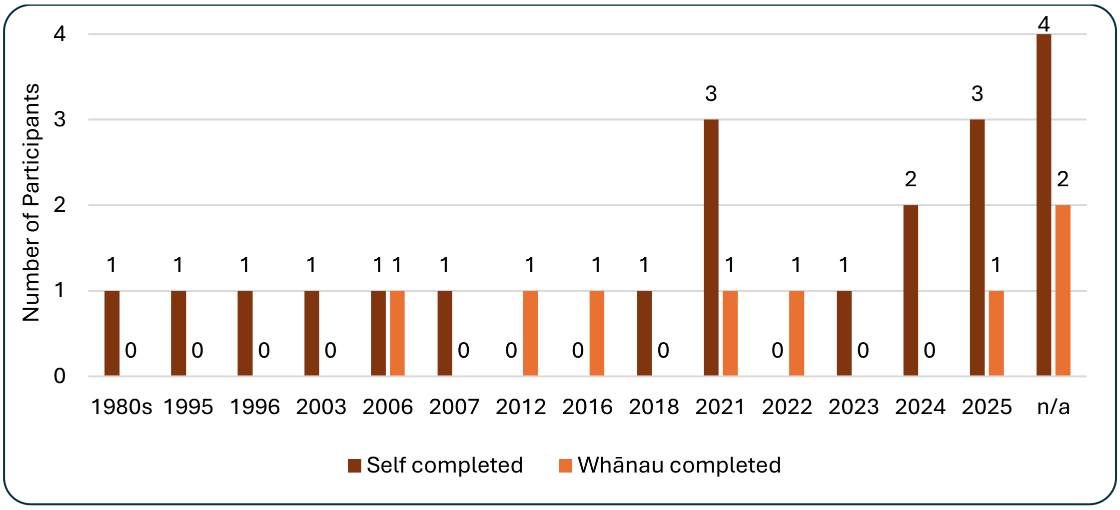


Figure 12. Year gout flares/attacks first started

Current health status

Most gout consumers (n=14) indicated that their current health status was "good" (n=10), "very good" (n=3) or "excellent" (n=1). The majority of whānau responses assessed their loved ones as having "fair" (n=4) personal health at the time of doing the survey.

Figure 13. Current health status

Ability to exercise

Most gout consumers were able to exercise, though levels of difficulty varied, with self-completing participants reporting higher capability than whānau-reported experiences. Overall, whānau responses more often highlighted limitations, suggesting self-reporting may understate the true impact of gout on physical functioning.

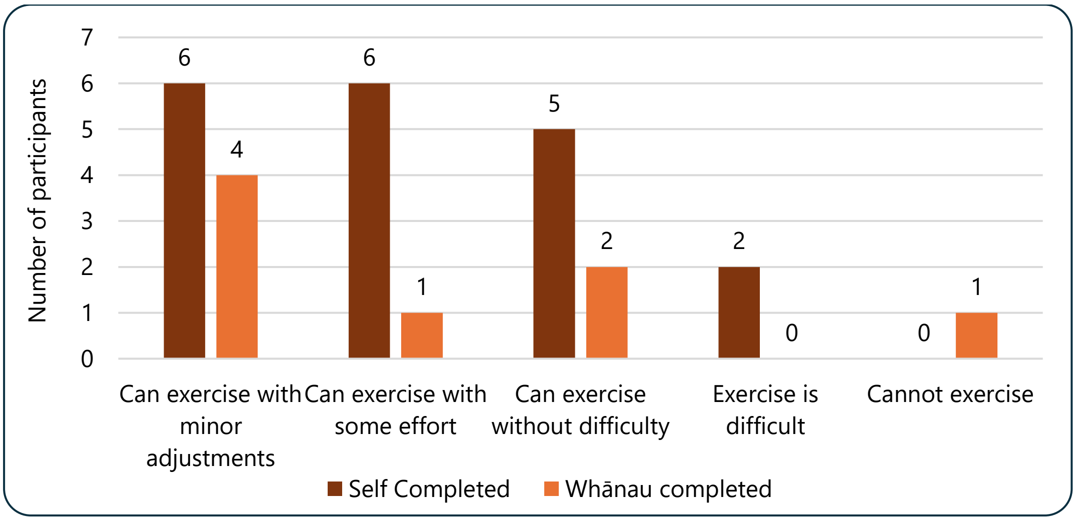


Figure 14. Current exercise ability level

Awareness of support services/resources for gout

Awareness of gout support services was generally higher among gout consumers, with most reporting high levels of awareness (very or extremely aware), while whānau participants tended to report lower, more moderate awareness. This suggests a gap in access to information for whānau, highlighting the need for clearer, more accessible communication and proactive engagement to support their role in care.

Figure 15. Participant-reported levels of awareness of support services and resources

Levels of understanding, met needs, trust, and mental health and wellbeing

Participants were asked to indicate their level of agreement with a set of statements using a six-point response scale: strongly agree, agree, neutral, disagree, strongly disagree, or don't know. The results are detailed below.

Understanding of risk factors for gout and associated gout prevention

Gout consumer understanding of risk factors and prevention differed to those who have whānau members living with gout. A larger proportion of gout consumers have more confidence in their own understanding of gout risk factors and gout prevention when compared to whānau members reporting on behalf of others with gout.

Available resources meet needs

There was a mixed level of agreement amongst all participants as to whether resources meet needs. Six out of eight whānau members were "neutral" about this measure and one "agreed" and one "strongly disagreed". Half the gout consumers either "strongly agreed" (n=6) or "agreed" (n=4) with this statement.

Health professionals understand my needs

The results for this statement from whānau members was almost identical to the next measure on trust, with 3 agreeing and 3 being neutral. Gout consumers were more likely to "strongly agree" (n=6) or "agree" (n=4), although some still selected "neutral" (n=6). Three people living with gout told us they "strongly disagreed".

Levels of trust in health professionals

Slightly more than half of gout consumers (n=11) selected either "strongly agreed" (n=5) or "agreed" (n=6). In comparison those reporting on behalf of whānau with gout were less inclined to agree with the statement (three "agreed" and three "neutral") with one whānau member selecting "don't know" and one selecting "strongly disagreed".

Mental health impacts

Gout participants were more likely to report negative impacts on mental health, with nearly half agreeing this was significant (n=9) and others neutral (n=7). In contrast, whānau views were more mixed and less likely to indicate strong impacts, highlighting a clear difference between participant experiences and whānau perceptions.

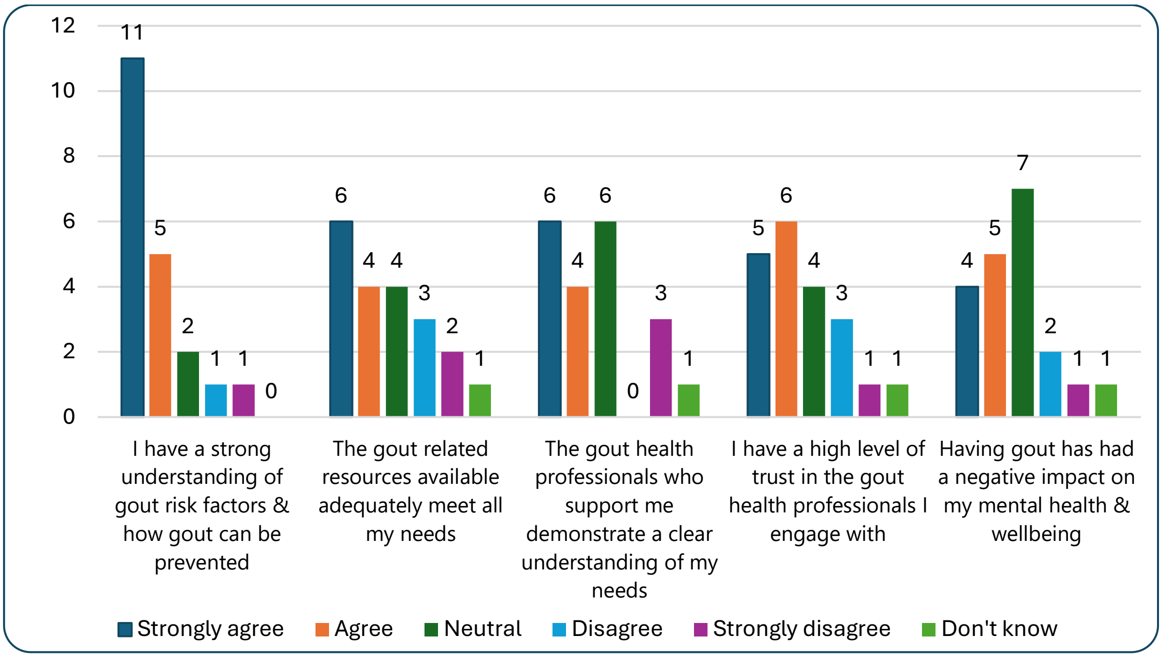


Figure 16. Self-completed survey responses to levels of understanding, met needs, trust, and mental health and wellbeing

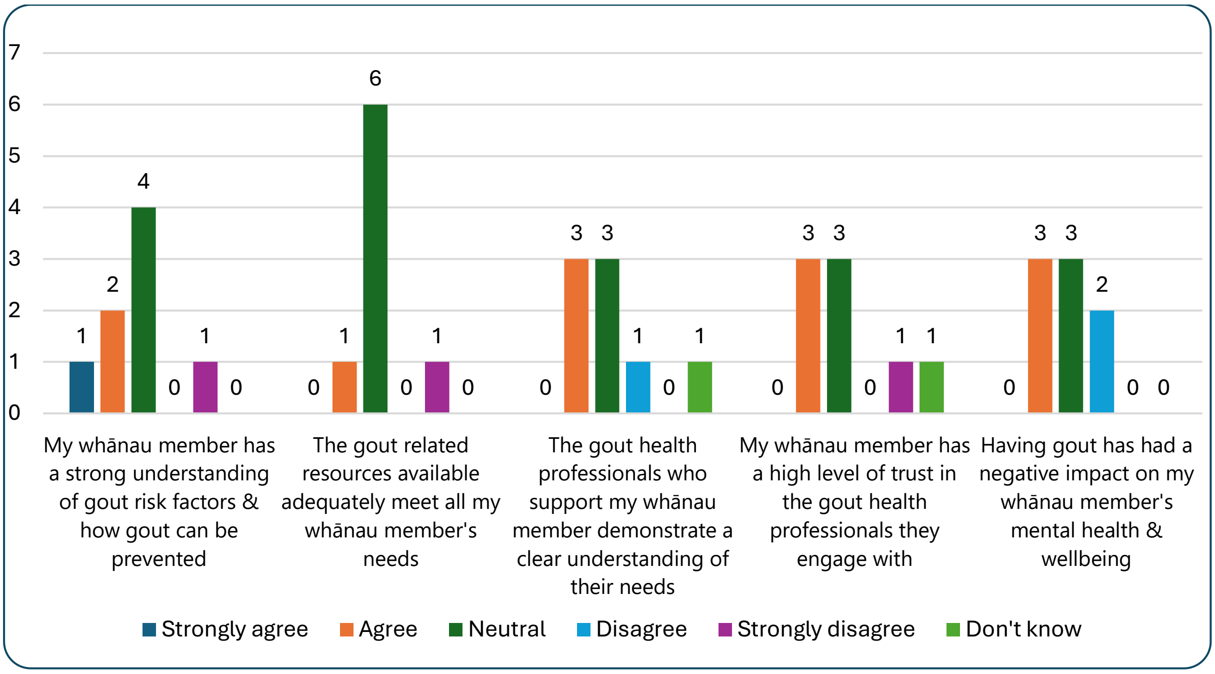


Figure 17. Whānau completed survey responses to levels of understanding, met needs, trust, and mental health and wellbeing

Accessible gout advice and a plan

Most gout consumers reported positive experiences of explanations and prevention planning (n=12), though some indicated partial or limited understanding. Whānau perspectives were more mixed, with responses spread across positive, neutral, and negative experiences, highlighting variability in how well information was communicated.

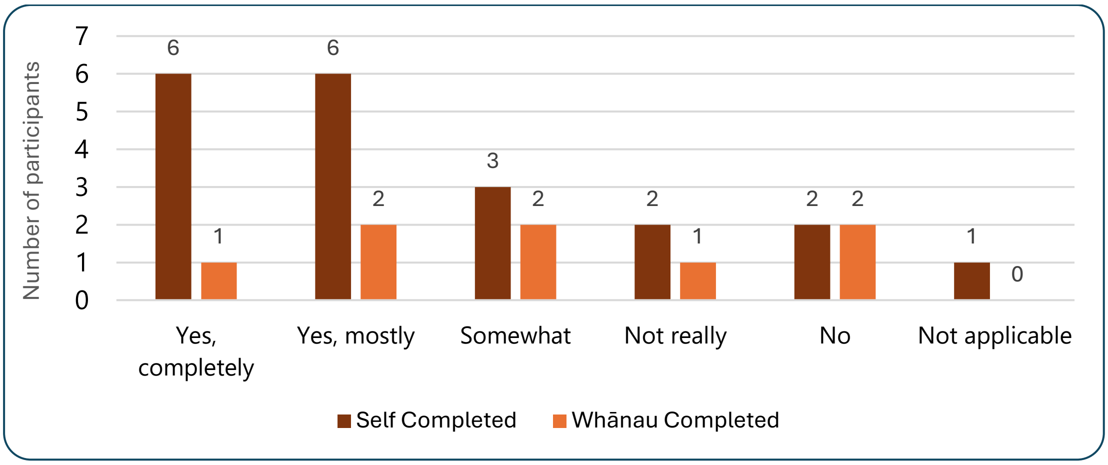


Figure 18. The level to which gout participants' doctor/health professionals explained the condition/offered a prevention plan

Things that would potentially improve understanding of gout

Participants most often identified visual information and follow-up support as the most helpful resources for both participants and whānau, with similar overall totals (n=13 each). While gout consumers also prioritised culturally appropriate communication (n=7), whānau selected this far less often, and both groups similarly valued clearer language and more time.

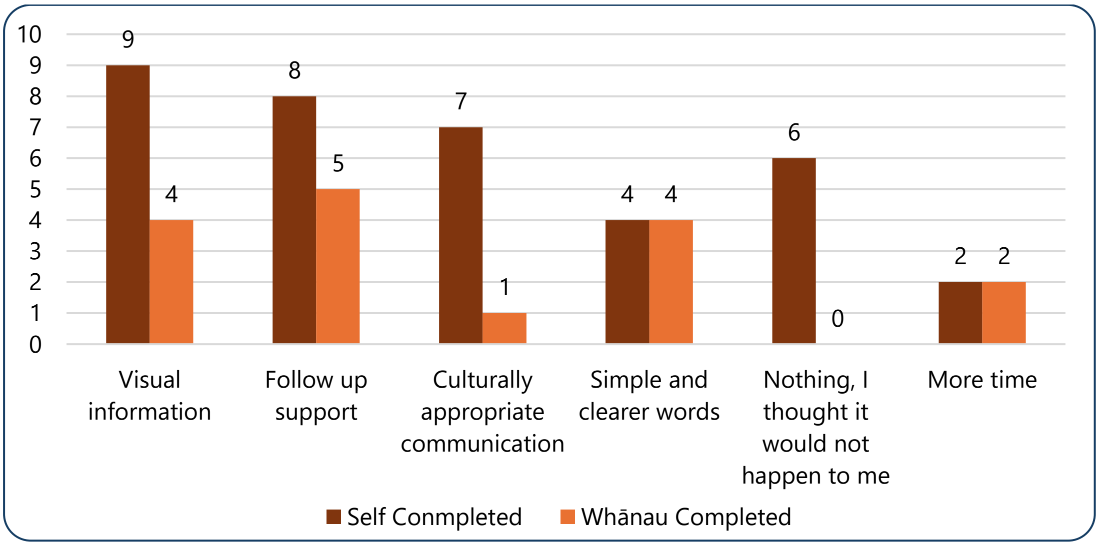


Figure 19. Participants' view of things that would potentially improve understanding of gout

Interestingly, five of the gout consumer participants selected "other" as an option with participants commenting:

> *"Over the years the majority [of clinicians] (90%) have treated my gout with the magic pill effect - That one pill a day and sometimes more for the onset gout attacks are*

necessary. No one has really worked on how to ween me off them. Also, I've had to tell doctors what the triggers were for me and then had to listen to them tell me it isn't or can't be." 45-54, tāne Māori, gout consumer

"Mainly for my other whanau that have gout." 45-54, wāhine Māori, gout consumer

"Nothing I thought it was good." 65-74, tāne NZ European, gout consumer

Understanding comorbidities of gout

Gout is intrinsically connected to a range of other long-term conditions and related issues such as heart disease, diabetes and stroke. People's knowledge and understanding of this was explored through asking participants about how well they thought they and/or their whānau understand the known connection between this form of inflammatory arthritis and other conditions. Understanding of gout's links to other conditions was mixed, with most gout consumers reporting moderate (n=8) or high (n=6) understanding, while a notable group reported limited or no understanding (n=6). Whānau responses were fewer but generally indicated some awareness, with participants selecting both "somewhat" and "very well."

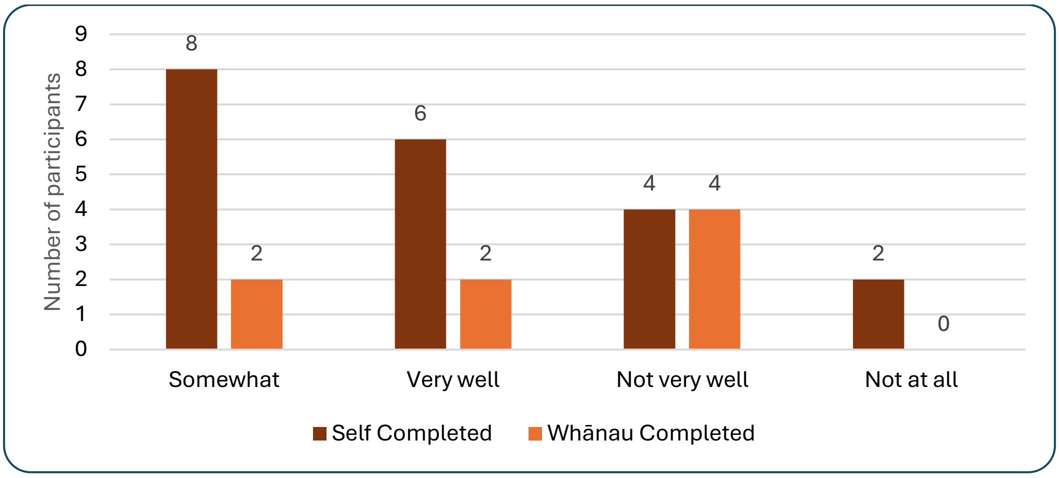


Figure 20. Participants' understanding of gout and other comorbidities

Appendix 5: Gout Survey Findings Qualitative Data

Participants were asked four open-ended questions to provide deeper insights into stroke experiences, with responses analysed separately for participants and whānau, highlighting key themes for each group and supported by direct quotes.

Gout consumer and whānau gout prevention strategies

What kind of things do you or your whānau member do to prevent gout from happening?

Gout consumers described a consistent and proactive approach to preventing gout, centred primarily on daily medication use (particularly allopurinol) as a core and routine strategy. Alongside this, they emphasised actively identifying and avoiding personal dietary triggers, such as purine-rich foods, alcohol, and specific items like red meat, seafood, or tomatoes, often based on lived experience. Reducing or eliminating alcohol intake was highlighted as a key preventative action. Many consumers also adopted broader healthy lifestyle practices, including maintaining a balanced diet, staying well hydrated, exercising, and managing stress. A smaller number further demonstrated active self-management through ongoing education about their condition, monitoring their health, and sharing knowledge with whānau to build awareness and support prevention within the wider family context. In contrast, the small group experiencing both gout and stroke described more limited or general approaches, often focusing on managing pain, maintaining basic function, or addressing broader health needs, with less emphasis on targeted gout prevention strategies. This suggests that the complexity of multiple conditions may shift focus away from condition-specific management.

> *"Take allopurinol 100mg x3 per day, no red meat, pork or kaimoana, stopped drinking wine, upped veges, decreased carbs, taking cherry juice" 55-64 wāhine Māori, gout consumer*

> *"Diet aware, I wouldn't have kaimoana more than 3 times in a week. I also drink a lot of water to remove the excess uric acid" 45-54 tāne Māori, gout consumer*

> *"Watch what I eat. Communicate to my children. Develop further understandings based on diet and activity and STRESS." 45-54 tāne Māori, gout consumer*

Whānau members described gout prevention largely in terms of practical, day-to-day management strategies, particularly supporting their loved ones to avoid known dietary triggers such as kaimoana and other perceived high-risk foods, although they noted that these are not always consistently followed. Medication use was also commonly mentioned, with whānau emphasising the importance of ensuring medicines are available and taken, though sometimes framed as part of simply managing an ongoing condition. Reducing alcohol consumption was identified as another key strategy, reflecting shared awareness of its role in triggering gout flares. However, some whānau expressed uncertainty about how to effectively prevent gout, indicating gaps in their knowledge and understanding of the condition. In some cases, prevention was minimal, with a focus instead on coping with flare-ups as they occur, highlighting a more reactive approach where individuals "just get on with it" rather than actively engaging in preventative behaviours.

"They usually know what triggers their gout however every so often they give in because it's usually food and alcohol." 25-34 *wāhine Māori, whānau member*

"Not much, taking basic medication but it is something that is just having to live with. My father is a farmer so there is not much that can be done." 25-34 *wāhine Māori, whānau member*

"Nothing as not [sure] what triggers it or what to do." 35-44 *tāne Pacific, whānau member*

Barriers to living well with gout

What gets in the way of you and your whānau living well with gout?

Gout consumers described a range of challenges that make it difficult to live well with gout, with dietary habits emerging as a key barrier, particularly the temptation or difficulty of avoiding trigger foods despite knowing their impact. The physical effects of gout, especially pain, reduced mobility, and joint damage, were also significant, limiting participation in every day and whānau activities and affecting overall wellbeing. In addition, some consumers experienced challenges with using medication, including forgetting to take prescribed treatments or reluctance to rely on long-term medication. Broader pressures, such as the cost of living, alongside psychological factors like fear and willpower, further compounded these challenges, highlighting that living well with gout is influenced by a combination of behavioural, physical, and socioeconomic factors.

"Nothing, I know that if I eat food that may trigger a reaction that I have to take precautions in the days following to stop any potential flare ups." 45-55 *wāhine Māori , gout consumer*

"Joint damage from flare ups." 25-34 *tāne Māori/Pacific, gout consumer*

"Though I haven't had a flareup for some time, I'm in need to be reassessed by a doctor and blood tests [need to be] done to lower my medication treatments." 55-64 *tāne Māori, gout consumer*

Whānau members described similar barriers to living well with gout, with pain and reduced mobility emerging as the most significant challenges, often limiting daily activities and independence. They also highlighted the burden of ongoing medication use, recognising the difficulty of maintaining long-term adherence. Restrictions around food and alcohol were another key issue, as these limitations affected lifestyle and enjoyment, despite being necessary to manage gout. In addition, financial and resource constraints, such as access to education, support, and affordability, were identified as further barriers. For those supporting whānau with both gout and stroke, the focus was even more strongly on managing pain, mobility limitations, and medication demands, with less emphasis on lifestyle triggers, reflecting the compounding impact of multiple health conditions on everyday life.

"They usually get it in the feet area and that limits mobility." 25-34 *wāhine Māori, whānau member*

"Certain kai [and] not being able to have it." 35-44 *wāhine Māori, whānau member*

Examples of “great care” (or an absence of care)

What is an example of great care you and your whānau received to help manage your gout?

Gout consumers described “great care” in mixed terms, with many highlighting a lack of positive experiences, often feeling unsupported, facing delays in accessing care, or needing to self-manage due to limited guidance from health professionals. Where good care was identified, it was mostly linked with receiving effective medication that successfully managed uric acid levels and reduced flare-ups. Positive experiences were also associated with strong, proactive relationships with GPs who provided regular monitoring, clear explanations, and ongoing support. In addition, some consumers valued practical lifestyle guidance that helped them make meaningful changes, such as improving diet, reducing alcohol intake, and increasing physical activity. Receiving this guidance demonstrated that when care is both clinically effective *and* supportive of self-management, it can lead to improved wellbeing and confidence in managing gout.

“There is not one, information available is not clear, poorly written, disease and [is] deficit focused, and punitive not positive.” 55-64 wāhine Māori, gout consumer

“I can’t say or remember if there has been any. I’ve had to work out myself what works best for me. Medical and health professionals have not been helpful.” 45-54 tāne Māori, gout consumer

“My GP… was very good. Gave me a lot of reading and was very thorough explaining how it was a form of arthritis. He checks on me regularly.’ 35-44 tāne Māori/Pacific, gout consumer

Whānau members described relatively few standout examples of “great care”. While some noted that their interactions with healthcare providers were pleasant, this did not necessarily translate into exceptional or memorable support. Where positive care was identified, it was most often linked to receiving effective medication to manage gout symptoms and pain. Accurate and timely diagnosis was also valued, particularly when it clarified the condition after delays or uncertainty. In addition, whānau highlighted the benefits of coordinated care plans, including regular monitoring, blood tests, and clear medical advice, which helped ensure their loved one stayed on track with treatment. Overall, responses suggest that while elements of good care are present, experiences are often basic or inconsistent, with “great care” typically defined by a clear diagnosis, effective treatment, and structured ongoing management.

“None that I can think of sticks out. But the people have been lovely.” 45-54 wāhine Māori, whānau member

“Just a base level of care in terms of a nurse practitioner actually doing tests to confirm diagnosis.” 35-44 tāne Pacific, whānau member

“My husband was put on a program to ensure he was on the right track with his gout. Regular blood tests and being put on the correct medication.” 35-44 wāhine Māori, whānau member

Services and supports that would help gout consumers/whānau live well with gout

What other services and supports would help you and your whānau to live well with gout?

Gout consumers highlighted a clear need for more accessible, relevant, and high-quality support to help them live well with gout, particularly improved education and information that is easy to access and draws on lived experience. Many expressed a desire for practical dietary support, including guidance from dietitians, to better manage triggers and maintain a balanced lifestyle. There was also some interest in alternative or non-medication-based strategies for managing gout, reflecting a desire for broader self-management options beyond daily medication. In addition, consumers emphasised the value of peer-based support, noting that guidance and encouragement from others with lived experience would provide meaningful understanding, motivation, and practical advice for managing the condition.

"Resources and information developed by people with lived experience here in our rohe." 55-64 wāhine Māori, gout consumer

"Education on how we can naturally prevent gout, medicines taken daily isn't a solution." 45-54 tāne Māori, gout consumer

"I manage ok[;] others within my whānau could use more support in terms of eating better with their flare ups." 45-54 wāhine Māori, gout consumer

Whānau members emphasised the need for more accessible, culturally relevant information and education as a key support for living well with gout, highlighting gaps in awareness and understanding of the condition and its long-term impacts. They also identified the value of peer support, such as connecting with others through group settings, to share experiences and gain practical advice. In addition, whānau expressed a desire for stronger support to enable healthier lifestyle choices, including improvements in diet, exercise, and overall wellbeing. Proactive and structured care, such as preventative care plans and regular follow-ups, was also seen as important for maintaining health and preventing flare-ups. For those managing both gout and stroke, there was a clear preference for organised, ongoing care, though fewer specific needs were identified, potentially reflecting the added complexity and fatigue associated with managing multiple long-term conditions.

"More knowledge [is needed] out there, a lot of things as Māoris are chalked up to [being] gout but not enough on what it actually is, we need more awareness." 25-34 wāhine Māori, whānau member

"Attending men's groups. Talking with other people that have had gout." 55-64 wāhine Māori, whānau member

Additional Comments

At the conclusion of each survey, participants were invited to share any final reflections or thoughts in response to the question: *"Is there anything else you'd like to share with us?"*

The responses provided valuable insight into the lived experiences of stroke survivors and their whānau. These comments have been included as a closing section to this segment, offering readers the opportunity to reflect on the voices and experiences shared throughout the survey findings. The comments highlight a range of emotions, perspectives, and priorities, allowing readers to draw their own conclusions and identify the themes and insights most relevant to their reading and understanding.

> *"My dad had Alzheimer's and it took some time to hear from drs he had gout. Even though he had a large lump on the top of his foot and he was getting pain behind his knee. We were not told about precautionary measures. He was eventually prescribed allopurinol. About 5 years ago I also got gout, unexpectedly, in the joint of my big toe. I wasn't able to walk for about a week. I restricted what I ate and took the alternative meds I'd bought for my dad. I've had one short 'bout since. I associate it with having a buildup of tomato-based meals & fresh tomato in my diet. But I'm not overly sure that's what it is."* *55-64, wāhine Māori, gout consumer*

Appendix 6: Demographics of Stroke Participants

Stroke Survivors (self-completed) vs whānau completed

The majority of responses for the stroke section of the survey were completed by whānau members (n=21). The remainder were completed by stroke survivors (self-completed) reporting on their own previous experiences (n=9).

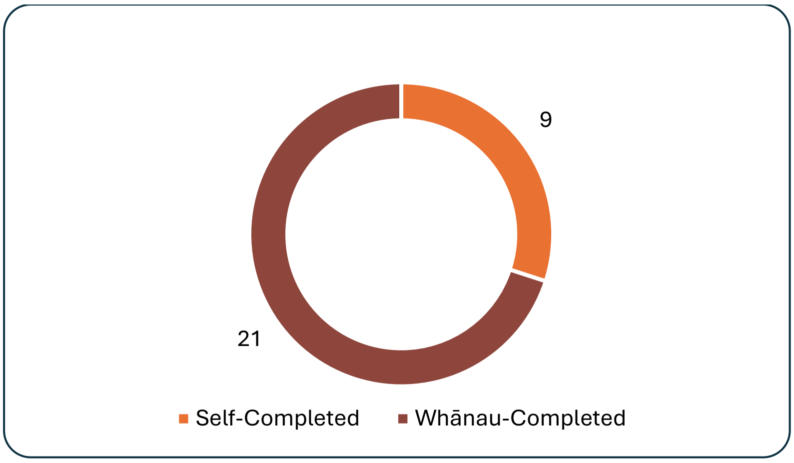


Figure 21. Demographics for stroke participants

Age Distribution

Participants were represented across all age groups, with the highest number of responses in the 45–54 and 55–64 age ranges. Fewer responses related to younger age groups, while older age groups were also represented in smaller numbers. Overall, the survey primarily reflects experiences of people in mid-to-older adulthood but still captures experiences across the life course.

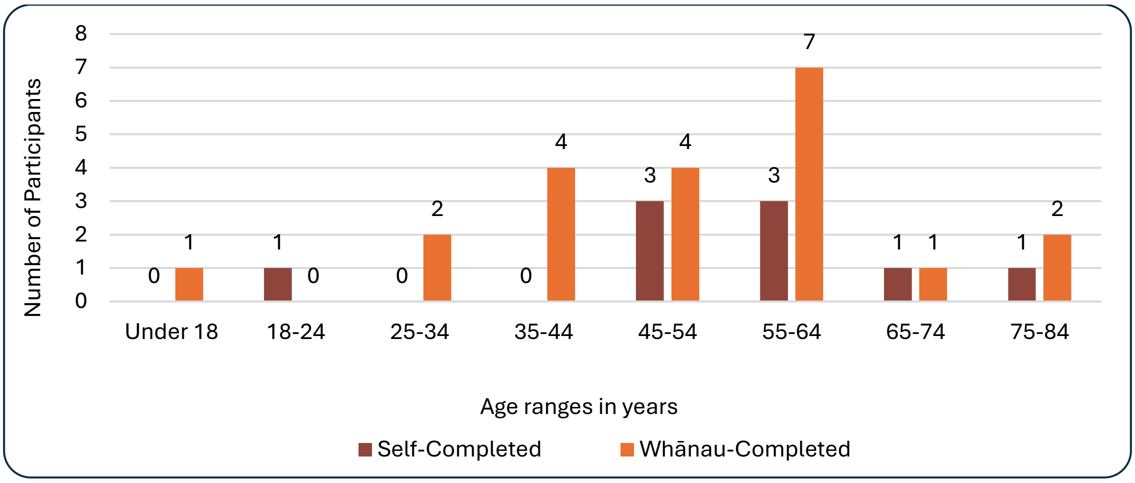


Figure 22. Age range of stroke participants

Gender Distribution

More experiences were reported for females than males, especially in whānau-completed surveys (female n=15 vs male n=4), compared with self-completed responses (female n=7 vs male n=4).

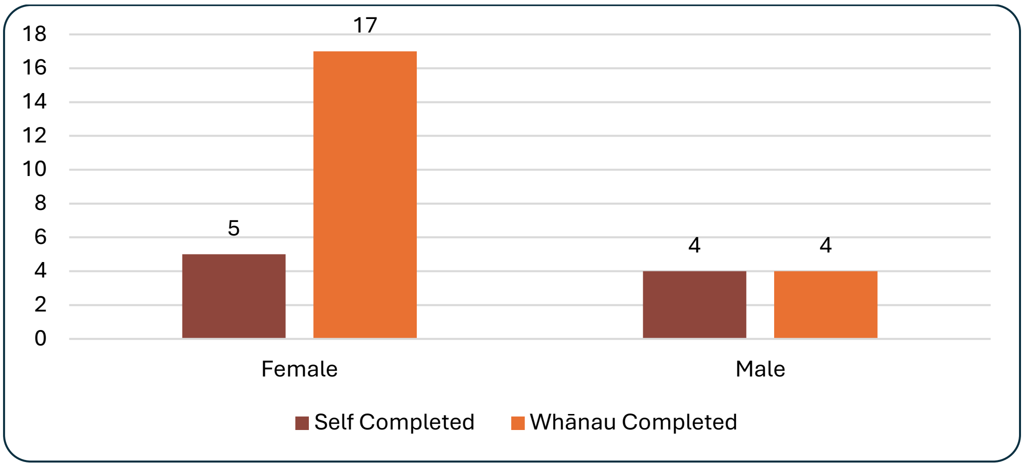


Figure 23. Gender distribution of stroke participants

Geographical Distribution

Participants were spread across all four whaitua, with the highest numbers from Pōrirua (n=10), followed by Kāpiti and Te Awa Kairangi (n=7 each) and Pōneke (n=6).

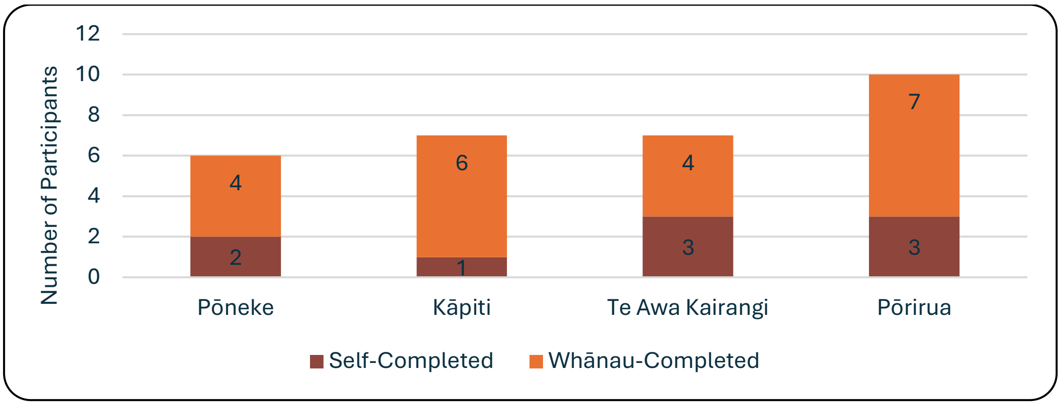


Figure 24. Location of participants by whaitua

Ethnicity of participants

Most participants identified as Māori (self-completed n=6; whānau n=13), with only small numbers reporting other ethnicities.

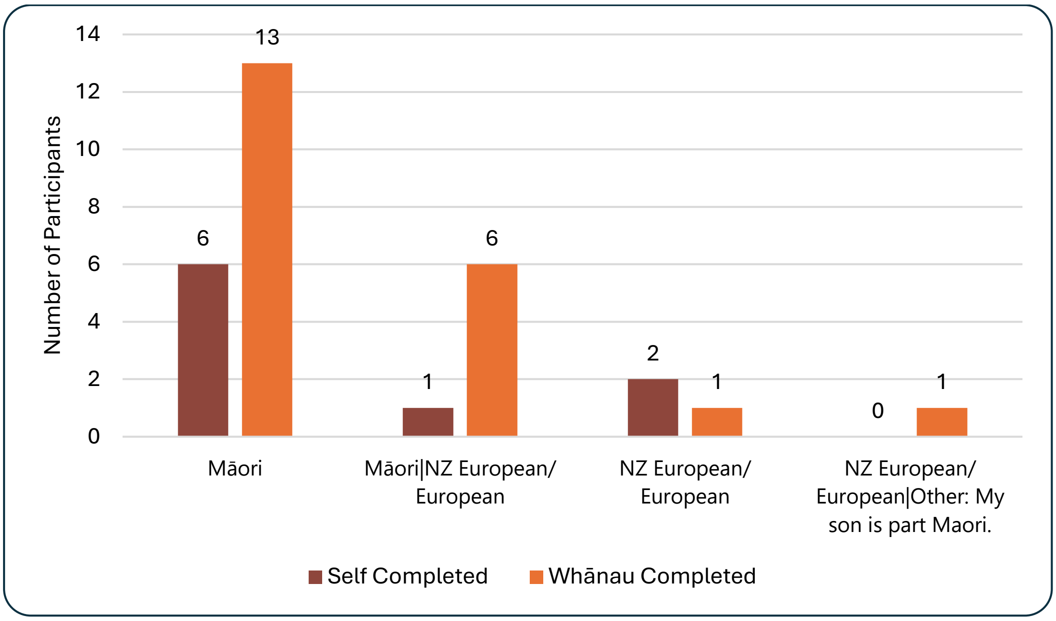


Figure 25. Stroke whānau and individual participants' reported ethnicities

Iwi affiliations

Ngāti Toa (n=14) and Ngāti Porou (n=11) were the most common iwi affiliations, followed by Ngāti Raukawa (n=7) and Te Āti Awa (n=6). Overall, participants reflected a diverse range of iwi affiliations, spanning both local and wider rohe connections.

Iwi Affiliation	No. of Participants
Ngāti Toa	14
Ngāti Porou	11
Ngāti Raukawa	7
Te Āti Awa	6
Kai Tahu	4
Ngāti Raukawa	3
Ngāti Ruanui	3
Kahungunu ki Wairarapa	2
Rangitāne	2
Ngapuhi	2
Ngāti Kahungunu	2
Ngāti Whāitua ki Ōrakei	2
Ngāti Awa ki Whakarongotai	2
ART Confederation	1
Te Arawa	1
Ngāti Rongomai	1

Kahungunu ki Wairoa	1
Ngāti Ruanui	1
Nga Ruahine	1
Ngāti Awa	1
Rauru	1
Tainui	1
Muaūpoko	1
Waikato Maniapoto	1

Figure 26. Stroke whānau and individual participants' reported iwi affiliations

How did you hear about this survey?

Most participants heard about the survey through social media (whānau n=15; self-completed n=5), with far fewer through email (n=6 total), posters (n=2), or word of mouth (n=4). Overall, social media was the dominant reach channel, with minimal engagement from other sources and one self-completed response providing no answer.

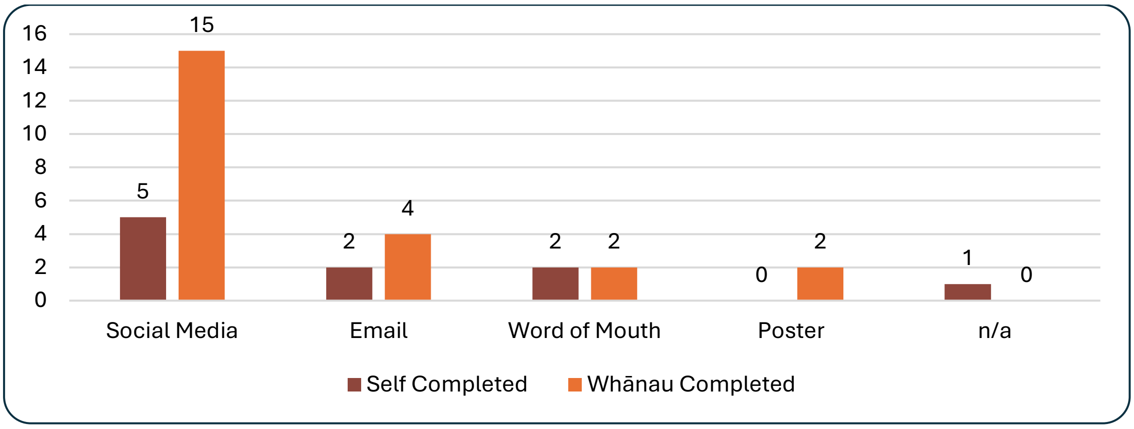


Figure 27. Communication channels/ways participants heard about the survey

Follow-up kōrero and overall results

Participants had mixed views on follow-up engagement, with whānau participants more likely to want both results and further kōrero (n=12 vs n=9). Among self-completing participants, most wanted to receive results (n=7 vs n=2), while interest in follow-up kōrero was more evenly split (n=5 vs n=4).

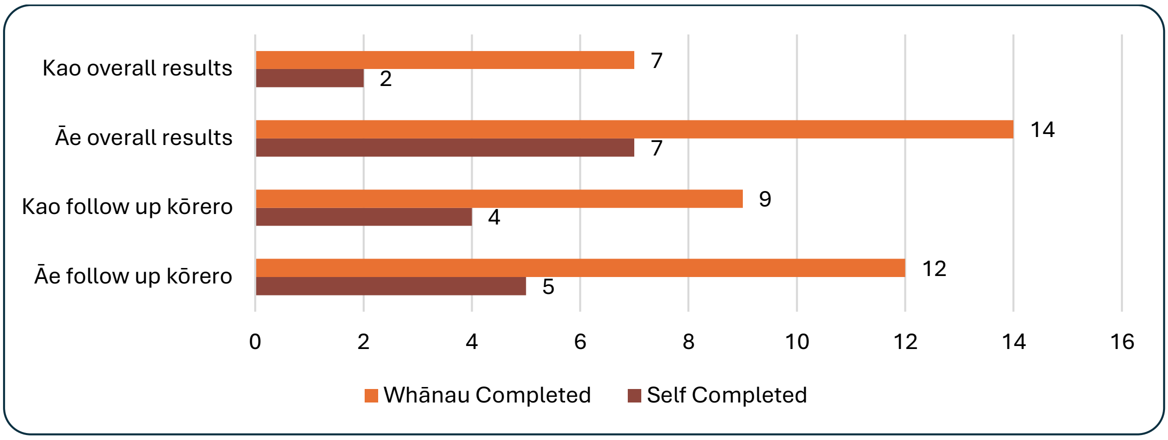


Figure 28. Participant interest in having a follow up kōrero and receiving survey results

Appendix 7: Demographics of Gout Participants

Gout consumers (self-completed) vs whānau completed

Most gout survey responses came from gout consumers and those with lived experience of both gout and stroke (n=20), with a smaller number from whānau members (n=8).

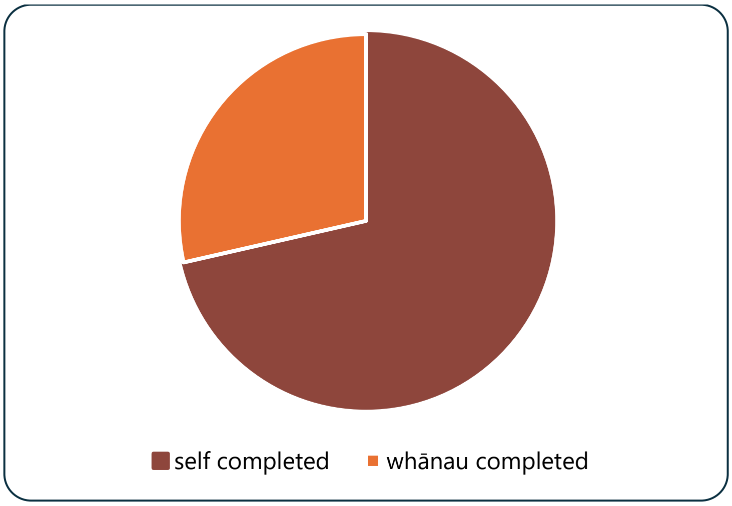


Figure 29. Type of participants who completed the gout component of the survey

Age distribution

Participants spanned across age groups with those experiencing gout mainly aged 45-74 and whānau completed surveys mostly aged 25-44.

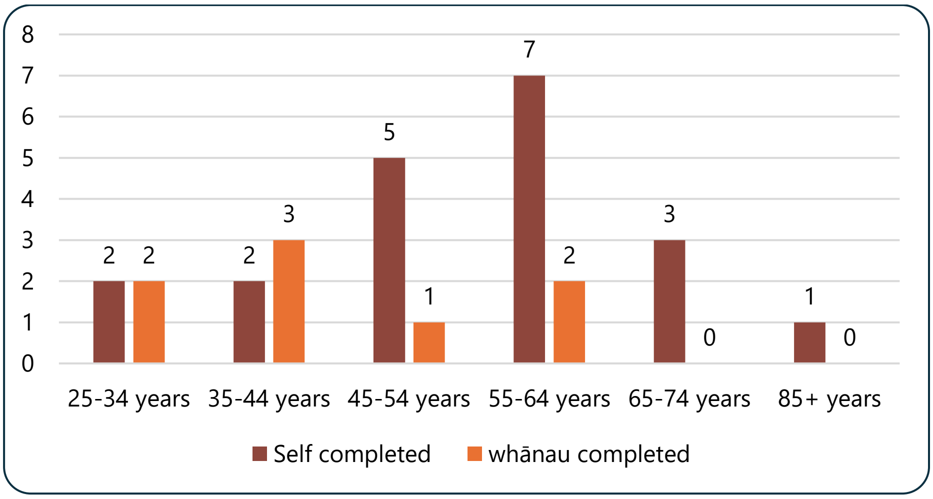


Figure 30. Age range of gout participants

Gender distribution

Most gout consumers were males (n=13 vs n=7), while most whānau-completed survey participants were females (n=6 vs n=2). Overall, this reflects the higher prevalence of gout among men, with whānau responses adding a different gender perspective. However surprisingly some 1/3 of gout consumers were female which brings a unique lived experience point of view.

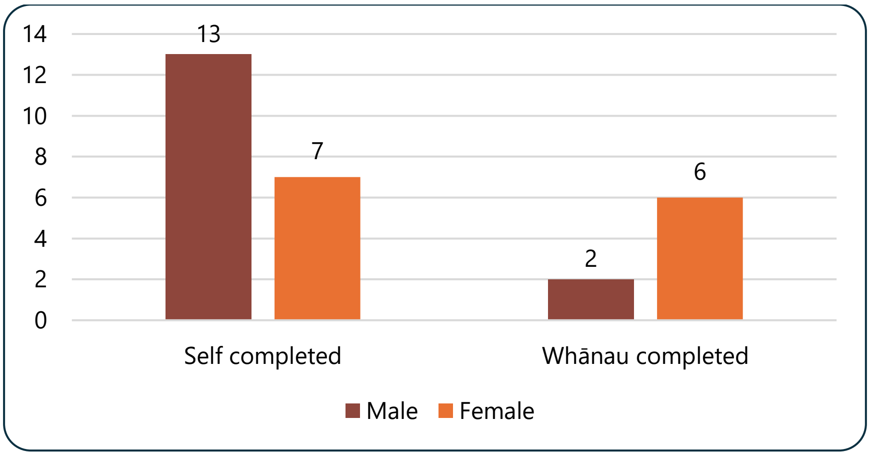


Figure 31. Gender distribution of gout survey participants

Geographical distribution

Participants were spread across all four whaitua, with the highest numbers from Pōneke (n=10), followed by Te Awa Kairangi (n=6) and Kāpiti (n=3).

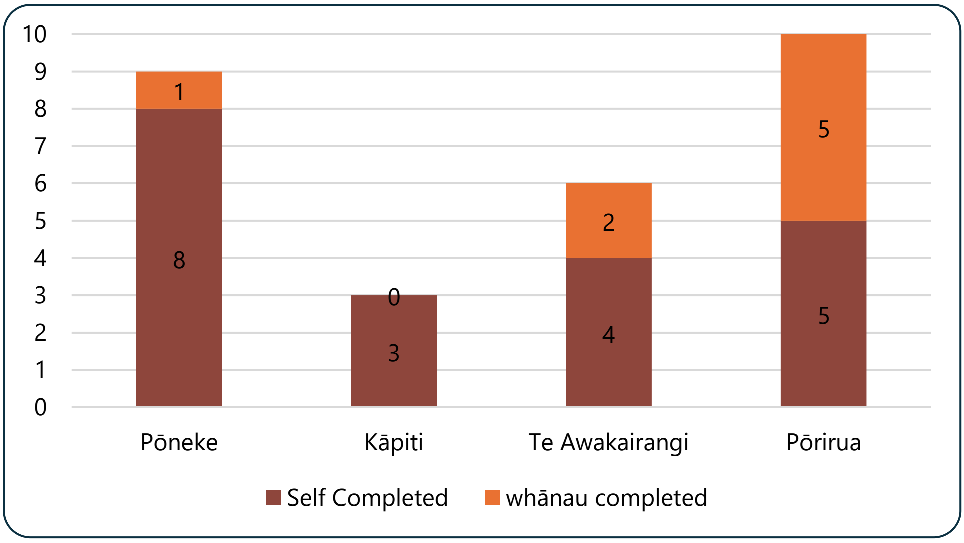


Figure 32. Location of gout participants by whaitua

Ethnicity of participants

Most participants identified as Māori only (self-completed n=9; whānau n=6), with smaller numbers reporting other ethnicities.

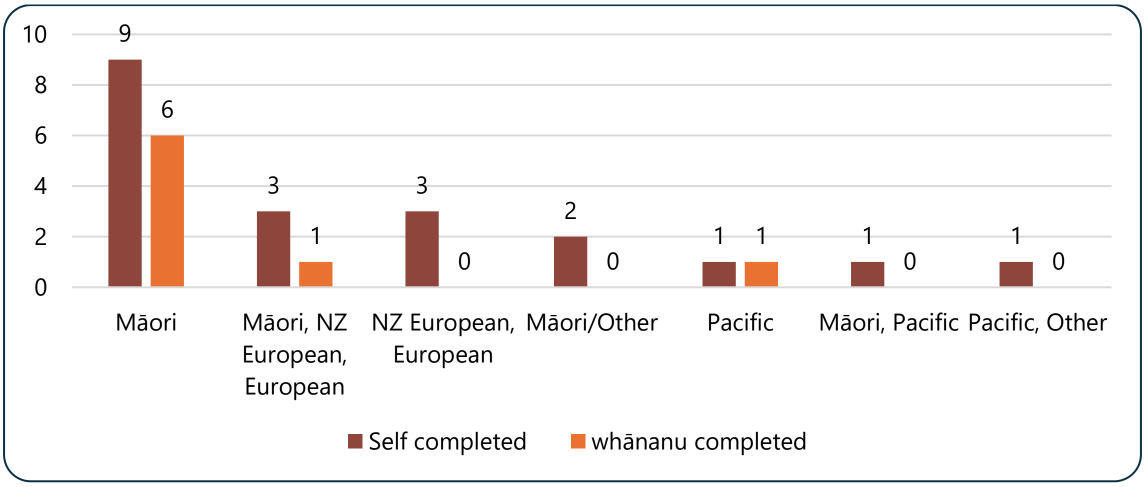


Figure 33. Gout participants' reported ethnicities

Iwi affiliations

Ngāti Toa (n=6), Ngāti Porou (n=5), and Ngāti Koata (n=4) were the most common iwi affiliations, followed by smaller numbers across several other iwi. Overall, participants reflected a diverse range of iwi affiliations.

Iwi Affiliation	No. of Participants
Ngāti Toa	6
Ngāti Porou	5
Ngāti Koata	4
Ngāti Raukawa	3
Te Āti Awa	3
Te Arawa	3
Ngāti Kahungunu	2
Waikato Maniapoto	2
Ngāi Tahu	2
Ngāi Tūhoe	2
Kahungunu ki Wairarapa	1
Rangitāne	1
Ngapuhi	1
Ngāti Awa	1
Tainui	1
Ngāti Ranginui	1
Ngāti Ruahinerangi	1
Ngāti Whatua	1
Ngāti Wāhiao	1
Ngāti Whakaue	1
Ngāti Huia	1
Ngāti Hori	1
Ngāti Kuia	1

Ngāti Apa Kite Rā Tō	1
Ngāti Tū Wharetoa	1
Rangitāne ki Wairau	1
Taranaki	1

Figure 34. Gout survey participants' iwi affiliations

How did you hear about this survey?

Most participants heard about the survey through social media (self n=15; whānau n=5), with far fewer through email, posters, or word of mouth. A small number selected "other" (see comments below) or did not specify, highlighting social media as the dominant channel for reaching both participants and whānau.

> *"Tū Ora Compass health shared it on their socials" 35-44 tāne Pacific, whānau member*
>
> *"My boss sent it to me" 55-64 tāne, Pacific, gout consumer*

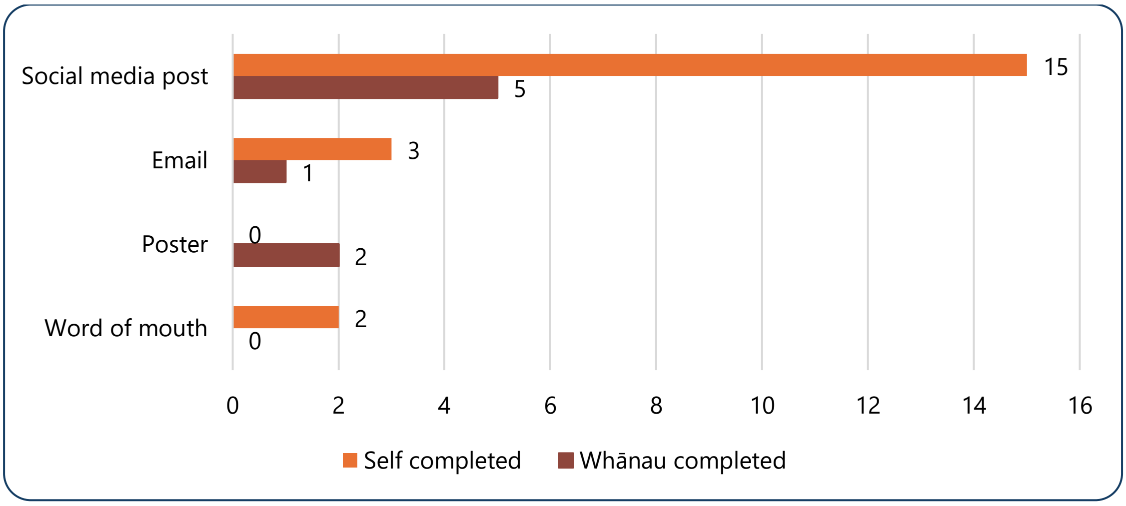


Figure 35. Communication channels/ways participants heard about the survey

Follow-up kōrero and overall results

Most participants were interested in follow-up kōrero (self n=12; whānau n=5) and in receiving the survey results (self n=15; whānau n=6).

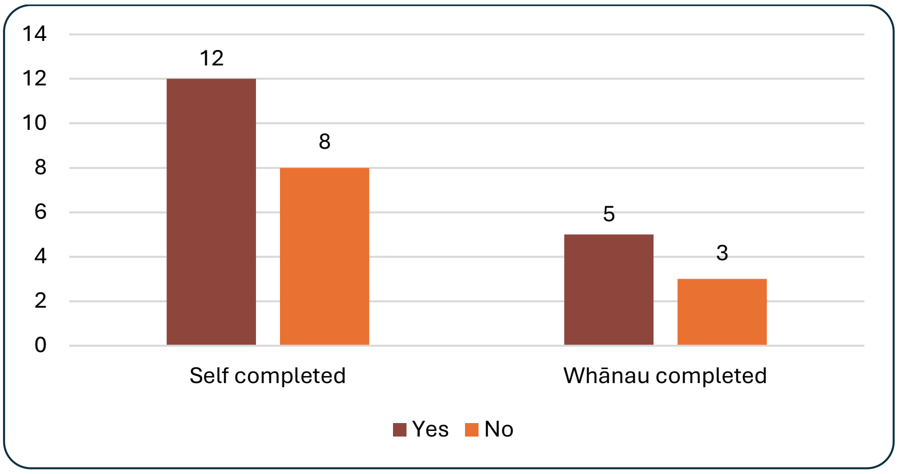


Figure 36. Participants' interest in having a follow up kōrero

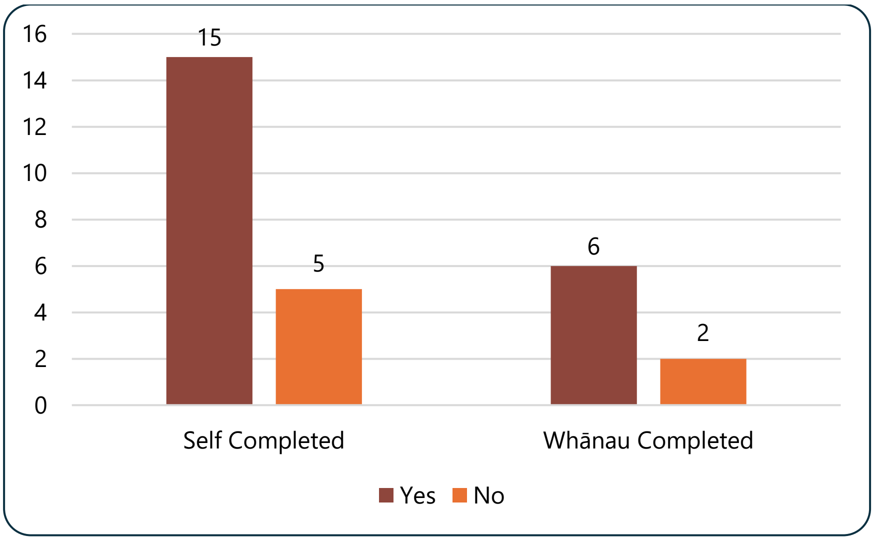


Figure 37. Participants' interest in receiving the survey results

Appendix 8: Survey Methodologies

Target audience and data collection

The survey was designed to capture the experiences of whānau Māori living within the Wellington rohe (Pōneke, Porirua, Kāpiti, and Te Awakairangi) who had either personally experienced stroke and/or gout, or were supporting a whānau member with these conditions. Participants completed the survey either as individuals with lived experience (self-completed) or as whānau members responding on behalf of someone in their care. A detailed breakdown of participant numbers and proportions, including self-completed and whānau responses, is provided at the beginning of the appendix under "Stroke participants" and "Gout participants."

The survey was administered online only and supported through a targeted distribution approach. Promotional materials, including posters and QR codes linking directly to the survey, were physically distributed across local health clinics, GP practices, Māori health providers, community hubs, and marae throughout the region. The survey was also promoted through newsletters, iwi pānui, social media platforms, and communications shared by the three partner organisations (Āti Awa Toa Hauora Partnership Board, Stroke Aotearoa, and Arthritis New Zealand).

This approach was intended to maximise reach within the priority population while ensuring that whānau could access the survey in trusted and familiar environments.

Survey design

The survey was designed to capture both quantitative and qualitative insights into the experiences of whānau Māori affected by stroke and/or gout. It included a mix of question types, such as multiple-choice, scaled (e.g. Likert-style) questions, and open-ended responses, allowing participants to both select structured responses and share their experiences in their own words.

The questionnaire was intentionally kept concise and accessible, taking approximately 5–10 minutes to complete, to reduce participant burden and support higher completion rates. Questions were framed using a whānau-centred approach, recognising the collective nature of experiences with stroke and gout, and enabling participants to respond either from their own lived experience or on behalf of a whānau member.

The survey was developed collaboratively across the partner organisations (Āti Awa Toa Hauora Partnership Board, Stroke Aotearoa, and Arthritis New Zealand) to ensure alignment with kaupapa Māori principles and relevance to community priorities. The full survey questionnaire is provided in the appendix: Survey administered to participants.

Survey timing and duration

The survey was open for a six-week period, launching on Friday 16 January and closing on Friday 27 February. The questionnaire was designed to be brief and accessible, taking approximately 5–10 minutes to complete, to reduce participant burden while still capturing meaningful insights.

Survey incentives

To support engagement and acknowledge participants' time and contributions, an incentive approach was used. Participants were offered entry into weekly prize draws for grocery vouchers valued at $50, as well as a grand prize of a $400 prezzy card voucher drawn at the close of the survey period. Participants could win a weekly prize once but remained eligible for the grand prize. This structure also encouraged early participation, as those who completed the survey earlier had more opportunities to be included in multiple weekly draws. Entry into the prize draw was optional and required participants to provide contact details, which were stored separately from survey responses to maintain confidentiality.

Prize draw process

Winners for both the weekly and grand prize draws were selected using a random name selector (https://wheelofnames.com/) from the pool of eligible participants who opted into the prize draw. This approach ensured a fair and unbiased selection process. Participants who had already won a weekly prize were excluded from subsequent weekly draws but remained eligible for the final grand prize draw, in line with the stated prize conditions.

Formstack

The survey was administered using Formstack, a secure online survey platform that enabled efficient data collection and management. Formstack supported the use of a range of question types, mobile-friendly access, and the integration of survey links and QR codes for ease of distribution across different settings.

The platform also allowed for the collection of optional participant contact information for prize draw entry, with contact details captured separately from survey responses to maintain confidentiality. Access to the survey data was restricted to authorised personnel, ensuring appropriate handling and storage of participant information.

Appendix 9: Quantitative Analysis

Quantitative responses were analysed manually by the research team using Microsoft Excel. Data were cleaned and organised prior to analysis, and a counting method was then applied, in which responses were systematically tallied to provide an overview of patterns within the dataset and to support interpretation. The dataset was reviewed multiple times to ensure accuracy and consistency in data cleaning and counts, and to identify meaningful trends across different participant groups.

Reporting time of stroke amongst participants

Responses to "When did you or your whānau member experience a stroke?" were entered as free text, so answers varied (e.g., exact dates, years, or phrases like "2 years ago"). To standardise these into a graph, responses were grouped into time-since-stroke categories:

- n/a = invalid or non-time answer (e.g., "At home")
- recent = within the last 12 months
- Mid-term = 1–5 years
- Long-term = 6–10 years
- over 10+ years = more than 10 years ago

Where an answer could not be interpreted precisely (for example, where only a partial timeframe was given, or where multiple years/events were mentioned), the response was coded into the lesser (more recent) time period to avoid overstating how long ago the stroke occurred.

Responses that did not describe *when* the stroke happened (e.g., "at home") were coded as n/a because they cannot be converted into a time-since-stroke estimate.

Reporting on iwi affiliations

Reporting on iwi affiliation in this report follows the 2023 Census approach to iwi affiliation reporting. Participants were able to report more than one iwi affiliation, meaning individuals may be counted under multiple iwi. As a result, the figures presented reflect the frequency with which iwi were identified, rather than the number or proportion of unique participants affiliated with each iwi.

Appendix 10: Qualitative Analysis

Reflexive thematic analysis

The qualitative analysis section of this report uses a reflexive thematic analysis approach to identify patterns across stroke survivor, gout consumer and whānau responses. Data were first familiarised with, then systematically coded, and codes were grouped into emerging themes through iterative refinement. It should be noted that, in some sections, reflexive thematic analysis was shaped by an uneven dataset, meaning that, in some cases, only one quote was available to support a theme. In this case, themes were constructed using a balanced interpretive approach that prioritised meaning over frequency while ensuring participant voices were not overgeneralised or overstated. For example, in the stroke survey section “barriers to living well with stroke”, there were limited survivor responses (9 in total, including 3 nil responses and 2 non-substantive positive responses).

Rapid thematic analysis

Open-ended responses were also analysed using a rapid thematic approach to identify recurring issues and priorities described by participants. Analysis was conducted question-by-question to remain close to the wording and intent of each prompt. Themes were summarised in plain language and supported by de-identified quotes, with limited contextual descriptors (e.g., age group, respondent type) to aid interpretation while protecting privacy.

Microsoft Copilot analysis

Microsoft Copilot was used as a supportive tool to assist in structuring qualitative data, suggesting initial themes, and highlighting recurring patterns. Its use was limited to early-stage sense-making, and all outputs were carefully reviewed, validated, and refined by the researcher. Final theme construction and interpretation were conducted using a reflexive thematic analysis approach to ensure that the findings accurately reflected participants' experiences and were not over-reliant on automated processes.

Quotes

Participant quotes were included in full to preserve meaning. Minor grammatical errors were corrected where necessary to improve readability, and any words added by the researcher for clarity were clearly indicated using square brackets (e.g., [for]).

Appendix 11: Data Security and Protection

Ethics and privacy

Personal identifiers collected for follow-up purposes (e.g., name, email, and mobile number) were not accessed or used in the analysis or reporting of findings. All data used for analysis were de-identified prior to review. Findings are reported in aggregate form to ensure individual participants cannot be identified, and all qualitative quotes have been carefully de-identified to protect anonymity.

Data confidentiality and storage

All data were stored securely in encrypted protected systems accessible only to the research team. Any hard copy materials of identifiable information were kept in secure storage in accordance with organisational data management policies. Data handling procedures followed standard confidentiality requirements to ensure participant information was protected throughout the research process.

Informed consent

Participation in the survey was voluntary, and informed consent was obtained prior to participation. Participants were advised of the purpose of the research, how their data would be used, and their right to withdraw at any stage prior to data submission.

Anonymisation of qualitative data

To ensure anonymity, all qualitative responses were reviewed and de-identified prior to analysis and reporting. Any potentially identifying information within free-text responses was removed or generalised before inclusion in the final report.

Use of data in reporting

Only aggregated findings are presented in this report. Individual responses are not identifiable in any outputs, and care has been taken to ensure that quotes cannot be attributed to specific individuals or whānau.

Appendix 12: Glossary

Māori terms

Term	Definition
Aotearoa	The Māori name for New Zealand.
Iwi	Tribe or extended Māori kinship group.
Kaupapa Māori	A Māori approach grounded in Māori values, principles, and ways of working.
Rohe	A defined geographical area (in this report: Wellington region).
Whaitua	Sub-regions within a rohe (e.g., Pōneke, Porirua, Kāpiti, Te Awa Kairangi).
Whānau	Extended family group; central to wellbeing, care, and decision-making.
Whānau-centred care	A model of care that actively involves whānau in assessment, planning, and support.

English terms

Term	Definition
Chronic (long-term) condition	A health condition that lasts over time and requires ongoing management.
Comorbidities	Other health conditions occurring alongside a primary condition.
Culturally safe care	Care that respects and responds to a person's cultural identity, values, and needs.
Gout	A long-term form of arthritis caused by high uric acid levels, leading to painful joint flares.
Gout flare	A sudden episode of joint pain and inflammation caused by uric acid crystal build-up.
Health literacy	The ability to understand health information and make informed decisions about care.
Primary care	First-contact healthcare services (e.g., GP, nurse, community provider).
Stroke	A condition where blood flow to the brain is interrupted, causing brain injury or disability.
TIA (Transient Ischaemic Attack)	A short-term stroke-like event where symptoms resolve within 24 hours.

Appendix 13: Abbreviations

Term	Definition
AF	Atrial Fibrillation (irregular heartbeat linked to stroke risk)
NSAID	Non-steroidal anti-inflammatory drug
TIA	Transient ischaemic attack
ULT	Urate-lowering therapy
GP	General Practitioner
HQSC	Health Quality & Safety Commission
NZ	New Zealand

Appendix 14: Survey

Have you or a close whānau member experienced **stroke**, **gout** or **both conditions**? Do you live in the **Wellington rohe (Pōneke/Porirua/Kāpiti/Te Awakairangi)?** Are you of **Māori** descent? Then we want to hear from you!!!

Āti Awa Toa Iwi Māori Partnership Board has partnered with Stroke Aotearoa and Arthritis NZ to better understand how stroke and gout affect whānau and what services and support would help. Stroke and gout are two preventable long-term conditions (chronic illnesses) that disproportionality affect Māori in our rohe. With this research we want to understand early prevention, care and management, quality of life pre and post diagnosis and what support whānau require; we also want to learn more about your experiences so we can help advocate for policies and services that reflect your voices and needs.

We invite you to share your and/or your whānau member's experience of stroke and/or gout. Importantly, the answers you provide will be anonymous to protect your privacy – they will not be linked back to you and won't affect the healthcare you receive in any way.

We will share the overall results of this survey with you. We will also use the results to inform our ongoing work, including our advocacy for improved services and our communications with whānau and the wider health sector.

The survey will run for **six weeks, and we ask that you complete it only once.** We estimate that it will take around **10 minutes to complete**. By completing this survey, you will automatically go in the draw to win one of our weekly prizes. Whānau who complete both the stroke and gout survey will be given two entries. All completed surveys will also go into the draw to win our grand prize announced at the end of the survey period.

Screening Questions

Who are you completing this survey for?

- ☐ Myself, as someone who has had a stroke
- ☐ As someone who has a whanau member who has had a stroke
- ☐ Myself, as someone who has gout
- ☐ As someone who has a whanau member who has gout
- ☐ Myself, as someone who has had both stroke and has gout
- ☐ As someone who has a whanau member who has had both a stroke and has gout

Do you live in the Wellington rohe (Pōneke/Porirua/Kāpiti/Te Awakairangi)?

- ☐ Yes
- ☐ No

Logic
If you selected, [No], you may continue the survey but will not be eligible for the prize draw. Thank you for your time and consideration, we apologise for the inconvenience, however we are only looking to hear from whanau who live in the Wellington rohe. Please continue to browse our websites for more information about what we do.

What Rohe do you live in?

- ☐ Pōneke
- ☐ Porirua
- ☐ Kāpiti
- ☐ Te Awakairangi

Tell us about yourself! No hea koe?

Which age group are you? [Dropdown box]

- ☐ Under 18 years of age
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75-84
- ☐ 85 years or older
- ☐ Prefer not to say

What is your gender?

- ☐ Male
- ☐ Female
- ☐ Non-binary
- ☐ Prefer not to say

What is your ethnicity?

- ☐ Māori
- ☐ NZ European/ European
- ☐ Pacific
- ☐ Asian
- ☐ Other:

Logic: What are your iwi and hapu affiliations? [open textbox]
What suburb in Wellington do you live in? [open textbox]

Stroke Survey

When did you or your whanau member experience a stroke? [open textbox]

Which of the following best describes your health status or that of your whanau member?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Prefer not to say

How many strokes (including Transient Ischaemic Attacks) have you or your whanau member experienced that you are aware of?
[Dropdown box: 1-10+]

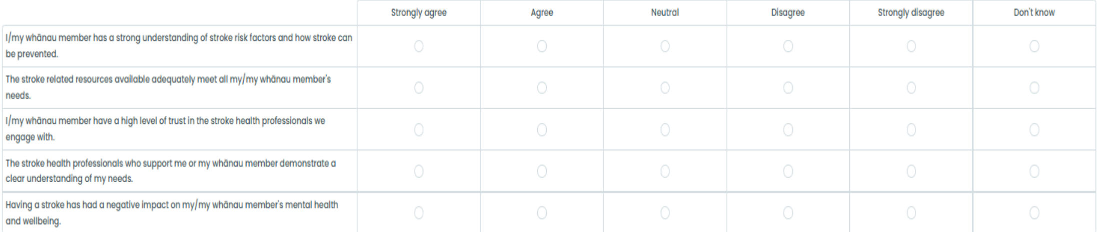
Which of the following best describes your or your whanau member's ability to exercise?

- ☐ Can exercise without difficulty
- ☐ Can exercise with minor adjustments
- ☐ Can exercise with some effort
- ☐ Exercise is difficult
- ☐ Cannot exercise
- ☐ Prefer not to say

Which of the following best describes you or your whanau awareness of support services/ resources for stroke?

- ☐ Extremely aware
- ☐ Very aware
- ☐ Somewhat aware
- ☐ Slightly aware
- ☐ Not at all aware
- ☐ Prefer not to say

Please rate your level of agreement with each of the follow statements:



	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
I/my whānau member has a strong understanding of stroke risk factors and how stroke can be prevented.	○	○	○	○	○	○
The stroke related resources available adequately meet all my/my whānau member's needs.	○	○	○	○	○	○
I/my whānau member have a high level of trust in the stroke health professionals we engage with.	○	○	○	○	○	○
The stroke health professionals who support me or my whānau member demonstrate a clear understanding of my needs.	○	○	○	○	○	○
Having a stroke has had a negative impact on my/my whānau member's mental health and wellbeing.	○	○	○	○	○	○

What kind of things do you or your whanau member do to prevent stroke from happening again? [Open textbox]

What gets in the way of you and your whanau living well with stroke? [Open textbox]

What is an example of great care you and your whanau received during your stroke journey? [Open textbox]

What is an example of something that didn't go so well? [Open textbox]

What other services and supports would help you and your whanau to live well after stroke? [Open textbox]

Did your GP/ pharmacist explain stroke and the plan to prevent future episodes in a way that made sense for you and your whanau?

- ☐ Yes, completely
- ☐ Yes, mostly
- ☐ Somewhat
- ☐ Not really
- ☐ No
- ☐ Not applicable

Logic: In regard to the previous question, what would have helped you/ them to understand better?

- ☐ Nothing, I thought it would not happen to me
- ☐ Simple and clearer words
- ☐ More time
- ☐ Culturally appropriate communication
- ☐ Visual information
- ☐ Follow-up support
- ☐ Other:_________ [open textbox]

How well do you think you and your whanau understand the connection between stroke and other long-term health conditions such as heart disease, diabetes and gout?

- ☐ Very well
- ☐ Somewhat
- ☐ Not very well
- ☐ Not at all

Gout Survey

When did you or your whanau member experience gout? [open textbox]

How many times have you or your whanau member experienced a gout flare up that you are aware of?

[Dropdown box: 1-10+]

Which of the following best describes your health status or your whanau member?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Prefer not to say

Which of the following best describes your or your whanau's ability to exercise?

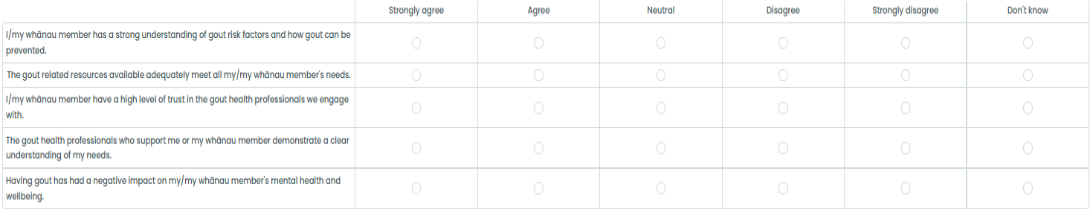
- ☐ Can exercise without difficulty
- ☐ Can exercise with minor adjustments
- ☐ Can exercise with some effort
- ☐ Exercise is difficult
- ☐ Cannot exercise

- ☐ Prefer not to say

Which of the following best describes you and your whanau awareness of support services/resources for gout?

- ☐ Extremely aware
- ☐ Very aware
- ☐ Somewhat aware
- ☐ Slightly aware
- ☐ Not at all aware
- ☐ Prefer not to say

Please rate your level of agreement with each of the following statements:



	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
I/my whānau member has a strong understanding of gout risk factors and how gout can be prevented.	○	○	○	○	○	○
The gout related resources available adequately meet all my/my whānau member's needs.	○	○	○	○	○	○
I/my whānau member have a high level of trust in the gout health professionals we engage with.	○	○	○	○	○	○
The gout health professionals who support me or my whānau member demonstrate a clear understanding of my needs.	○	○	○	○	○	○
Having gout has had a negative impact on my/my whānau member's mental health and wellbeing.	○	○	○	○	○	○

What kind of things do you or your whanau member do to prevent gout from happening? [open textbox]

What gets in the way of you and your whanau living well with gout? [open textbox]

What is an example of great care you and your whanau received to help manage your gout? [open textbox]

What other services and supports would help you and your whanau to live well with gout? [open textbox]

Did your doctor or health professional explain gout and the plan to prevent future attacks in a way that made sense for you and your whanau?

- ☐ Yes, completely
- ☐ Yes, mostly
- ☐ Somewhat
- ☐ Not really
- ☐ No
- ☐ Not applicable

In regard to the previous question, what would have helped you/ them to understand better?

- ☐ Nothing, I thought it would not happen to me
- ☐ Simple and clearer words
- ☐ More time
- ☐ Culturally appropriate communication
- ☐ Visual information
- ☐ Follow-up support
- ☐ Other:_________ [open textbox]

Logic: How well do you think you and your whanau understand the connection between gout and other long-term health conditions such as heart disease, diabetes and stroke?

- ☐ Very well
- ☐ Somewhat
- ☐ Not very well
- ☐ Not at all

Final Questions

Is there anything else you'd like to share with us? [open textbox]

How did you hear about this survey?

- ☐ Social media post
- ☐ Email
- ☐ Word-of-mouth
- ☐ Poster
- ☐ Other:______[open textbox]

We're keen to know more from people who complete our survey. Would you be interested in a follow-up korero about your or your whanau member's experience of stroke and/or gout?

- ☐ Yes
- ☐ No

Would you like to receive the overall survey results when they are available?

- ☐ Yes
- ☐ No

To enter the draw for our giveaways, please provide your name, email and mobile number below (this is not mandatory but is required to enter our draws).

First Name:______________________________
Last Name:______________________________
Email:__________________________________
Mobile number:_________________________

Our organisations would like to stay connected. Please select which organisations you would like to receive communications from. You can opt out at any time.

- ☐ Ati Awa Toa lwi Māori Partnership Board
- ☐ Stroke Aotearoa New Zealand (stroke)
- ☐ Arthritis New Zealand (gout)
- ☐ None

Submission Message

E mihi ana ki a koe, ki te whaipānga o to whakaaro ki tēnei kaupapa! Kei te whakahira tō kōrero ki a mātou!

We acknowledge you and your valuable insight in this project! Your voice is important to us!

After completing this survey, you will go into the draw to win one of our weekly giveaway prizes and our grand prize drawn at the end of the survey period. We will contact all winners!

Mihi nui!

ĀTI AWA
TOA HAUORA
PARTNERSHIP BOARD

Stroke
Aotearoa NZ

Arthritis NZ
Mateponapona
Aotearoa