



Arthritis NZ
Mateponapona
Aotearoa

Submission to the Health Select Committee by Arthritis NZ

14 May 2025

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Executive Summary and Recommendations

This submission summarises the current situation of the treatment and management of gout arthritis (gout) and suggests that nothing had changed since 2019 when Arthritis NZ last presented to the Health Select Committee. We are making some of the same recommendations that we made then, but this time, we urge the committee to ensure that these recommendations are both actioned and reported back to the Select Committee.

We suggest that gout is one of the most poorly understood and managed long-term conditions in this country, but evidence shows that it can be well managed with the right programmes in place. We estimate that 250,000 people now suffer from gout and NZ is known as the “gout capital” of the world.

Gout is caused by a buildup of uric acid and good management programmes include the prescription of uric acid lowering medication.

This medication is not expensive. Allopurinol, the medication usually prescribed to lower uric acid, is low-cost but the data available suggests that only 43% of people with gout are on a managed medication programme. This means that approximately 135,000 are **not** getting the medication they require.

Arthritis NZ has successfully submitted to Medsafe that allopurinol should be reclassified to enable ease of access for consumers once their GP has prescribed it. This submission was supported by 17 agencies and health professionals, showing widespread industry support for this change. This has opened opportunities within the community to successfully improve the management of gout.

Arthritis NZ has also researched the effectiveness of our education programme conducted in Porirua. We believe this research shows potential for significantly improving the management of gout in affected communities.

Our recommendations are

We recommend that the committee expresses strong support for:

- Health New Zealand viewing gout as a priority
- Setting and delivering the target of 55% of people with gout being on a managed programme by 2028. Health New Zealand to report annually to the committee progress against this target.
- Health New Zealand to build awareness about the causes and management of gout and build on the improved accessibility of allopurinol following its reclassification with funding for pharmacies to undertake added responsibilities.

1. Background

Gout is arguably one of the worst-managed chronic conditions in New Zealand.

It is popularly thought to be caused by food and drink, being hard to manage and primarily a result of poor lifestyle choices by the person with gout. None of these stereotypes are accurate.

Gout is a disease characterised by sudden attacks of severe pain and swelling in the joints.

- 1.1.** It is caused by a build-up of uric acid, which naturally leaves the body via urine. When someone's body is unable to break the acid down, it hardens into needle-shaped crystals that cause terrible pain and can lead to permanent joint and organ damage.
- 1.2.** Gout is a form of arthritis and in this country, it is the second most prevalent form of arthritis. Based on the Health Quality and Safety Commission (HQSC) Gout Atlas (1) we estimate 250,000 people re affected by gout. South Auckland has been called the gout capital of the world, so significantly is that population affected.
- 1.3.** It can be a sentinel event alerting clinicians to the likelihood of other chronic conditions such as diabetes, cardiovascular disease, kidney disease (2) and stroke. For example, research also shows a 30% increase in the risk of stroke for people with gout (3).
- 1.4** It is not uncommon for a person newly diagnosed with gout to be prescribed anti-inflammatory medication to reduce the pain and inflammation, but not be prescribed what are known as uric acid medicines -most commonly allopurinol (4)
- 1.5** Allopurinol is not an expensive medication.

Arthritis NZ is aware of members of parliament both former and current, who have gout. There is a strong social stigma attached to gout- primarily because it is seen as a condition caused by an unhealthy lifestyle. Some of the MPs we have talked to do not wish to publicise their gout because of this stigma.

Breaking Down the Stigma - Simon Bridges talks about his gout

Well-known public figure Simon Bridges discovered he had gout arthritis when he was a cabinet minister.

At first, he thought he'd simply sprained his ankle. *"I couldn't really walk, and it was getting worse and worse, and I thought, 'oh, if I just take some anti-inflams it would be okay'. It wasn't going away, so I went to the doctors, and I think we did some tests and it was gout arthritis."*

Bridges was aware he had a family history of gout arthritis but found the misconceptions about the disease difficult to deal with.



"I knew my dad had kind of had it a bit older than me ... And I knew on my Māori side, there was a bit of it... But I really thought of it from things I'd read about 17th century politicians, drinking sherry and stuff."

He'd make up excuses about his inability to walk, such as a sprained ankle from a jog, as it seemed credible as he had done a lot of running in the past. In the end, he realised it's nothing to be ashamed of.

"There's probably a stigma about these things, even though there shouldn't be, because so much of it is fundamentally genetic. You don't want to tell people."

Bridges believes that talking about gout arthritis is the best way to reduce misunderstandings around this condition.

"I found personally, losing some weight – famous last words – hopefully keeping off some weight, has been really good in terms of the symptoms and the flare-ups and so on. But there's no shame in obviously getting treatment, going on the pills and getting on with having some fun."

2 Current Gout Management in New Zealand

- 2.1** Arthritis NZ last presented to this committee in 2019 (Appendix 2) when we proposed setting a target of increasing the percentage of people on a managed gout programme from 43% to 55%. At the time this equated to an additional 23,123 individuals on such a programme.

Based on an estimated annual healthcare cost of \$10,000 p.a. for a person with gout (including direct, indirect, and wellbeing costs), the potential cost avoidance would have been approximately \$231 million if such targets had been set and achieved.

This target was not set or achieved so we are once again presenting to the committee about this condition.

- 2.2** We also showed in 2019 that gout is a serious health concern for Māori and Pacific communities. Overall, Māori have approximately twice the prevalence of gout (8.5% of the population) and Pacifica three times the prevalence (14.7% of the population) compared to non-Māori, non-Pacific populations (1).

These rates increase significantly for those over 65 with one in three Pacific people and one in four Māori having been diagnosed with gout arthritis (1).

Māori and Pacific peoples are also less likely to be on a managed programme (Table 1). This 2019 data is the most reliable available (1).

In 2021 and 2022 Pharmac published 2 reports on gout and its impact on Māori and Pacific (5; 6). They noted that an estimated 10,400 more Māori and 8,700 more Pacific peoples need to be prescribed uric acid lowering medication each year.

Table 1:Gout population and use of urate-lowering medicine

Ethnic Groups	Number with gout arthritis (2019)	Number who are regularly receiving medication (2019)	Percent
Māori	41,002	16,168	39.43%
Pacific	29,980	10,768	35.92%
Non-Māori / non-Pacific	137,121	60,220	43.92%
Total	208,103	87,156	42.30%

Source: (HQSC, 2019)

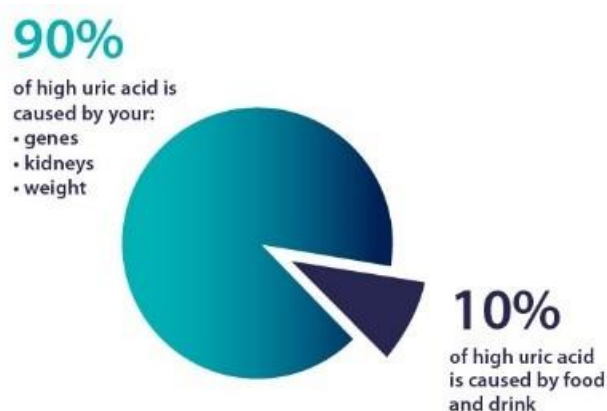
These concerning figures have not spurred improved management of gout in this country and no further reliable data since 2019¹ is available on a regional breakdown to show where gout is most prevalent.

Table 2: Prevalence of Gout by Health New Zealand region (2019)

Region	Count	Regional Rate	Percent of all gout
Northern	86,336	6.3%	41.4%
Te Manawa Taki	44,619	6.4%	21.4%
Central	38,355	5.4%	18.4%
Te Waipounamu	39,403	4.3%	18.9%
Aotearoa-New Zealand	208,713	5.7%	100.0

Source: (HQSC, 2019)

There are longstanding misconceptions that gout is self-inflicted and caused by behaviour such as drinking too much beer or wine or eating too much kai moana. However, research (7) shows that 90% of the factors in the build-up of uric acid that leads to gout are related to genetics, obesity, and kidney function. Food and drink consumption contribute only 10% to high uric acid in the body.



Misconceptions about the causes of gout can lead to a delays in accessing effective health care.

¹ Arthritis NZ understands HQSC gout figures are likely to be updated later in 2025

- 2.3** Arthritis NZ was encouraged to see that gout was included in the Pacific Health Strategy *Te Mana Ola* (8) which acknowledged that Pacific peoples needed high quality care and evidence-based management for chronic conditions such as gout.

However, we do not see evidence of significant action following these words. Gout is not mentioned in Māori or non-Māori or non-Pacific health strategies so there are not even any words to give hope of any gout specific action for Māori or non-Māori. Arthritis NZ submits that the time for reports has passed, and immediate action is needed.

Teariki Tuiono- my journey with gout



Teariki is a community leader, advocate, educator and publisher based in South Auckland. He talks about his gout journey.

"I didn't know much about gout until it affected me and probably thought the usual myths about it all being caused by food and drink were correct until I started having pain that turned out to be gout. The pain was very bad- it was a hideous journey that really affected quality of life.

I was fortunate to be working with several health professionals who are real movers and shakers. They opened my eyes, and I became a lot more informed. I learned a lot, and found the common stereotypes are dead wrong. I realised that we need to become much better informed about the causes of gout and how it can be successfully managed.

I also feel strongly that much more education and knowledge about gout is very important- I used to be blasé and think that there was nothing much that you could do about gout but now I am passionate about helping to educate people so they can get effective treatment and stop believing the myths.

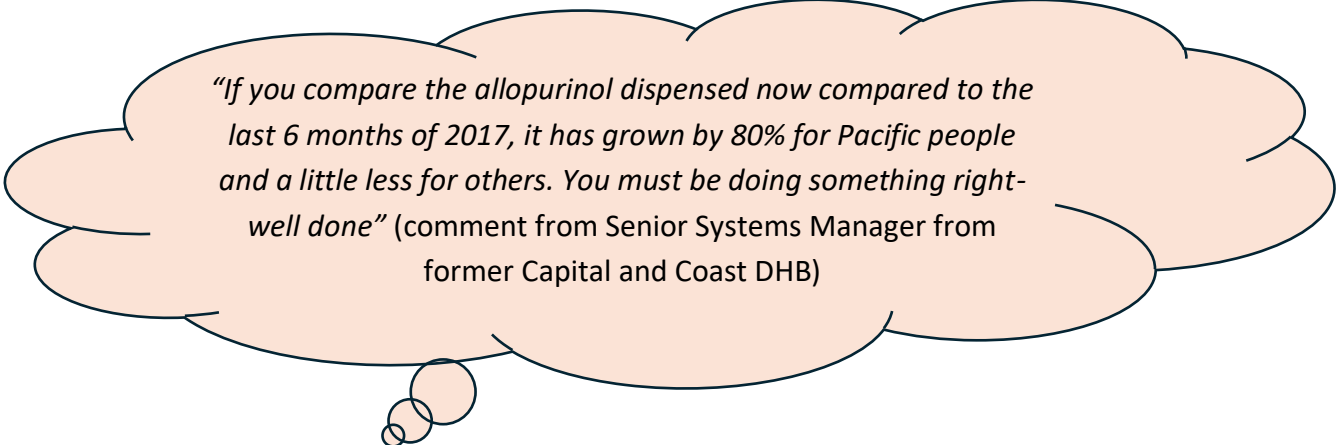
I also need to say that at times our medical system lets me down having to re-order a prescription every few months when I know that is needed for the rest of my life is time consuming and unnecessary. I was really pleased to learn that Arthritis NZ has proposed that allopurinol be made easier to access.

*I hope that Arthritis NZ keeps on pushing to **cut the red tape** so people with gout can easily access the medication that can transform their lives."*

Please make it easy for people with gout to get good information and treatment.

3 Building blocks for the future

- 3.1 Successful gout programmes have been initiated in Northland (Mahitahi Hauora's 'Gout Stop Programme'), Whanganui (Whanganui Regional Health Network's 'Gout Stop Programme') and Counties Manukau ('Owning My Gout'). While these show there are pockets of excellence in gout management, the challenge is to now expand to a national programme.
- 3.2 The common factor in these programmes has been the use of community pharmacies as a crucial engagement point and the support of a holistic community workforce to engage with and support clients.
- 3.3 This submission focuses on an Arthritis NZ-led project in Porirua and the recently completed research on this project that we believe is a benchmark for future gout management in this country. We are also funding additional studies in South Auckland and the wider Wellington and Wairarapa region. These studies are not yet published but their preliminary findings are consistent with the Porirua research.
- 3.4 The Porirua project is a key programme developed by Arthritis NZ to demonstrate how gout education can be an empowering process that has a significantly beneficial effect on not just those with the condition *but also* their families and wider communities. Health partnerships have been built with community groups and health providers such as Maraeroa Marae Health Clinic, Taeaomanino Trust, Porirua Union Health, and Cannons Creek and Waitangirua Pharmacies both during and prior to this project. Ultimately the programme has directly linked those with gout to local pharmacists who provide education and information about gout and its management.



"If you compare the allopurinol dispensed now compared to the last 6 months of 2017, it has grown by 80% for Pacific people and a little less for others. You must be doing something right-well done" (comment from Senior Systems Manager from former Capital and Coast DHB)

3.5 Porirua research results

A consumer-focused study conducted from 2022-24 explored the knowledge and management of gout within predominately Māori and Pacific communities in Porirua and the Hutt Valley areas in the Wellington region. (Appendix 1) The researchers engaged community members through informal, conversational interactions. In total 250 people participated.

While community awareness of gout was widespread, understanding of its chronic nature and the importance of proactive self-management was found to be limited. A number of challenges including low rates of preventive medication, high usage of pain relief medication, low reporting of flares and low health system engagement were evident.

The majority of participants highlighted that attempting the lifestyle approach was unsustainable and unsuccessful. Many participants stressed this was the first time they had been taught about and invited to manage their health as opposed to being told what to do by health providers. Some community members described their interaction with the researchers as a turning point or as “transformational” for their personal health journeys.

Feeling the pain of gout- stories from Porirua research participants

Participant A

Whenever he has a flare, he has to seek refuge on one side of his house as the other side is closer to the train tracks and the vibrations of the passing train cause him “unbearable pain”.

Participant B

Gout 'turns beautiful things like a breeze against the skin into a painful experience.'

Described Experiences

Bedsheets and blankets cause pain and are avoided even on freezing winter nights.

Wheeled desk chairs are adapted as in-home vehicles. When nothing similar is available, they 'drag themselves along the

3.6 Other current gout research

Arthritis NZ is funding other important gout research projects by New Zealand experts working in the social, community and biomedical fields. This work is ongoing, and preliminary results indicate many of the challenges and trends identified in Porirua are evident in other parts of the country. These include:

- **University of Auckland** - *NIU (Nesians Improving Urate-Lowering Therapy)*. *Improving the uptake of allopurinol through education*: research in South Auckland with gout consumers to co-design a new educational gout resource which is more accessible, user-friendly and highlights the significance of regular urate-lowering therapy.
- **The Family Centre** – *Gout and Pacific Peoples*: research being done with Samoan and Tokelauan New Zealanders living in the Wellington and Wairarapa communities to help address the stigma associated with gout and subsequent treatment and further support for Pacific peoples.
- **University of Otago** - *Investigating alterations to immune cell metabolism by Māori and Pacific genetic variants*: a study investigating genetic variation in Māori and Pacific peoples to improve diagnosis and reduction in the burden of disease for gout consumers from these populations.

4 Reclassification of allopurinol - a first step forward

- 4.1** Over years of work focusing on gout education Arthritis NZ has seen the benefits of increased involvement of community pharmacy services working with people who have gout. This has led to a successful submission to Medsafe proposing reclassification of allopurinol to enable ease of access to medication for consumers following their prescription for allopurinol being made by a GP.
- 4.2** This change was supported by key stakeholder groups including New Zealand Rheumatology Association and Community Pharmacy Gout Management Service. It will allow the management of gout arthritis to be more pharmacy-focused, in addition to the continued coordination and collaboration with GP practices. The role of the doctor will be to diagnose and initiate treatment, while the pharmacist would titrate the dose and aid adherence and long-term continuation of treatment. This collaborative GP-pharmacist model would benefit both the patient and the health system.
- 4.3** The value of pharmacies within the community was clearly demonstrated through the COVID-19 pandemic and, more recently, the rollout of the Minor Aliments Service in winter 2023. Pharmacies are seen in the community as front-line health professionals, which was reinforced in a recent two-year community gout research programme by South Auckland and the Pacific Research Collective of Auckland University.
- 4.4** Using pharmacies to focus on the awareness, accessibility, and adherence of gout arthritis medication within the community will help:
- Reduce pressure on GP practices through:
 - providing timely care – many practices are full and non-urgent wait times for appointments can be weeks
 - providing more time to inform and support those with gout – many patients do not get the opportunity to discuss gout as a condition with their GP as it not their primary condition
 - reducing demand on GPs for repeat prescriptions, and also providing continuity of medication for the patient
 - Reduce ongoing pressures within ED – a comprehensive gout program will reduce ED admissions- many gout sufferers have already visited a pharmacy with initial symptoms for pain relief for a gout flare (but with no ongoing intervention programme).
 - Reduce hospitalisations and the need for outpatient appointments owing to poorly controlled gout including tophi.

- Support those who are not already enrolled within the health system – as noted many of these see pharmacies as their health professional, who could then refer them to a GP as required.
- Create future opportunities – we believe pharmacies can also assist in the management of other conditions with co morbidities (such as stroke, diabetes etc).
- POC testing is a convenient and easy test that is cheaper and more time affective. The result from this testing reinforces action

5. Recommendations

We recommend that the committee expresses strong support for:

- Health New Zealand views gout as a priority
- Setting and delivering the target of 55% of people with gout being on a managed programme by 2028. Health New Zealand to report annually to the committee progress against this target.
- Health New Zealand to build awareness about the causes and management of gout and build on the improved accessibility of allopurinol following its reclassification with funding for Pharmacies to undertake added responsibilities.

References

1. **Te Tāhū Hauora Health Quality and Safety Commission.** Gout. *Atlas of Healthcare Variation*. [Online] Published: 29 Oct 2021; Modified: 18 Dec 2024. [Cited: 14 March 2025.] <https://www.hqsc.govt.nz/our-data/atlas-of-healthcare-variation/gout/>.
2. **Dalbeth, N, et al.** *Gout in Aotearoa New Zealand: the equity crisis continues in plain sight*. Auckland : NZMJ, 2018. pp. 8-12. Vols. 131, 1485.
3. **Gow, P and He, J.** SAT0534 How Healthy are our patients with gout? A study of health status and management of patients with gout at two primary care practices . s.l. : Annals of the Rheumatic Diseases, 2014. Vol. 73, 784.
4. **Health Literacy New Zealand.** Change your life: stop the pain of gout by bringing your uric acid down. *Health LiteracyNZ*. [Online] [Cited: 14 03 2025.] <https://www.healthliteracy.co.nz/projects-and-resources/>.
5. **Arnold, J, Harris, R and Graham, K.** *Gout insights Impact on Māori: Establishing the baseline*. Wellington : Pharmac Te Pātaka Whaioranga, November 2021.
6. **Arnold, J, et al.** *Pacific peoples health - Gout data insights*. Wellington : Pharmac Te Pātaka Whaioranga, April 2022.
7. **Health Literacy NZ.** Change your life: stop the pain of gout by bringing your uric acid down. *HealthLiteracyNZ*. [Online] [Cited: 14 03 2025.] <https://www.healthliteracy.co.nz/projects-and-resources/>.
8. **Minster of Health.** *Te Mana Ola: The Pacific Health Strategy*. Wellington : Ministry of Health, 2023.
9. **Arthritis NZ.** *Submission to the Health Select Committee in support of the petition from*. 2019.
10. —. *The Economic Cost of Arthritis in New Zealand in 2018*. Wellington : Arthritis NZ, 2018.

Attachments

- Appendix 1** **Research on the Porirua Community Gout programme**
Appendix 2 **2019 submission on gout from Arthritis NZ.**