



SYNERGIA

Evaluation of Gout Stop and Owning My Gout management programmes

A final report for Arthritis New Zealand and its partners

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The expertise and experiences of all the stakeholders, through data collection and sensemaking, have enabled the evaluation to provide a detailed overview of these programmes and provide useful insights and recommendations for the ongoing response to gout and to achieve equity of access and outcomes for those it affects.

EXECUTIVE SUMMARY

Gout is a chronic long-term condition that impacts people's quality of life and is a social and economic burden. The effects of gout are preventable but access to appropriate medication is variable and only one in four people in New Zealand diagnosed with gout is on regular long-term medication to control gout's damaging effects. This is despite effective treatment being available and publicly funded/subsidised. Māori and Pacific peoples have two and three times the prevalence of diagnosed gout respectively, compared to people of other ethnicities. Maori and Pacific peoples also have poorer access to long-term medication to control gout¹.

Arthritis New Zealand, PHARMAC and the Health Quality and Safety Commission are seeking to contribute to the evidence base around what works for access to effective treatment and delivery of gout management in primary care, so that funders can understand the critical components of a successful gout management programme. Synergia has been contracted to complete a process and outcome evaluation focused on two successful gout management programmes; Gout Stop and Owing My Gout (OMG). Data collection was completed between November 2019 and January 2020 for reporting in February 2020.

This report presents the findings from the evaluation of these two programmes and the insights and considerations for future programme roll out developed from a synthesis of this evidence.

The programmes

Usual gout management care requires people to visit their GP frequently and have blood tests regularly in order for the painful symptoms of a gout flare to be controlled (by nonsteroidal anti-inflammatory drugs (NSAIDs), prednisone or colchicine) and the titration of medication (allopurinol) to lower and maintain their serum urate (SU) to a safe level (under 0.36mmol/L for most people). Usual care is highly varied in practice and isn't working well, particularly for Māori and Pacific peoples, and these two gout programmes are designed to address barriers to treatment and management of gout for their communities:

Gout Stop is a 91-day gout management programme provided by Mahitahi Hauora PHE. The programme began as a pilot in 2015 and is now district wide across Northland District Health Board (35 pharmacies and all general practice). The programme centres around a model of collaboration between GPs (who prescribe a four-stage gout medication pack pre-loaded in MedTech), community pharmacists and kaiāwhina, working together to improve accessibility to medication and health literacy.

Owing My Gout is a community pharmacist and nurse led collaborative gout management model in a pilot started in 2015 that included six community pharmacies and partner primary care practices in the Counties Manukau region. This collaborative model of care has GPs issue a standing order for community

¹ HQSC Atlas of Healthcare Variation <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/>

pharmacists to prescribe gout medication. The practice nurse and pharmacist build health literacy in patients and the pharmacist titrates urate lowering medication guided by monthly point of care testing to achieve the recommended serum urate levels. This programme is in the process of expanding to 22 community pharmacies in the Counties Manukau District Health Board.

Evaluation of the gout management programmes

This mixed method evaluation design has used the following data sources

- Programme data from Gout Stop (June 2015 to June 2019, n=1421 enrolments) and OMG (October 2015 to December 2019², n= 158 people enrolled).
- Interviews with programme leads/stakeholders (six), providers (seven) and clients (three).

Analysis and synthesis of findings was supported by a sensemaking session with evaluation and programme stakeholders in January 2020. The small number of interviews from OMG providers and with clients from the programmes, limits the level of evidence relating to the delivery and outcomes of the education components of the programmes.

Gout programme enrolment

Both gout management programmes are **achieving equity of access for Māori and Pacific peoples that considers both their population profile and level of need**. Gout is often associated with older people but a third or more of those enrolled on both programmes are also aged under 45. Providing such **access for younger people with gout is** a valued feature of the programmes, as younger people can derive the greatest preventative benefits from appropriate medication and treatment. Programmes were enrolling a higher than expected proportion of males (around eight in ten people).

Gout programme participation

Both gout management programmes have around **a quarter of enrolments drop out of the programme around the time the painful acute symptoms of gout have passed**; 24% of Gout Stop patients do not collect their second prescription pack, and 27% of OMG patients do not have a second contact with the pharmacy recorded. **Providers are aware of this and employ several responses to minimise it**. Responses include timing the Gout Stop kaiāwhina input to be delivered at this time point, dispensing allopurinol early to encourage ongoing persistence and enabling reconnection or re-enrolment on the gout managing programme at any time. Additionally, programmes were **less likely to retain Māori, Pacific and younger people** than those of other ethnicities or older people, as **these groups experience greater barriers to access**.

Achieving clinical outcomes

The programmes have different structures and definitions of success, so are not directly comparable:

- **Gout Stop measures successes as reaching SU <0.36mmol/L within 91 days**. Of the 1421 enrolments that had occurred more than 91 days ago, around half (47%) completed the programme with, **253 (18%) reaching the SU target, 167 (12%) continuing with titration**.

² The majority (114) of these people were enrolled in or after 2017

- **OMG measures success as SU <0.36mmol/L for three months and is not a time limited programme.** Of the 148 people on OMG for three or more months, **48 (29%) had SU <0.36mmol/L at their last three recordings and a further 5 (3%) were continuing with titration.** It took around six months (median 5.3 months) for this SU to be reached.
- **Programmes were more successful at maintaining engagement with Non-Māori Non-Pacific peoples** and as a result, **this group was more likely to achieve clinical success.**
- The programmes do not engage with patients long enough to determine a successful transition to long term allopurinol; the ultimate programme aim and a result that could be directly compared with trends in Health Quality and Safety Commission's Atlas of Variation for Gout and PHARMAC's Medicine Access Equity Monitoring and Outcomes Framework data insights, which is under development. These results, along with the improvements in health literacy, should position patients well on that journey to long term gout management.

Improving health literacy

Education components of programmes are designed to build health literacy in providers and patients are a key difference to usual care. Though limited, the feedback we received from providers, stakeholders and the patients suggested this intent was being realised. **Feedback emphasised the importance and value of an iterative, rather than transactional approach, to building health literacy of providers and patients.**

Educational outcomes for providers were identified as updated gout clinical knowledge, local programme processes and knowledge to support building health literacy in patients. Educational outcomes for patients related to their understanding of gout causes and triggers, the need for medication and the personal benefits for them of managing gout with medication long term.

Building provider and patient health literacy was an important programme component to address bias, de-stigmatise gout and encourage and enable people to access care.

Programme contributions

The value chain created by the programmes enables the assumption that the programmes have contributed to the identified benefits for patients and communities. The programmes have also contributed to the broader health system by promoting integrated teamwork, contributing to health equity, reducing the burden of gout on the sector through a management focus, and providing good value for the resource required locally. Both programmes have continued to develop iteratively and have identified improvements to enhance or sustain programme benefits.

Responding to barriers

Patients experience several barriers to engaging with gout programmes. These include those **generic to primary care**, such as cost, travel and availability, **as well as those more specific to gout**, such as timely access to labs, over the counter pain relief options and the reduced incentive to complete the programme when pain fades. **Patient's preconceptions relating to gout were identified as strongly influencing participation;** this includes old beliefs about the causes of gout, whakamā or shame associated with gout and lack of acceptance that gout is a long-term condition.

Good programme design can reduce some of these access barriers and the effective building of health literacy is important to support behaviour change, and programme participation. **Both gout management programmes provide standardised pathways for all patient groups**; further differentiation may improve programme participation.

Collaborative healthcare service delivery in primary care

The interdisciplinary delivery of gout programmes represents a shift in the traditional roles of GPs, nurses and pharmacists and introduces opportunities for practice nurses and non-regulated roles, such as kaiāwhina.

While **pharmacists we engaged with were keen** to embrace this opportunity to work to top of scope there is awareness of a more **mixed reaction from general practice** for a variety of philosophical, clinical practice and business reasons.

The main incentive provided by the programmes has been **the funding of community pharmacy activity**; Gout Stop pharmacists are paid on each programme entry and (successful) completion. OMG pharmacists have only recently begun to be paid and this is per patient contact. The pharmacists we spoke with were passionate about lifting the health of their communities indicating community **pharmacy funding may be an enabler, but without leadership and commitment, may not be a sufficient incentive to drive effective pharmacy delivery of gout management programmes.**

The Gout Stop **kaiāwhina role** provides an **informed, trusted and relatable source of information** and encouragement for patients. Support provided to most patients is by a one-off phone conversation, but there is **flexibility to respond to different needs** and provide more support to patients and their whānau. As such, the kaiāwhina is a valued link between healthcare providers and patients. The **kaiāwhina also promotes awareness raising about gout in the wider community**, such as workplaces and marae to address outdated beliefs about gout and encourage and help people to seek support.

We were not able to interview any OMG practice nurses but others described their role as overseeing the programme for the practice and supporting patients with building their health literacy.

Feedback identified the value for patients of engaging with providers in a range of roles where they provided **consistent key messages and individualised support.**

Informing future roll out

The two gout management programmes are not an instant panacea to all the barriers providers and patients experience, but they have enabled real world learning to inform the future roll out of gout programmes. The programmes have enabled the evaluation to identify the following critical success factors in terms of programme components and enablers of delivery.

Essential **core components** of gout management programmes are:

- **Easy access to medicine for patients**
- **Activities to build provider and patient health literacy**
- **Accessible gout information resources**
- **Awareness raising.**

The key **enablers of delivery** have been identified as:

- **Systems to provide easy access to the right medication**
- **Systems to share patient information**
- **Collaborative leadership of gout management programmes**
- **A common gout programme framework and measurement model**
- **Sound planning and ongoing improvement activity.**

These components and enablers will need to be adapted to local context. It is recommended that programmes are set up not as pilots but with a view to ongoing quality improvement and long-term sustainability. Future gout programme rolls out will require resourcing, for example for community pharmacy participation, and benefit from leadership at national, district and organisational levels.

Gout is a significant health issue for New Zealand. Gout is also an equity issue and our commitment to Te Tiriti o Waitangi requires a response to the current inequitable access and outcomes for Māori. Evidence and insights from the evaluation of two gout management programmes that go beyond usual care show that gout programmes provide value not only to patients, whānau and communities, but also to the health sector through their interdisciplinary delivery.

1. INTRODUCTION

Gout is a chronic long-term condition that impacts people's quality of life and is a social and economic burden. The effects of gout are preventable but only one in four people in New Zealand with gout is on long term medication to control gout's damaging effects. Māori and Pacific peoples have two to three times the prevalence of gout than other ethnicities and have poorer access to the long-term right medication³.

Arthritis New Zealand (Arthritis NZ), PHARMAC and Health Quality and Safety Commission are seeking to contribute to the evidence base around what works to successfully manage gout. Synergia has been contracted to complete a process and outcome evaluation focussed on two gout management programmes; Mahitahi Hauora Primary Health Enterprise's (PHE) Gout Stop programme, and Counties Manukau Health's Owing My Gout programme (OMG), now known as the Community Pharmacy Gout Management Programme. The evaluation has been funded by Arthritis NZ, PHARMAC and the Health Quality Safety Commission (HQSC). PHARMAC has supported this evaluation as it has a strategic priority to eliminate inequities in access to medicines. Gout management has been identified as one of the priority conditions for this mahi in access equity. Data collection for the evaluation was completed between November 2019 and January 2020.

This report presents the findings from the evaluation of these two programmes and the insights and considerations for future programme roll out from a synthesis of this evidence.

District Health Boards (DHBs) and Primary Health Organisations (PHOs) are the intended audience for the evaluation. There are a small number of gout management programmes based on best practice guidelines throughout New Zealand, but knowledge of their development, learning and evidence of success is not easily accessible. By contributing to the evidence base this evaluation is intended to inform DHBs and PHOs about the effective components of gout management programmes and what to consider and expect in terms of design and implementation.

1.1 Report structure

The report begins with some background context about gout in New Zealand and follows with a summary of the evaluation approach and methodology. The report then describes the two programmes before unpacking the process of programme delivery and the factors that influence it. Programme outcomes and benefits are described and summarised before recommended developments are identified. Before the final summary, the report identifies the critical design and implementation considerations for future programme roll out.

Green shaded boxed highlighting key points are inserted throughout the report.

A glossary of acronyms used in the report can be found in the appendix.

³ HQSC Atlas of Healthcare Variation <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/>

2. BACKGROUND AND CONTEXT

2.1 Gout in New Zealand context

Gout is a chronic condition caused by excess monosodium urate crystal deposition in and around joints, ligaments and tendons. Gout is caused by high levels of urate in the blood as weight, impaired kidney function and genetic factors prevent the kidneys from eliminating urate. Acute gout causes painful inflammation and swelling, limits function and has a negative impact on quality of life.

New Zealand research has shown that Māori and Pacific peoples are much more likely to have these genetic factors than other groups⁴. Māori and Pacific peoples are two and three times more likely to get gout, and, at a younger age and more severely than other population groups⁵.

There is also sub-optimal and geographical variation in relation to gout in that rates of regular treatment with urate-lowering medicines are poor across all population groups⁶ but especially Māori and Pacific peoples who are less likely to receive regular urate-lowering medications despite having a higher prevalence of gout. In addition, Māori and Pacific peoples are five to ten times more likely to be admitted to hospital with gout than other population groups. Poor and inequitable access to medication is a trend that the Gout Atlas of Healthcare Variation identifies as not improving. PHARMAC has highlighted the importance of supporting equity through their medicines access equity work and the theory of change informing actions to improve access to medicines. The prevalence of diagnosed gout is increasing. The contributors to this trend are multifaceted as the following quote summarises:

Barriers ... include, not adhering to best practice guidelines, delaying initiation of preventative therapy, suboptimal monitoring, long standing community, patient and beliefs that gout is caused by food and drink, patient non-adherence and health professionals biases. Furthermore, recent research has identified that the model of care for chronic arthritis management including gout in New Zealand is fragmented due to the lack of collaboration among health care providers⁷.

Usual care requires people to visit their GP frequently, and have blood tests regularly, in order for the painful symptoms of a gout flare to be controlled (by NSAIDs, prednisone or colchicine) and the titration of medication (allopurinol) to lower and maintain their urate to a safe level (under 0.36mmol/L for most people). Usual care is highly varied in practice and isn't working well, partially for Māori and Pacific peoples,

⁴ Merriman, T. R., Choi, H. K., & Dalbeth, N. (2014). The genetic basis of gout. *Rheumatic Disease Clinics*, 40(2), 279-290.

⁵ HQSC Atlas of Healthcare Variation <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/>

⁶ HQSC Atlas of Healthcare Variation <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/>

⁷ Dalbeth, N., Gow, P., Jackson, G., Shuker, C., Te Karu, L., Gerard, C., & Winnard, D. (2016). Gout in Aotearoa New Zealand: are we going to ignore this for another 3 years?. *NZ Med J*, 129(1429), 10-3.

The two programmes included in this evaluation are programmes that have demonstrated success, have sought to address some of these barriers and are sources of learning for other regions and programmes. These are:

Gout Stop a 91-day gout management programme provided by Mahitahi Hauora PHE. The programme began as a pilot in 2015 and is now district wide across Northland District Health Board (35 pharmacies and all general practice). The programme centres around a model of collaboration between GPs (who prescribe a four-stage gout medication pack pre-loaded in MedTech), community pharmacists and kaiāwhina, working together to improve accessibility to medication and health literacy.

Owning My Gout is a community pharmacist and nurse led collaborative gout management model in a pilot started in 2015 that included six community pharmacies and partner primary care practices in the Counties Manukau region. This collaborative model of care has GPs issue a standing order for community pharmacists to prescribe gout medication. The practice nurse and pharmacist build health literacy in patients and the pharmacist titrates urate lowering medication guided by monthly point of care testing to achieve the recommended serum urate levels. This programme is in the process of expanding to 22 community pharmacies in the Counties Manukau District Health Board.

3. EVALUATION OF THE GOUT PROGRAMMES

This section describes the aim, objectives and key evaluation questions developed for the evaluation and describes the approach, methodology and data collection processes.

3.1 Evaluation aims and objectives

The aim of this evaluation is to contribute to the evidence base around what works for the effective treatment and management of gout in primary care. The evaluation will present a synthesis of what works well so that funders can understand the critical components of a successful gout management programme.

Table 1: Evaluation objectives and key evaluation questions

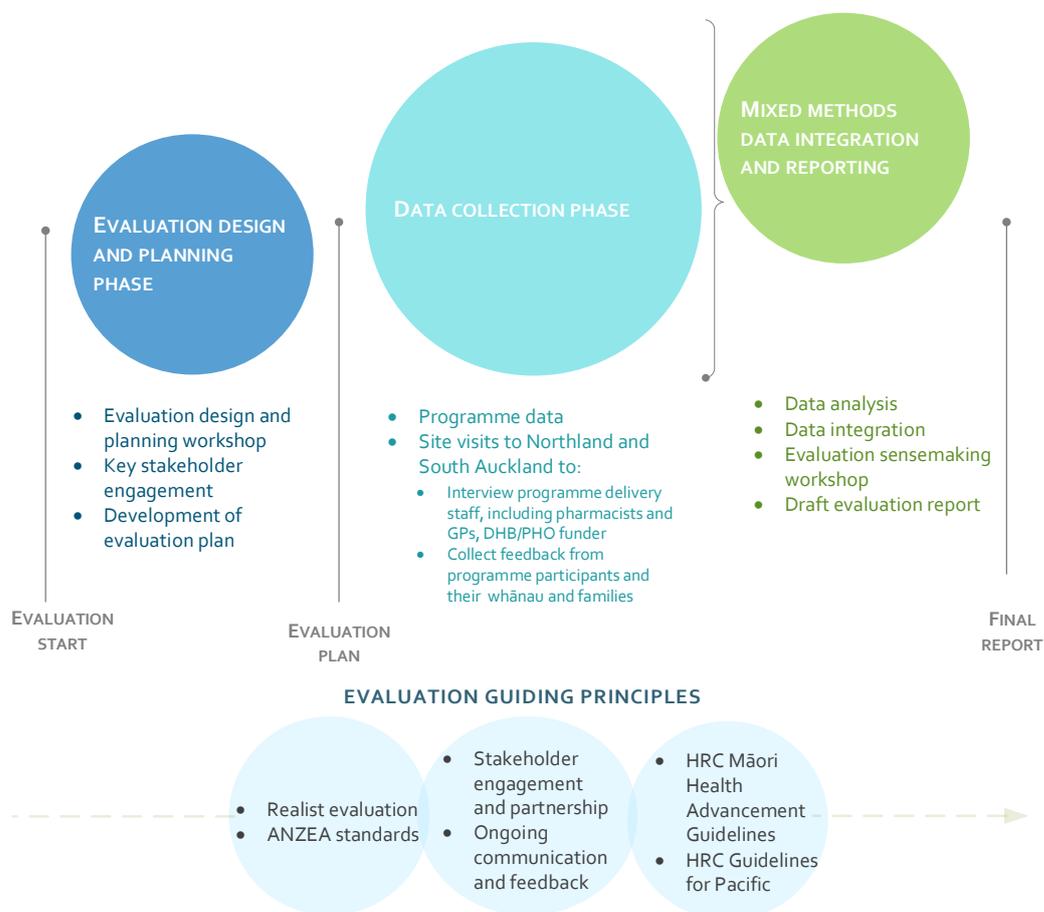
Evaluation objective	Key evaluation Questions
Documenting the programmes	How was each programme delivered? <ul style="list-style-type: none"> • What differed between the two? • What approaches were used for different patient groups (including at different stages of their treatment pathway)? • Are the programmes fit for purpose? Were there any unintended consequences?
Process evaluation objectives	
Determine how well the programmes have engaged and been delivered to the different clinical patient groups, including patient groups who were along various stages along the therapeutic pathway for gout.	To what extent were the programmes appropriately focused towards patient groups who were at various stages along the therapeutic pathway for gout? <ul style="list-style-type: none"> • E.g. Starting allopurinol for the first time, restarting allopurinol, and titrating dosage for those who had not yet reached the target of 0.36mmol/L.
Identify patients' treatment experiences and pathways within the programmes.	Are participants being reached as intended? <ul style="list-style-type: none"> • How satisfied are they? • Why did participants with gout stay or not stay engaged in the programmes?
Review the appropriateness of the measures used for the programme and identify opportunities for improvements.	Were the measurements used for the programmes appropriate and how could the measurement regimes be improved?

Outcome evaluation objectives	
Determine programme success in terms of clinical and educational outcomes for patients and the contribution of each programme to this success.	<p>Comparison of clinical and educational outcomes across both programmes.</p> <ul style="list-style-type: none"> • Did either programme produce the intended outcomes in the short, medium and long term? • For whom, in what ways, and in what circumstances? • What workforce development occurred, how this came about, and how has this contributed to programme success? • What other factors have impacted on the delivery and success of programmes?
Determine programme success in terms of supporting system outcomes and alignment to government/DHB/PHO priorities.	<p>How well do the programmes align with other government/DHB/PHO priorities?</p> <ul style="list-style-type: none"> • Did either programme improve equity in terms of Māori and Pacific peoples? • How have programmes supported pharmacists and other health professionals to work to top of scope?
Determine the value of having incentives and their contribution to key outcomes.	<p>What incentives were offered to practices, pharmacies and participants in these programmes?</p> <ul style="list-style-type: none"> • Why were incentives offered and when were they used? • What effect did the incentives have and for how long? • Have the programmes provided value for money?
Summarise the key factors relevant to successful programme design and implementation.	<p>What were the critical success factors?</p> <ul style="list-style-type: none"> • Including, but not limited to, the interest, passion and drive of the respective people leading each project? • To what extent can behaviour changes (health professionals and participants e.g. prescribing behaviour, allopurinol uptake and adherence) be attributed to the programmes? • Are there any differences in outcomes for pharmacies co-located in primary care practices and community pharmacies?
Identify improvements to enhance the implementation and effectiveness of the programmes.	<p>What improvements have been identified?</p> <ul style="list-style-type: none"> • By those connected to and participating. • From a synthesis of evidence.

3.2 Evaluation approach and design

Synergia has completed a process and outcome evaluation of two gout programmes and has worked collaboratively with the project team and key stakeholders (programme leads) to deliver a mixed methods evaluation across three main phases illustrated in Figure 1. This diagram also identifies the evaluation approach, including the key methods and outputs from each phase.

Figure 1: Evaluation approach, methods and key outputs



The evaluation design and planning phase included a review of key documentation to support our understanding of the two gout programmes and their delivery. The evaluation planning and design workshop with the project team built on this early contextual understanding and resulted in a shared understanding of the evaluation in terms of its purpose, scope and key outputs.

3.3 Evaluation methods and data collection

This evaluation was carried out using a mixed methods approach designed to support insights that have both breadth and depth.

- Access to providers for interview was facilitated by programme leads. Access to patients was to be facilitated by programme providers. The evaluation had a short timeframe to complete data collection prior to Christmas 2019 and this impacted on the number of GPs, pharmacists and patients we were able to interview, particularly for the OMG programme.
- Programme data was accessed from the respective programmes and organisations (as available) to understand the demographic profile of patients, clinical profile on entry into the programmes, activities within the programmes (such as monitoring) and clinical outcomes (urate levels). This data was varied in its content and, with the Gout Stop data dating from June 2015 to June 2019; while the Owing My Gout dataset dated from October 2015 to December 2019.

- Interviews: A total of 16 interviews were used to inform the qualitative insights into this evaluation. A two-day site visit took place in Northland in late-November 2019, where programme leads, pharmacists and GPs were interviewed in both Whangarei and Kawakawa. Clients of the Gout Stop programme were interviewed over the phone in the following weeks. A total of 11 individuals were interviewed for the Gout Stop programme. Five interviews took place to support insights into the Owning My Gout programme, including the programme leads, a pharmacist and GPs. Because of the timing we were unable to be connected with patients from this programme.
- The evaluation team has interpreted and synthesised the evidence from across the different data sources to answer the key evaluation questions. Data has been analysed using descriptive statistics for the quantitative service data, and thematic analyses of the qualitative data. Evaluation questions have guided the mixed methods analysis, which was supported by a sensemaking session with stakeholders on 23 January 2020.

3.3.1 Limitations

The number of interviews complete for both programmes was fewer than anticipated within the timeframe available for the evaluation, particularly for OMG and for programme participants from both programmes. This means:

- The themes from the views and experiences expressed may miss themes identified from a broader range of provider or patient experiences.
- There is potential bias in that provider staff interviewed were those leading and/or supportive of the programmes.
- Very limited insight into the general satisfaction of patients using the programmes and the broader delivery and experiences of patients enrolled in the programmes.
- The nurse role in OMG is described only from the perspective of others.

4. THE GOUT PROGRAMMES

Stop Gout and OMG are designed to promote best practice management of people with gout, which includes short-term prophylaxis and titration of allopurinol so people can transition to a long-term dose that keeps their urate levels under <0.36. Gout Stop does this with a series of four medication packs embedded in MedTech, OMG enables pharmacies to titrate and dispense medication under a Standing Order. Patients' health literacy is built with pharmacists, nurses (OMG) and a kaiāwhina and pharmacists (Gout Stop). Gout Stop is district wide; OMG is a very small-scale pilot now expanding.

This section describes Gout Stop in Northland and Owning My Gout in Counties Manukau DHB. The components and delivery of the two programmes will be described and a pathway through each programme, using a patient lens, illustrated.

4.1 Gout Stop

According to the Ministry of Health, Northland has a population that is significantly older than the national average, and the percentage of Māori (33%) is twice as high as the rest of the country. Northland also has high levels of deprivation, with (38%) in the most deprived quintile⁸

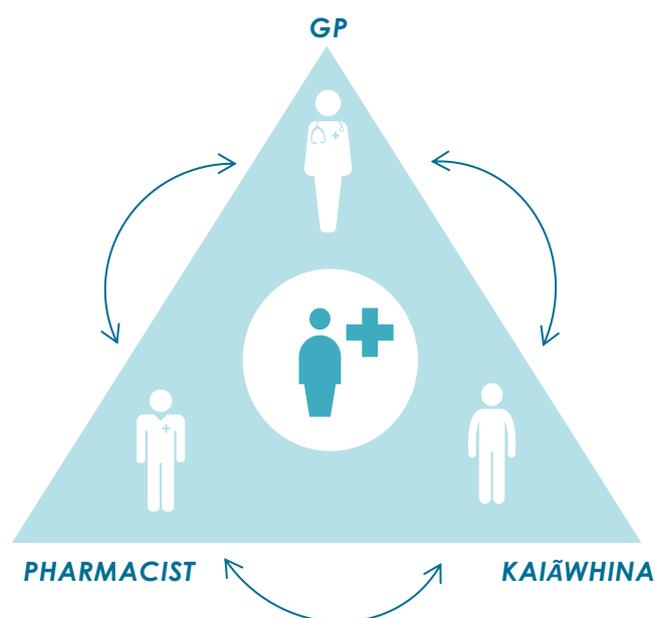
The programme was originally intended to discover and reduce barriers to accessible gout treatment and described by programme leads as having a specific focus on Māori and Pacific peoples to support the achievement of equity in gout-related health outcomes.

The Gout Stop programme began in 2015 as a pilot, funded for three years by Manaia PHO (now part of Mahitahi Hauora Primary Health Entity (PHE)). The programme continues to be led by Mahitahi Hauora PHE, in partnership with community pharmacy and general practice. Over an 18-month period, the programme grew to cover the entirety of the Northland region, with all but one of its 36 pharmacies participating in the programme. The programme became business as usual with the establishment of the PHE in July 2019. The programme is identified in the local HealthPathways (an online decision support resource for primary care).

Gout Stop aims to simplify gout management. Key features of the model include:

- The “Gout Stop Pack” prescription options, with variations of the combination of medications to be prescribed for an acute gout attack, followed by long term

Figure 2: Gout Stop model of collaboration



⁸ <https://www.health.govt.nz/new-zealand-health-system/my-dhb/northland-dhb/population-northland-dhb>

urate lowering medication with long term prophylaxis pain relief. The pack options include various combinations of prednisone, allopurinol and colchicine dependent on the patients' renal function and diabetes status. There are now four packs in total, of various time lengths, for a period of 13 weeks (91 days). Figure 3: Gout Stop Pack prescription options based on renal function and diabetes status.

Figure 3 describes the different options in more detail.

Figure 3: Gout Stop Pack prescription options based on renal function and diabetes status

Renal function (eGFR)	Blister Pack 1 (14 days)	Blister Pack 2 (28 days)	Blister Pack 3 (28 days)	Blister Pack 4 (21 days)
Option 1 eGFR >60	Prednisone 40 mg for 4 days, 20 mg for 4 days, 10 mg for 3 days, 5 mg for 3 days.	Allopurinol 100 mg daily Colchicine 500 mcg twice daily	Allopurinol 200 mg daily Colchicine 500 mcg twice daily	Allopurinol 300 mg daily Colchicine 500 mcg twice daily *Laboratory form
Option 2 eGFR 31–60	Prednisone 40 mg for 4 days, 20 mg for 4 days, 10 mg for 3 days, 5 mg for 3 days.	Allopurinol 50 mg daily Colchicine 500 mcg once daily	Allopurinol 100 mg daily Colchicine 500 mcg once daily	Allopurinol 200 mg daily Colchicine 500 mcg once daily *Laboratory form
Option 3 eGFR 10–30	Prednisone 40 mg for 4 days, 20 mg for 4 days, 10 mg for 3 days, 5 mg for 3 days.	Allopurinol 50 mg every other day Colchicine 500 mcg every other day *Laboratory form	Allopurinol 50 mg daily Colchicine 500 mcg every other day *Laboratory form	Allopurinol 100 mg daily Colchicine 500 mcg every other day *Laboratory form
Diabetes alternative eGFR >60	Naproxen 500 mg twice daily	Allopurinol 100 mg daily Colchicine 500 mcg twice daily	Allopurinol 200 mg daily Colchicine 500 mcg twice daily	Allopurinol 300 mg daily Colchicine 500 mcg twice daily *Laboratory form

- A kaiāwhina role to work with patients and the community. The kaiāwhina role replaced the Arthritis NZ nurse educator who had been involved at the beginning of the pilot. The use of a non-regulated health worker was intentional, to relate to clients, using non-medicalised language to communicate and build knowledge and skills with patients.
- Pharmacies ask patients for permission for the kaiāwhina to contact them and contact is usually made two weeks into the programme. Home visits or follow up calls can be arranged but most patients only received a one-off phone call so persistence in taking the medication could be supported. The kaiāwhina also visits workplaces, marae and other places where this particular group of patients tend to gather, to raise awareness through serum urate testing (with the BeneCheck® meter) and providing written patient resources on gout.
- The programme has been monitored by a strategic and operational oversight group, comprised of a clinical lead, programme coordinator, general practitioner, community pharmacist, specialist rheumatology nurse, gout kaiāwhina and the funder. The group met monthly during the pilot phase of the programme, and now, post pilot, is to meet annually going forward. The Clinical Director of Mahitahi Hauora also monitors the programme at a high level.
- Key learnings and adaptations have been the introduction of a diabetes gout pack and the employment of a local kaiāwhina. The kaiāwhina is a Māori male who brings mana to the role along with local networks. This was identified as a significant advantage for the programme.

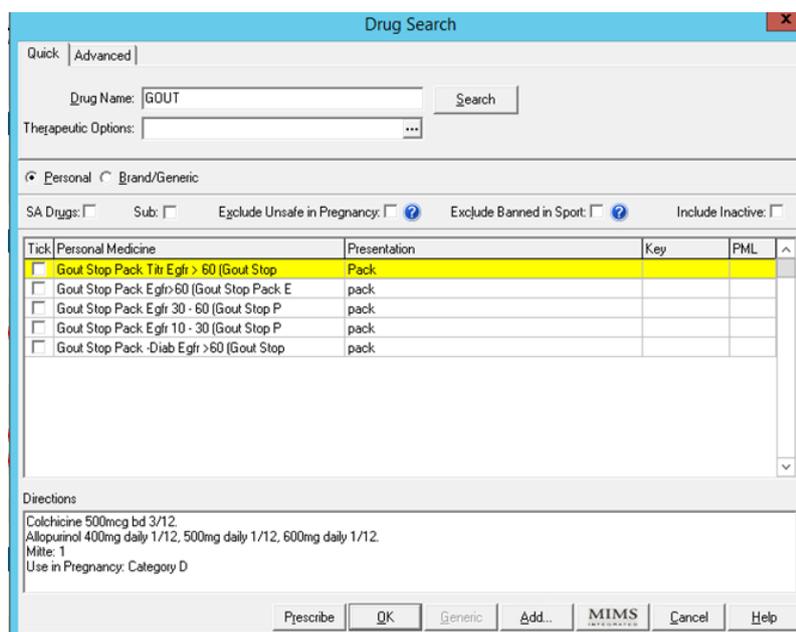
4.1.1 Patient pathway

The patient pathway through the Gout Stop programme starts with a presentation of a patient with acute gout to a general practice. Patients that are diagnosed with gout and,

have experienced two or more flares in a year, are enrolled into the programme (with consent) and prescribed one of the four medication pack options depending on their renal function (eGFR). The pack options are pre-loaded into Medtech software, for ease of use (Figure 4).

Pharmacy receives the prescription from the patient and issues a laboratory form to the patient to test their serum urate levels and other markers. The pharmacist then communicates to the patient's GP, the patient's initial serum urate levels, last dose of allopurinol and date of last prescription to finish. Following the programme, the patient revisits the GP after the 91-day course to check serum urate level and other lab results.

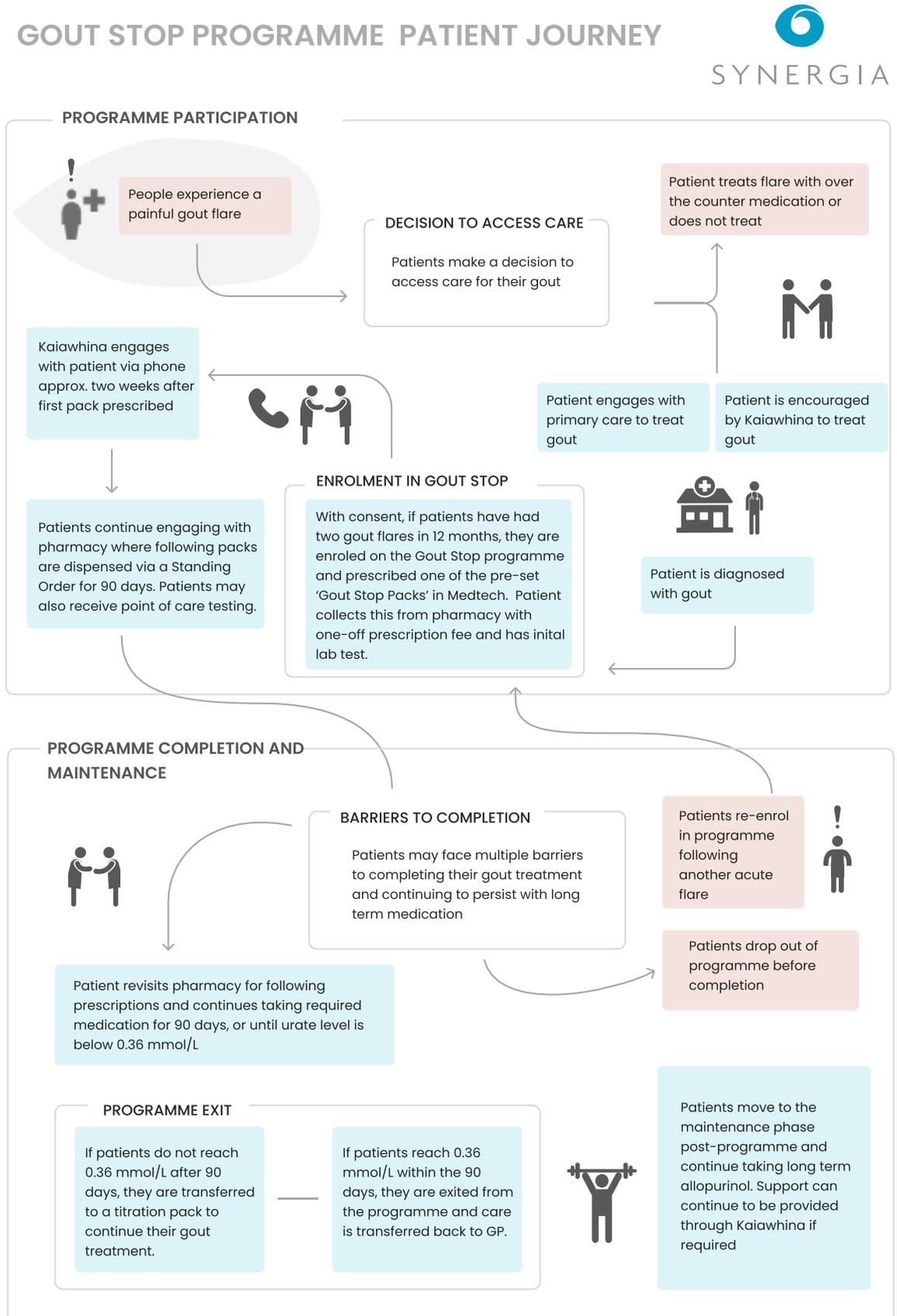
Figure 4: Gout Stop options in Medtech



If the serum urate level is below 0.36mmol/L, allopurinol maintenance therapy begins based on the last allopurinol dose. This continues as long-term medication under GP care. If the serum urate is above 0.36mmol/L, allopurinol is prescribed in a titration regime, increasing monthly with prophylaxis cover until the target is reached. Allopurinol is then continued as a long-term medication under GP care.

Figure 5 on the following page describes the programme pathway in more detail and is based on the programme descriptions and feedback on the pathways provided.

Figure 5: Gout Stop patient journey



Patient decisions to access care and the barriers to completing programmes of treatment are not programme specific and are explored and discussed in Section 6 of this report.

The Gout Stop programme published its positive results in the *Journal of Primary Health Care* in 2019. The research phase of the programme was from 2015-2017, during which time 160 clinicians prescribed therapy at 887 patient presentations⁹. The programme was deemed to be working well for Māori and Pacific with 71% of participants identifying as Māori or Pacific. The publication reports that the completion rate was higher for Non-Māori, Non-Pacific (84%) than it was for Māori and Pacific patients (55%). However, the research reports that following programme completion, 68% of Māori and Pacific patients continued to take allopurinol, with 65% of Non-Māori, Non-Pacific doing the same. In the publication, patients were reported as having a high level of satisfaction with the programme and a reduction in prescribed non-steroidal anti-inflammatory drugs (NSAIDs) without urate-lowering treatment (ULT) across Northland was achieved.¹⁰

4.2 Owing My Gout

The South Auckland region served by Counties Manukau DHB has been labelled as the 'gout capital of the world'¹¹. The population in this region tends to be much younger than the national average and has the highest proportion of Pacific peoples living in the region (21%) than other parts of New Zealand¹². As in Northland, Counties Manukau DHB has high deprivation with (37%) in the most deprived quintile.

Owing My Gout is a gout management programme being piloted through Counties Manukau DHB. The model explores using community pharmacists alongside practice nurses to lead the delivery of gout management services to patients. This pilot began in July 2017 and recruited six pharmacies to participate. Originally, the intention was to recruit co-located pharmacies and general practices, however a variety of practice and pharmacy types were included in the pilot. These pharmacies and general practices were motivated by the potential health gain for their community. A payment for the community pharmacists was introduced in late 2018 when funding became available. The aim of the project has been to enable 90% of patients to self-manage their gout, with primary drivers identified to facilitate this, including; activated clinicians, activated patients and a collaborative model of care. Key features of this programme include:

⁹ Lawrence, A., Scott, S., Saparelli, F., Greville, G., Miller, A., Taylor, A., & Gow, P. (2019). Facilitating equitable prevention and management of gout for Māori in Northland, New Zealand, through a collaborative primary care approach. *Journal of Primary Health Care*, 11(2), 117-127.

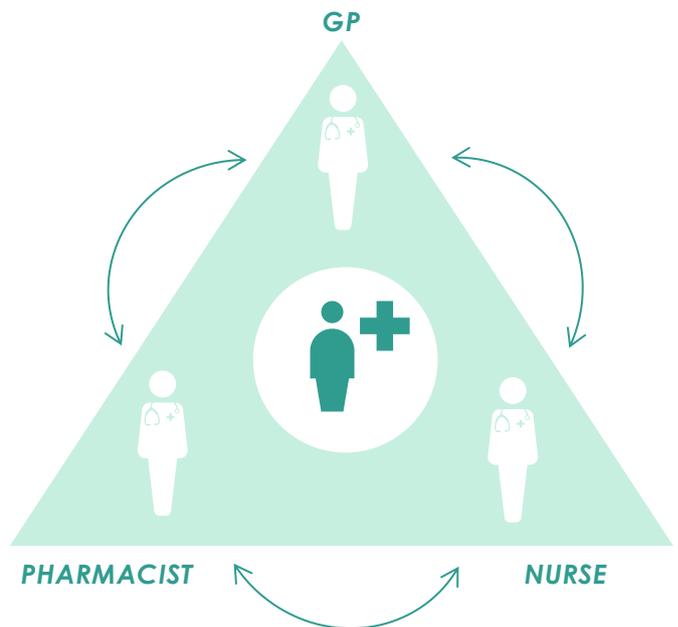
¹⁰ HQSC Atlas of Healthcare Variation <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/>

¹¹ Phone, D. (201). Owing My Gout- A Pharmacist-led collaborative gout management model at Counties Manukau DHB. Conference presentation

¹² <https://www.health.govt.nz/new-zealand-health-system/my-dhb/counties-manukau-dhb/population-counties-manukau-dhb>

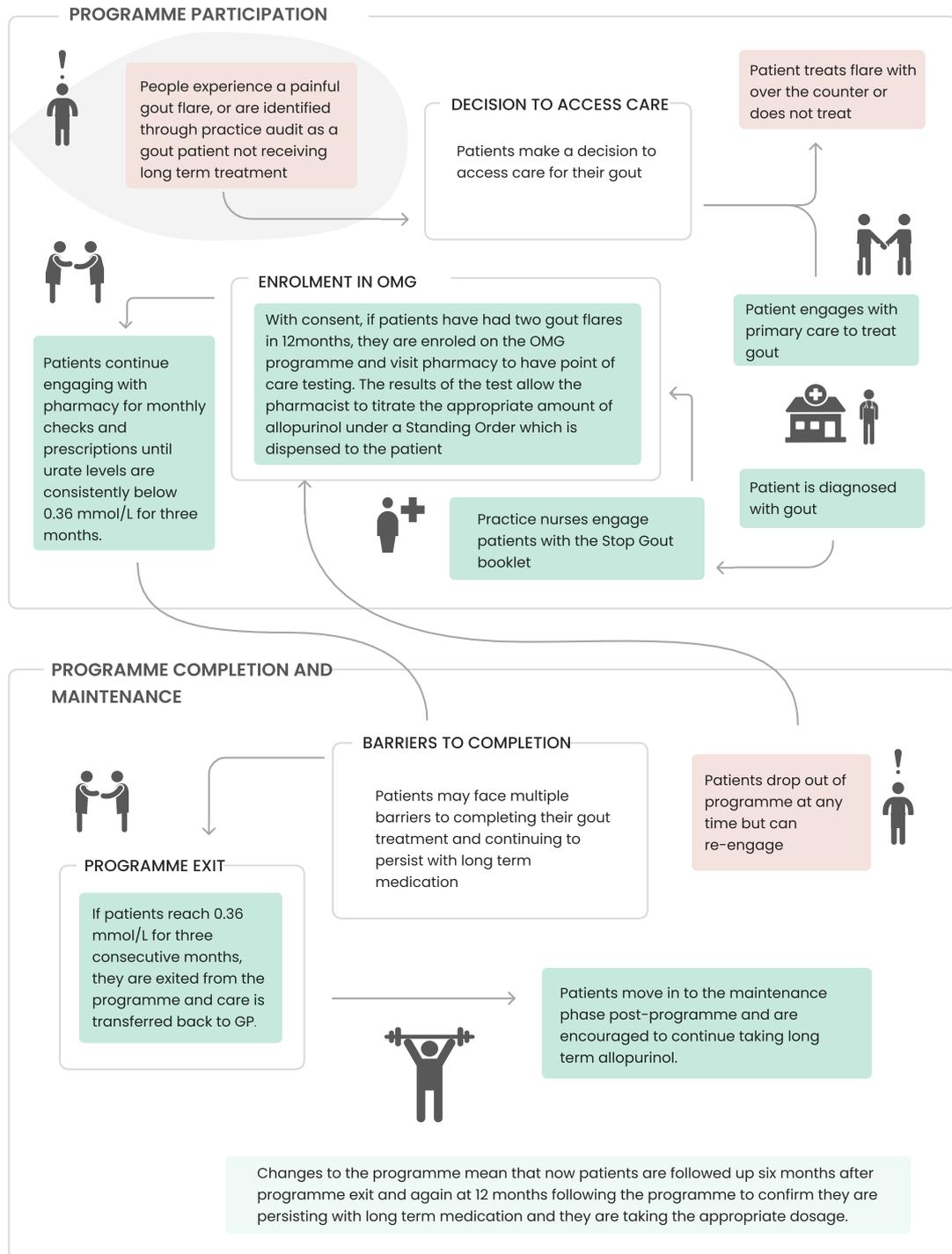
- The programme involves local community pharmacists using a Standing Order to titrate allopurinol in collaboration with GPs and practice nurses. In early phases of the pilot, a proactive approach was taken to identify programme participants. A query build identified patients who had showed symptoms of a gout attack and invite them to participate in the programme pilot. Practice nurses have a practice champion role and oversee and manage the process and interface between general practice and pharmacy. The nurses also provide gout education to patients.
- The pilot with six pharmacies and partnering practices has been led by Counties Manukau DHB, and following pilot success, a business case was put forward and accepted in 2019 for the programme to fund an expansion to include up to 22 pharmacies. This report includes data form the original pilot only.
- Pharmacists use a BeneCheck © meter to test serum urate levels. The pharmacist then titrates the allopurinol dosage based on the urate levels and dispenses a monthly prescription. The patient is required to return to the pharmacy each month for more point of care testing, and this process continues until the patient has maintained a serum urate level of below 0.36mmol/L for three consecutive months.
- Following this, care is transferred back to the patient's GP, who starts the patient on allopurinol as a long-term medication. The programme also makes use of an electronic shared-care plan to encourage communication and information sharing between health professionals, as well as the patient.
- The programme developed with a strong focus on quality improvement, using the Institute for Healthcare Innovation quality improvement framework which involves cycles of Plan, do, Study and Act (PDSAs) undertaken by the OMG project team.

Figure 6: Owning My Gout model of collaboration



4.2.1 Patient pathway

OWNING MY GOUT PROGRAMME
PATIENT JOURNEY



The Owing My Gout programme leads developed a business case to secure funding to support the programme to grow going forward. The business case highlighted some key successes of the programme including an average reduction of patient serum urate levels to below the targeted 0.36mmol/L.

The business case also highlights the impact of the programme on acute GP visits. A sample of 21 patients on the service were randomly selected to determine the number of acute GP visits prior to enrolment in the Owing My Gout programme and whilst they were on the programme. The results showed that the number of GP visits for acute gout had decreased from an average of 2.9 visits to 1.2 visits. Section 12 of this report considers the broader value of these programmes to the health system in more detail.

4.3 Similarities and differences between programmes

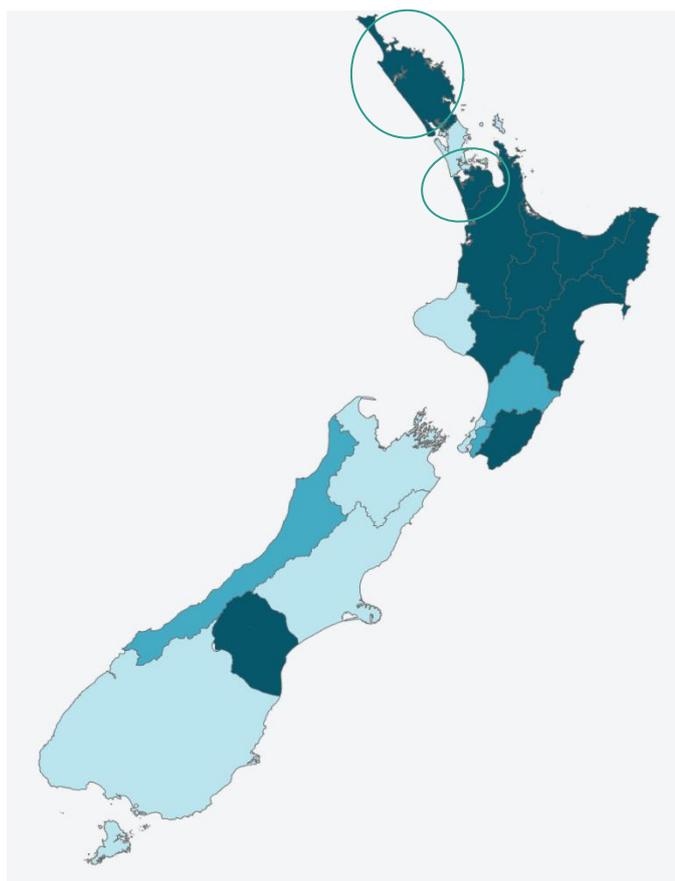
At their core, there are some considerable similarities between the two programmes. Both Gout Stop and Owing My Gout are based on best practice gout management guidelines; treating acute flares, building patients' health literacy about managing the condition and titrating to long term allopurinol usage. Both programmes are also designed to address the inequity in gout management and outcomes.

Figure 7 displays the gout prevalence by region in New Zealand¹³. The darkest shade of blue signifies the gout prevalence for that region is significantly higher than the national average, the mid-blue indicates the prevalence is in line with the national average, and the light blue signifies the prevalence for that region is significantly below the national average.

Both Northland DHB and Counties Manukau DHB regions are significantly above the national prevalence with rates of 8% and 7.6% respectively, compared with a national average of 5.3%¹⁴.

Both regions have the need for a programme to support gout management in the community and have enough people with a

Figure 7: Map of gout prevalence in New Zealand



¹³ HQSC Gout Atlas of Healthcare Variation. <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/gout/>

¹⁴ HQSC Gout Atlas of Healthcare Variation. <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/gout/>

diagnosis of gout to sustain the programmes.

Both programmes have been the result of people in positions of influence who have had the passion, drive and ability to lead the collaborative activity necessary to plan and deliver the programmes.

Table 2 summarises the key programme factors that are different between programmes.

Table 2: Comparison of programme factors

Factors	Gout Stop	Owning my Gout
Implementation	Regional approach All pharmacies and general practices in the DHB.	Pilot site, 6 pharmacies and partner practices so much smaller reach.
Lead	PHE initiated and led (single PHE across the district).	DHB led.
Status of programme Dec 2019	Business as usual.	In pilot expansion phase – increasing to 22 pharmacies.
Initiation driver	Response to need.	Quality improvement and equity in primary care.
Key provider roles	GPs, Pharmacists and staff, kaiāwhina.	GPs, Pharmacists and staff, Nurses.
Contract incentive	Pharmacy payment on entry and exit. Time, overheads and consumables funded.	Pharmacy payment each contact \$27.70 to fund time and consumables in expansion phase.
Prescriptions	Pre-prescribed packs 2,4,4 and 3 weeks. Free blister pack.	Pharmacists dispense monthly under a Standing Order Free blister pack.
Programme end/exit point	Measures 'success' in 91 days if SUL <0.36mmol/L achieved.	After urate levels <0.36 mmol/L for three months (monitoring up to 12 months recently introduced as part of expansion).
Information systems	Pharmacy data base. Fax referral for kaiāwhina. Pharmacy records pack option, eGFR, date packs collected, SU on exit and participation status.	Electronic shared-care plans. Pharmacy records SU against calendar month.

The following table provides more detail about key roles and responsibilities of those involved in the delivery of the gout programme.

Table 3: Comparison of key roles and functions

Key roles	Gout Stop	Owning My Gout
GP	Prescribes a Gout Stop pack. Four options depending on eGFR and diabetes status. Requests lab forms for bloods to test eGFR and serum urate levels. Refer to rheumatology specialist as required.	Prescribes prophylaxis and allopurinol under a Standing Order. Requests lab forms to test eGFR and serum urate levels. Refer to rheumatology specialist as required.
Nurse	No active role identified	Manages interface between general practice and pharmacy. Builds health literacy with patients using the Stop Gout booklet.
Kaiāwhina	Engages with patients over the phone two weeks after first prescription to build health literacy Stop Gout booklet and associated version developed by the Māori Pharmacists Association. Further contact is, as required. Engages in community activities to raise awareness about gout management in the wider district.	N/A
Pharmacist	Dispenses pack and builds health literacy with patients using the Stop Gout booklet and associated version developed by the Māori Pharmacists Association. Opportunity in some pharmacies for point of care urate testing using BeneCheck © meter.	Point of care testing of SU using BeneCheck © meter to titrate allopurinol. Dispense medication under Standing Order. Builds health literacy with patients using the Stop Gout booklet.
Patient	Sees GP for initial diagnosis and treatment. Collects four packs of medication over a 13-week period. Pays \$15 for three prescribed items. Returns to GP oversight once target SU is achieved. Builds health literacy in relation to new information about gout ad persists with taking medication.	Sees GP for initial diagnosis and prescription. Attends pharmacy monthly for point of care testing and medication. Pays \$15 for three prescribed items. Returns to GP oversight once target urate has been stable three months (now 12 months). Builds health literacy in relation to new information about gout ad persists with taking medication.

5. PROGRAMME DELIVERY

5.1 Programme enrolment

Gout Stop and OMG have enrolled a high proportion of Māori and Pacific peoples respectively. A third or more of those enrolled on both programmes are aged under 45 and eight in ten are male. Both programmes also experience a drop off in participation once the painful acute symptoms of gout have passed. Responses to minimise this include the timing of the kaiāwhina contact, dispensing allopurinol early to encourage maintenance and enabling reconnection or re-enrolment at any time. Further differentiation of the standard programme for key groups or needs may support continued participation.

Programme data provided by the two programmes gave an insight into the reach of the programmes. Gout Stop and Owing My Gout are at very different stages, with one programme operating district wide and considered business as usual, and the other completing its pilot phase with six participating pharmacies.

As such, programme data for the Gout Stop programme consisted of 1322 unique patients (some enrolled more than once) while the Owing My Gout programme data contained 164 unique patients. Some of these unique patients did not have all demographic information completed, so the total numbers may differ throughout this section.

5.1.1 Gout Stop demographic profile

Gout Stop programme data shows that **over 60% of participants on the programme identify as Māori, 4.9% identify as Pacific, and 32.5% identify as Non-Māori/Non-Pacific**. These proportions indicate effective reach into the general DHB population for enrolment there are (33% Māori, 2% Pacific, and 64% Non-Māori/Non-Pacific). Table 4 below presents the demographic programme participation statistics in more detail.

Table 4: Gout Stop demographics, age and ethnicity of unique participants with data available n=1308

Age	Māori	Pacific	Non-Māori/Non-Pacific	Total
15-29	7.4% (97)	0.9% (12)	1.1% (14)	9.4% (120)
30-44	17.1% (224)	1.8% (24)	4.9% (64)	23.8% (308)
45-64	27.2% (355)	1.5% (20)	13.0% (171)	41.7% (540)
65+	12.0% (156)	0.6% (8)	12.5% (191)	25.1% (355)
Grand Total	62.6% (817)	4.9% (64)	32.5% (440)	100.0% (1308)

Over two thirds of the programme participants (68%) were over the age of 45 across the programme. Māori are significantly over-represented in the younger age brackets, making up 72% of participants under the age of 44 (23% of total participants). Tables 7 and 8 in this report discuss the gout burden of disease in further detail with a comparison against the reach of the programmes.

5.1.2 OMG demographic profile

Owing My Gout data reflects the significant Pacific population in the Counties Manukau DHB region. **The Pacific population represent 56% of the total programme participants, with**

25% Māori, and the remaining 18.5% Non-Māori/Non-Pacific. These proportions indicate effective reach into the general DHB population (21% Pacific, 15% Māori, and 63% Non-Māori/Non-Pacific.) Table 5 below presents the demographic programme participation statistics in more detail.

Table 5: Owning My Gout demographics, age and ethnicity of unique participants n=158

Age	Māori	Pacific	Non-Māori, Non-Pacific	Total
15-29	2.5% (4)	8.2% (13)	5.1% (8)	15.2% (25)
30-44	7.0% (11)	16.5% (26)	8.5% (14)	32.0% (51)
45-64	13.9% (22)	26.6% (42)	6.3% (9)	43.5% (73)
65+	1.9% (3)	5.1% (8)	2.5% (4)	9.5% (15)
Grand Total	25.3% (40)	56.3% (89)	22.4% (29)	100.0% (164)

Just under half (44%) of Owning My Gout programme participants were between the ages of 15 and 44. Over half of these identified as Pacific (24% of total participants).

When exploring the breakdown of Pacific ethnicities in the Owning My Gout programme participants, majority were Samoan (36%), Tongan (29%) and Cook Island Māori (24%). This reflects reasonably well, the Pacific ethnic profile of Counties Manukau DHB. Table 6 below shows the full ethnic breakdowns for Pacific ethnicities in Owning My Gout.

Table 6: Owning My Gout breakdown of Pacific ethnicities

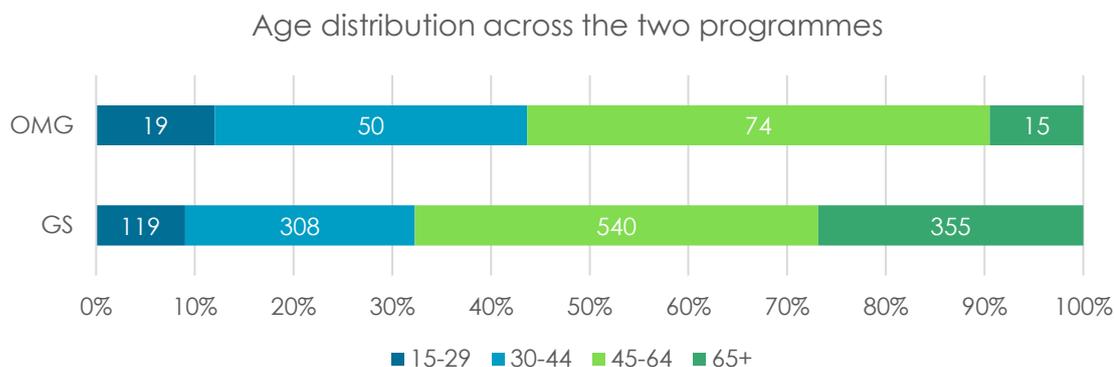
Pacific ethnicity	Percentage
Samoan	36% (32)
Tongan	29% (26)
Cook Island Māori	24% (21)
Niuean	4% (4)
Fijian	3% (3)
Tokelauan	2% (2)
Pacific Island (Other)	1% (1)
Total	100% (89)

5.1.3 Reaching younger people

Gout is perceived as a condition that affects older people and those reached by the programmes reflects this. However, it is the proportion of younger people in these programmes that is of real interest as 44% of those enrolled in OMG and 33% of those enrolled in Gout Stop are under 45 years old.

These younger populations have much to gain in terms of gout management, (continuous employment, participation in sport, whānau and community activities) however their work, contexts and community responsibilities, as well as the acceptance of the long-term nature of gout can be a barrier to persisting with long term treatment. The age profile of participants is a key consideration in the design and delivery of programmes.

Figure 8: Age distribution of both programmes



5.1.4 Reaching males

Both programmes are reaching a higher proportion of males than females with gout. Men traditionally experience higher rates of gout, as they have higher levels of uric acid than women for majority of their lives (this changes when women reach menopause)¹⁵. The following table presents the percentages and counts of unique programme participants by gender. These gender categories are taken from the dataset collected by both programmes. Owing My Gout had six patients where gender was not recorded.

Table 7: Gender breakdown of both programmes

Gender	Gout Stop		Owing My Gout	
	Percentage	Count	Percentage	Count
Male	82%	1078	87%	142
Female	18%	234	10%	16
Unknown	0%	0	3%	6
Total	100%	1312	100%	164

This is concordant with the HQSC Gout Atlas of variation, which identifies males being significantly more likely to have diagnosed gout. In New Zealand, gout is diagnosed in 8.4% of males, and 2.5% of females, over a three-fold difference. These programmes are reaching between four and eight-fold more males than females.

¹⁵ Phipps-Green, A. J., Hollis-Moffatt, J. E., Dalbeth, N., Merriman, M. E., Topless, R., Gow, P. J., ... & Merriman, T. R. (2010). A strong role for the ABCG2 gene in susceptibility to gout in New Zealand Pacific Island and Caucasian, but not Māori, case and control sample sets. *Human molecular genetics*, 19(24), 4813-4819.

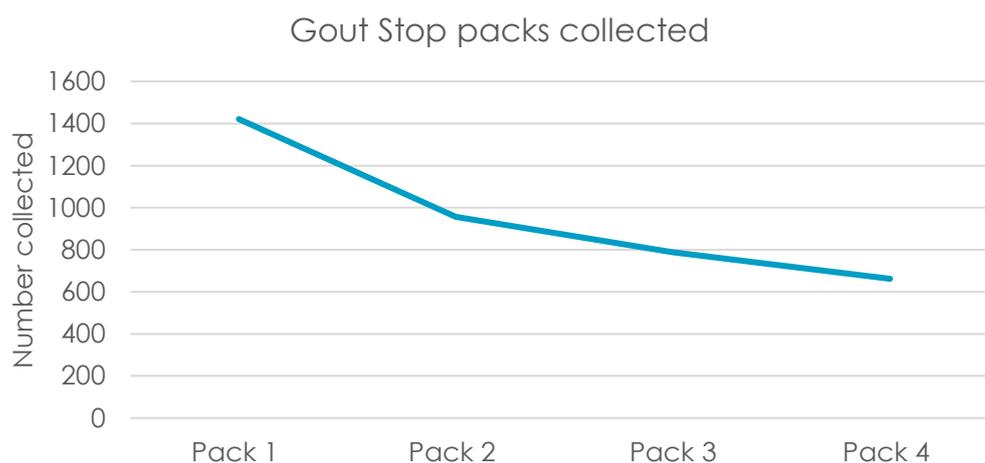
5.2 Programme participation

Best practice gout management progresses from treating the symptoms of an acute flare to titrating to a dose of long-term urate lowering medication e.g. allopurinol, that can keep urate levels at target of $>0.36\text{mmol/L}$ long term. It is a feature of both programmes that for many patients, participation does not last beyond initial symptom relief. This is not uncommon in terms of management of gout as there are well entrenched community beliefs that gout is an acute flare which needs short term pain relief. It can take some time for people with gout to understand and accept that gout is a long-term condition that needs to be managed with long-term medication.

5.2.1 Gout Stop participation

From the programme data that was available for this evaluation, it was difficult to ascertain the extent of 'participation' in the programme. An assumption was made that if patients were collecting programme packs, they are engaging with the programme to illustrate participation. We note that people other than the patient may collect their prescription packs, and collection does not mean that any knowledge, skills or understanding has taken place. Figure 9 shows collection trend for the Gout Stop programme over the course of the programme.

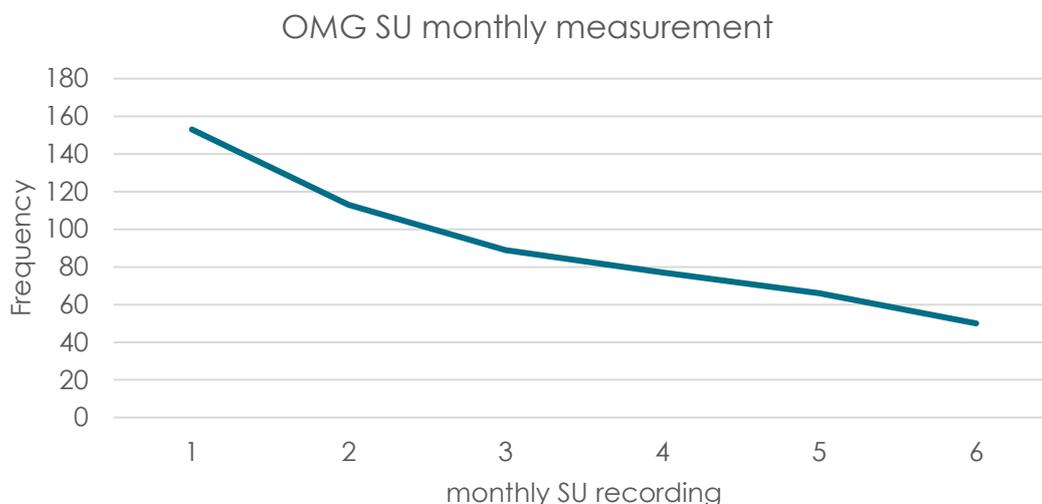
Figure 9: Gout Stop pack collection



Programme data shows that two in three (66%) participants progress to pack two. Seven in ten (70%) of those who collect pack two, go on to complete the programme, collecting all four packs. This highlights that the biggest loss in participants is between packs one and two, a trend well known to programme providers.

A similar trend is seen in the Owing My Gout programme data, where the steepest drop off point is within the first month. Programme engagement and participation is measured and recorded differently, as patients are required to re-visit the pharmacy for monthly point of care testing. The assumption here is that if the individual is visiting the pharmacy each month and picking up a prescription, then they are engaged and participating in the programme. Figure 10 below depicts a very similar trend to the Gout Stop programme data, with the highest drop off between the first and second visit once the pain has subsided. Data shows that seven in ten (73%) of those who are enrolled in the programme, and visit the pharmacy, go on to visit the second month.

Figure 10: Owing My Gout monthly participation of serum urate level testing



This point in the patient pathway is a key point for intervention and building of health literacy to encourage patients to continue taking allopurinol to reduce urate levels and minimise the risk of another acute flare. In the Gout Stop programme there are multiple opportunities to minimise the risk of drop off; the kaiāwhina attempts a first engagement with patients after two weeks, the point at which the pain has subsided, and the first course of pain-relieving medication has been completed.

“What that pack basically does is take the pain away – everyone loves that part. What they don’t do is the follow ups for the next packs and so I try to get in there and explain: ‘Do you know what you’re taking and why you’re taking it? The next pack is just as important because you’re pain free now, but we need to maintain that’.” (Gout Stop kaiāwhina)

This highlights not only the importance of building health literacy, but the timing of it. During an acute flare all the patient is focussed on is pain relief and at that time they are cognitively not able to take on new messages about gout. However, when the pain has diminished it is the ideal time to start talking about long term management and to start to build new health literacy knowledge of skills about the role of genes and how food and drink has not caused their gout

The kaiāwhina attempts to build rapport and relationships with patients, as there can be opportunities to support their participation via the wider whānau as well as identify others who would benefit from the programme.

“I’m very careful about how I approach them – they can hang up on me at any time. But I do mention say ‘hey, is this common in the whānau? Are there other members of the whānau who are suffering from gout and don’t know who to talk to?’ I’m more than happy to talk to and visit people – I’ve had a few take it up.” (GS kaiāwhina)

The Owing My Gout programme is structured in a different way from Gout Stop and does not have a time bound exit point. Patients continue in the programme until they reach their target for three consecutive months. As a continuous programme, there is little need for ‘re-entry’ as such, as patients simply disengage, then reengage and continue on the programme. Despite this, of the sample of 153 people, 13 were identified as re-entering the programme.

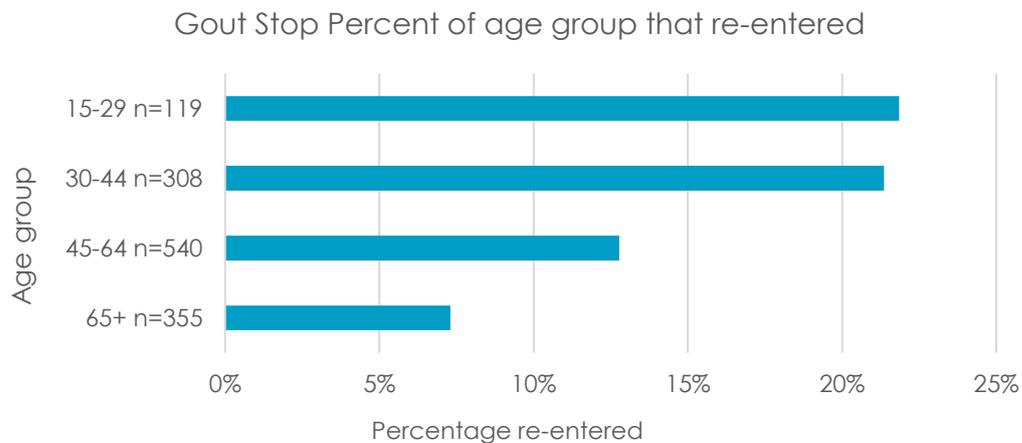
5.2.2 Drop off, re-entry and completion of the programmes

It is common for patients to drop out of the programmes and not reach urate success the first time they engage. Acknowledging and accepting that gout is a long-term condition can be challenging, particularly when outside of an acute flare, there are no symptoms. After the pain experienced during a flare is gone, there is little motivation to continue with urate lowering treatment, particularly for those where their health is a lower priority. Pharmacists often reported challenges in contacting patients for follow up prescriptions or point of care testing. Continuing engagement with patients on the programme can be challenging and time consuming, and sometimes re-engagement is only prompted by the experience of another flare.

“There are a few Missing In Actions there – sometimes cell phones disappear, sometimes we’re trying to get blood tests or send them back to the doctors, and there’s just no way to contact them so they fall off.” (GS Pharmacist)

Clear re-entry data was available for the Gout Stop programme. This data indicates that nearly a quarter of all participants drop off and re-enter the programme more than once. Re-entry rates by ethnicity indicate that Māori (18%), Pacific (22%) and younger people (22% of 15-29s and 21% of 30-44s) are more likely to re-enter the programme. In comparison, Non-Māori, Non-Pacific patients were more likely to complete the programme and were recorded as re-entering just 6% of the time. Figure 11 displays the percentage of different age groups re-entering into the Gout Stop programme in more detail.

Figure 11: Gout Stop percentage of re-entry by age



The design of the OMG programme is such that the concept of 're-entering' is much less common; patients simply re-engage with the pharmacist or GP and continue their gout management journey. Providing comparative data is difficult, but the trends of younger people disengaging was raised in interview feedback

It is important to note that re-entry (or re-engagement) into the programme is actually a positive outcome and contributes to the individuals' journey to gout self-management. Re-entry demonstrates understanding that gout is a long-term condition as well as continued engagement with the health system. Often it takes a significant amount of time for individuals to accept the long-term nature of gout and its management.

“Re-entry really does happen, and for some people it's two or three times before they finally get it and understand that actually, yes, they do need to be on this for life.” (GS Pharmacist)

5.2.3 Encouraging participation

Given the challenges patients experience in continuing to engage with the programmes, feedback from pharmacists suggest many are proactively following up with patients yet still have trouble maintaining engagement.

Evidence from interviews with pharmacists for both programmes indicate that there is enough variation in the Standing Orders that they operate under, and the packs they dispense that they can tailor dispensing to support participation and engagement.

Pharmacists have experimented with different dispensing methods, such as using blister packs, bottles with labels and sachets, to make medication adherence as easy as possible for their patients. Pharmacists are well placed in their communities to understand what works for patients and what supports continued adherence and engagement. Some pharmacists acknowledged traditional pill bottles were the most effective for patients, while other pharmacists supported using blister packs for those who are already on long term medication but could be confusing for those who had never taken long term medication before. Having the flexibility to dispense using their judgement about what best suited the patient, and autonomy, strongly supports the buy-in of pharmacists which is critical to programme success.

"My thinking is that people can only retain two or three key messages at once. This is why I stopped using blister packs, because I was using their cognitive capacity explaining how it works. Remember they are also in acute pain and they just want their tablets and get out of here." (GS Pharmacist)

Methods to support engagement and encourage participation have also included dispensing more medication at once to facilitate creating a habit of taking medication daily. Introducing allopurinol as a continuation of the initial anti-inflammatory medication can support patients to continue taking medication if it is dispensed as a whole, rather than a 'stage 2' medication. This aligns with the recommendations made by BPAC¹⁶.

"We originally dispensed the two-week acute treatment prescription, but we found 'oh wow, that fixed me', so they wouldn't come back for the next prescription. So we do a sachet pack and make up a six-week roll, which works better than the two week start pack." (GS Pharmacist)

5.3 Pathway standardisation and adaptations: Key insights

Both programmes provide a standard pathway for all those enrolled. Often programmes have differentiated pathways for different groups based on relevant status or needs. The gout programmes have no differentiation articulated for different groups such as first-time presenters, re-enrolled or younger people for example.

We learned about adaptations in delivery through our interviews, as providers responded to the needs of individual people. This included:

- For patients who are Māori or Pacific, it was seen as important to explain the genetic link for prevalence of gout and ensure patients understand this link. Key

¹⁶ <https://bpac.org.nz/2018/gout-part1.aspx>

research in New Zealand has identified specific gene variants that mean for Māori and Pacific peoples, the chance of gout is increased by more than five times¹⁷.

- Patients who are new to regular medication may need coaching to make this part of their routine. First time blister pack users also need guidance on how to use the pack.
- There are rare but well-known side effects of taking allopurinol, including nausea and skin rashes. Pharmacists identified the delicate balance in sharing this information and the appropriate level of risk, with patients who are hesitant to take long term medication.

"It's a trade-off – how much do you tell them about that [side effects], when we're trying to get them to take it every day." (OMG pharmacist)

- Pharmacists used their discretion with the dispensing mode and frequency to encourage persistence. For example, we learned of one pharmacist who provided a patient with three months medication at one time because they knew he would not return.

The programmes have been designed and are being delivered in the same way for all patients, however verbal messages to Māori and Pacific about genetic predisposition are provided to these people. The delivery of these messages relies heavily on the provision and quality of how health literacy is built with patients. This information is also in the gout booklets. In Northland the booklet developed by the Māori Pharmacists Association, 'Gout, how to live happily without the pain' (referred to as the green book), was provided as well as the 'Stop Gout' booklet it was developed from. "Stop Gout" (referred to as the brown book) was developed by the Ministry of Health and Workbase. Owing My Gout use the 'brown book' as its main resource as it is also available in Tongan and Samoan. Both booklets present key messages and information in a simple and visual format and contrast strongly in style with some other patient resources that were also used by some pharmacies.

The potential to increase programme effectiveness through programme differentiation should be considered. Younger Māori and Pacific men may respond to a more tailored form of support. This is an ideal opportunity for co-design.

¹⁷ Hollis-Moffatt, J. E., Xu, X., Dalbeth, N., Merriman, M. E., Topless, R., Waddell, C., ... & Stamp, L. K. (2009). Role of the urate transporter SLC2A9 gene in susceptibility to gout in New Zealand Māori, Pacific Island, and Caucasian case-control sample sets. *Arthritis & Rheumatism: Official Journal of the American College of Rheumatology*, 60(11), 3485-3492.

6. FACTORS INFLUENCING PATIENT PARTICIPATION

Patients experience a number of barriers to engaging with gout programmes, these include those generic to primary care (such as cost, travel and availability) as well as those more specific to gout (access to labs, over the counter options and reduced incentive when pain fades). Patient's mental models relating to gout were identified as strongly influencing participation; this includes outdated beliefs about the causes of gout, whakamā or shame associated with gout and lack of understanding and acceptance that gout is a long-term condition. Programme design can reduce some of these access barriers and effective building of health literacy is important to support behaviour change.

6.1 Accessibility of primary care for patients

The structural factors that influence patients accessing the programmes are complex and multi-faceted. Many of these reflect known common barriers to primary care engagement. Others are specific to the nature of gout and programme delivery.

- Providers we spoke with were aware that the cost of accessing primary care was a barrier for some people with gout. A recent HQSC survey¹⁸ showed that:
 - One in five people reported not visiting a GP or nurse due to cost in the last 12 months. For those aged 15 – 44 years this was almost one in four (37%).
 - One in five Māori and Pacific peoples reported not collecting a medicine due to cost in the past year.

These are the populations with most to gain from gout programmes, yet cost is a likely barrier.

- The providers we interviewed were aware the \$15 prescription cost (three charges of \$5 for three medications) was prohibitive for some. The subsidising of blister packs may benefit some patients, but this cannot be assumed as other methods, including the standard bottles and (cheaper) sachets, were preferred and used also.
- Time to access primary care was also identified during interviews with providers as a barrier. Many people with gout are working and have to prioritize time to attend GP appointments. We heard it was harder for those who live rurally or depend on others for transport to get time to see a GP, go to the laboratory, and may also have limited opportunities to go to the pharmacy. Others simply have complex lives where their health is not an immediate or high priority.
- Bias in primary care is both general and specific to gout. General, as not all organisations and providers able to engage effectively with all population groups, particularly if they are minority groups. Specific, in that variation to prescribing appropriate medication for gout occurs.
- The quality of the relationship people have with their GP and practice staff will influence their willingness to engage and trust their advice. Conflicting advice,

¹⁸ <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/health-service-access/>

hurried consultations and heavy locum use were factors identified in interview feedback from patients as contributing to negative experiences.

- The availability of over the counter (OTC) effective remedies for treating acute gout flares (for example Voltaren) can remove the painful symptoms that is usually the primary motivator for seeking medical help.
- Patients treated at emergency department and after-hours services, are provided with pain relief which removes painful symptoms. As a result, these patients have reduced motivation to follow the advice to see their usual GP for ongoing management.
- For the OMG programme, patients were required to use a pharmacy that is part of the programme. The regional reach of Gout Stop meant any pharmacy could be used.

6.2 Patients preconceptions about gout and medication

Peoples capacity to engage, accept and manage their gout varies significantly. This ability to change behaviour is influenced by people's thinking and understanding about gout. Interviews identified that this is influenced by:

- The whakamā or shame around gout that is rooted in outdated but strong beliefs that the illness is self-inflicted through laziness, alcohol and overindulgence. For Māori and Pacific peoples, the knowledge that there is a genetic predisposition for gout is important for reducing the shame around it.
- The severity of the symptoms and the impact on daily life from gout. Unbearable pain is a motivator to seek help but the determination to "staunch it out" remains for many.
- The side effects of medication may be a deterrent for some.
- The consistency, personal relevance and trustworthiness of new information about gout and its management.
- Understanding and acceptance that gout is a long-term condition that requires long-term treatment. For those already used to long-term medication one more pill may be easier to accept than lifelong medication for a 30-year-old.
- Reminders to pick up medication or to have blood tests can reinforce the seriousness of gout and can be motivating for people when they know someone is monitoring and checking up on them.

"I said I was sick of walking around with a sore foot. If you can help me get better and stay better, then I will do it" (Gout Stop patient)

"It's been really good having someone ring me every so often and see how I'm getting on." (Gout Stop patient)

"They don't understand the long-term implications; I try to anchor it in their own experiences – their relatives." (Gout Stop Pharmacist)

7. FACTORS INFLUENCING PRIMARY CARE PARTICIPATION

The interdisciplinary delivery of gout programmes represents a shift in the traditional roles of GPs, nurses and pharmacists and introduces opportunities for practice nurses and non-regulated roles, such as kaiāwhina. While pharmacists seem to embrace this opportunity to work to top of scope there is awareness of a more mixed reaction from general practice for a variety of philosophical, practice and business reasons.

7.1 Pharmacy influences

There is a shifting culture in pharmacies to work at top of scope, with pharmacists able, and willing, to move away from purely dispensing medications. These gout programmes offer a chance for pharmacists to gain contracts that support and fund time away from dispensing, developing their role to encourage health service provision.

"Pharmacists are hugely trained, very willing, have great relationships with their regulars and dare I say it, have 'time' and are 'free'. They are willing to go beyond their traditional dispensing role and want to become health practitioners." (Gout Stop PHE employee).

"I'm excited; it's great to be paid to work this way with people." (Gout Stop Pharmacist)

Pharmacists are motivated to change the way they work in a landscape that is changing around them: Retail sales are falling; pharmacies are reducing staff and new operators with business models that use free prescriptions as loss leaders are emerging.

The relationships and communication between pharmacy and general practice are central to the success of the programmes. Constant and open communication supports these health professionals to work in collaboration with one another to manage the patient. These trusting relationships enable the programme to function seamlessly. Co-location of pharmacies and general practice may contribute to these relationships and communication; however, they are not essential to success.

"It's so easy because if I have a query about anything that they've done when I see the patient next, I can just zip down the hall and ask [the pharmacist]. We've always worked as a team and it's easy because we're under the same roof." (OMG GP)

Fair compensation for the time pharmacists are required to spend with patients influences how willing they are to expand their role and take part in the programmes. Ensuring that the pharmacy service specification adequately covers the resources required for pharmacists to participate in the programme is a key driver of engaging. For the most part, these two programmes appear to have struck the right balance.

Pharmacists also report enjoying some degree of autonomy when dispensing. Understanding what works for the patient population they serve, pharmacists are well-placed to judge the dispensing method (e.g. blister pack, bottles or sachets), and how long they should dispense for (e.g. dispense two weeks, or a months' worth).

Implementation insights:

- The changing business environment of pharmacy with free prescriptions and falling retail sales has created the right climate for pharmacists to want to adapt their practice.
- Having an appropriate space for patient consultation is key to enable this wider scope of practice to take place safely for patients.

- Ensuring that the pharmacy is appropriately resourced to allow pharmacists to spend private time with patients carrying out point of care testing and building health literacy.
- Key to success is making sure pharmacists are trained adequately to deliver their components of the programmes, including the use of BeneCheck © meters, and how to meaningfully build health literacy with patients.
- Their ability to engage with community beyond the pharmacy door and their ongoing follow-up of patients.

7.2 General practice influences

Both programmes support integrated and collaborative working in general practice. This encourages shifting responsibility of gout patients to nurses and pharmacists. The willingness of GPs to share delivery of patient care is variable both in, and across, practices. This is not unique to gout patients and treatment. The culture of change in general practice is not strong, with new ways of working often taking significant time and resource to implement across the system. This new way of managing gout patients was reported to be particularly challenging to accept for GP business owners, as contracts were shifted out to pharmacies to manage patients that previously came in for regular consults.

"There's GPs that just get so worked up about nurses and pharmacists doing anything that they could do...They see it as a threat." (OMG GP)

General practices that operate in different ways, outside of the traditional owner-operator model are more willing to embrace new ways of utilising other health professionals to support patient care.

"We're a trust, so we're not for profit and we want to do as much as we can for the least amount of money." (OMG GP)

Those GPs that do embrace change, often act as a source of promotion to the hesitant. A natural part of implementing a new programme is working with the willing first to establish an effect, that can then create some reassurance for those who are late adopters. It may be that health professionals who are newer to the profession have less ingrained beliefs about roles and responsibilities.

"I started doing this [programme] from the start, but there were others at my practice that wouldn't have a bar of it. Over time they saw my patients were doing really well and I had more time to work with others and slowly they've all come around. I'm younger though and don't have as much of a stake in the business. I'm just trying to do what's easy and works well for my patients." (GS GP)

"Some GPs think its bad practice not to see patients, but they weren't seeing them anyway. It's a trade-off between thoroughness and efficiency and some don't understand [this is better] - it's a very old-fashioned view" (OMG GP)

We were unable to interview practice nurses supporting delivery of Owing My Gout and have limited reflections from others on this role in practice. Nurses building health literacy and oversight the programme alongside pharmacists is likely to be more acceptable to PHOs and practices who want to retain greater involvement and control over the delivery

of education. Nurse led models for chronic diseases, including gout, are becoming more prevalent and national and international evidence can inform this.

Another challenge for general practice, is considering where gout as a condition sits on the list of priorities. There are no national or regional targets associate with gout management or health outcomes, meaning that the condition has to compete with initiatives and programmes that do support targeted, audited conditions. Unless gout is selected as an option under the equity actions in a DHB Annual Plan there is no policy incentive at a regional or national level to support innovation or changing business as usual, which can be a barrier to general practice driving the programme. There are many other competing interests which do have these levers.

Programme engagement is particularly dependent on relationships between the programme leads and general practice. Understanding the context of primary care, their particular challenges, and pressure points, can support programme leads to build relationships and networks and gain traction. PHOs are in a strong position to lead or facilitate this.

"It's not a public sector where you can just say something, and they all do it. It's all about the relationships and about motivating private owners to do what you want them to. Takes a lot of relationship building, networks and nurturing. You have to make it seem like it's their idea – bring people on the journey. It's about co-design." (Gout Stop PHE Staff)

Implementation insights:

- The leadership role of the PHO, being close to primary care and having stronger relationships and understanding is crucial to supporting buy in.
- Work with the willing first, to set up systems and demonstrate outcomes to encourage those who are more hesitant.
- Newer health professionals and other initiatives driving integrated teamwork will support uptake of new programmes.
- Practice champions – GPs who believe in the programme and can demonstrate its effectiveness can bring an entire practice on board over time.
- Clinicians may have existing skills in building health literacy and cultural competency, but this cannot be assumed.
- Nurse led delivery, or co-led delivery is a model that retains greater control for general practice and may fit well with existing roles and programme delivery.

8. PROGRAMME OUTCOMES

This section presents findings that relate to programme outcomes in terms of clinical outcomes (target serum urate achieved), equity outcomes, then in terms of broader health literacy and community benefits.

8.1 Clinical success

Gout Stop measures successes as reaching SU <0.36mmol/L within 91 days. Of the 1421 enrolments in that had occurred more than 91 days ago, around half (47%) complete the programme with, 253 (18%) reaching the SU target, 167(12%) continuing with titration. OMG is not a time limited programme but of the 148 people on OMG at least three months, 48 (29%) had SU <0.36mmol/L at their last three recordings and a further 5(3%) were in titration.

A common definition and use of success criteria across programmes would be useful and should reflect the ultimate aim of transition to long term allopurinol.

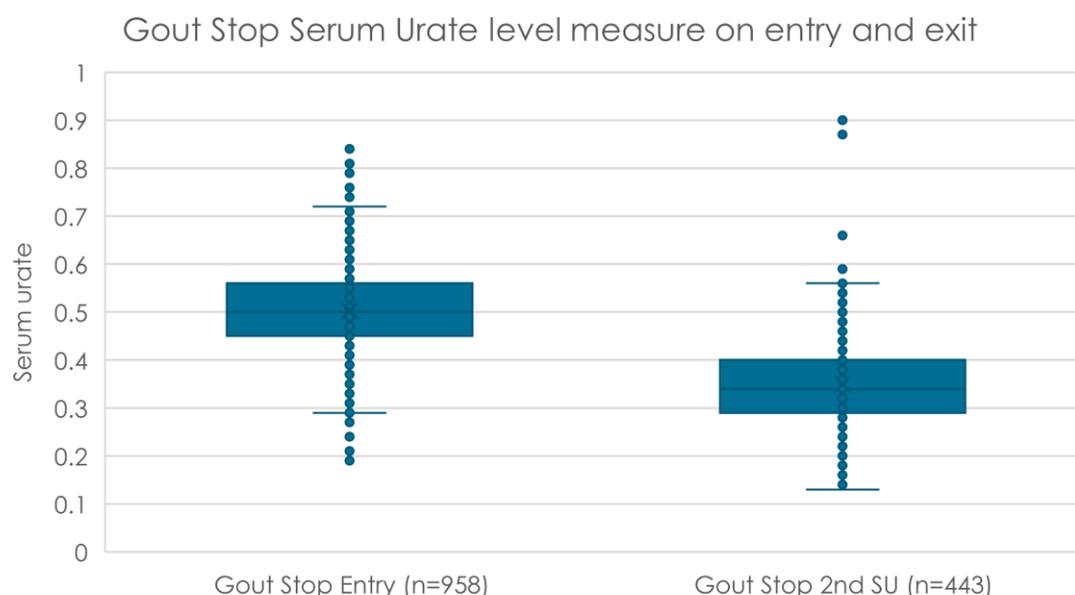
SU having reached below 0.36 mmol/L is considered clinical success as serum urate is at a safe level that won't cause long term damage. To have really achieved that safe level, 0.36 mmol/L should be maintained for three consecutive months.

8.1.1 Gout Stop clinical success

The first chart presents the distribution of entry and exit SU recorded for all enrolments. The 'box' represents this interquartile range with the lines extended above and below representing the quarter of people with the lowest and the quarter of the highest scores respectively. The median entry measure was 0.54mmol/L and the median second measure was 0.35mmol/L.

When people have a gout flare, their SU at the time of flare can be artificially low because the SU is crystallising rather than circulating in the blood stream. It is preferable for clinicians to have a recent SU measure rather than one taken during an acute flare of gout. If previous measures are available, they can be accessed online.

Figure 12: Gout Stop SU on entry and exit



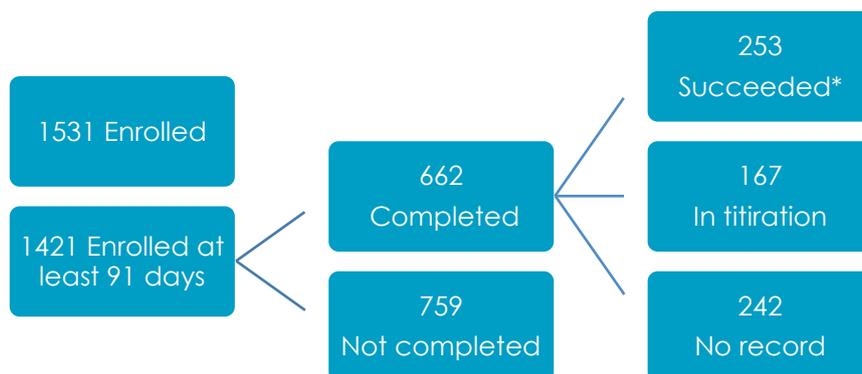
Of all enrolments, 958 had an entry SU entered. The date of the first SU measure is recorded by the pharmacist and 402 (42%) of these measures were taken in the 14 days before referral or the 7 days after referral, so these SU entry measures are likely to be on the lower side because of the acute stage of gout. For this reason, we have not taken matched pairs of data to look at individual patterns of change or calculate average change as both are potentially misleading.

The diagram in Figure 13 displays the flow of enrolments and their status. It shows that of the 662 enrolments that completed the 91-day programme, 443 had a second SU entered at the end of the programme. Of these 443 enrolments, 253 (57%) had 'succeeded' within the timeframe, i.e. had SU was <0.36mmol/L. This is a very narrow definition and measure of success as the reality is that people drop out before the end of the program or don't have a second SU recorded.

Overall programme success rate is reduced if it is considered as a percentage of all 1,421 enrolments that had occurred more than 91 days ago as 18% (n=253) 'succeeded' within the timeframe, i.e. had a SU of <0.36mmol/L recorded. A further 167 (12%) were in ongoing titration. Across the programme as whole this means around three in ten of all enrolments were on their way to longer term gout management.

Figure 13 illustrates the patient flow and how these numbers relate to the initial number of people enrolled.

Figure 13: Gout Stop enrolment flow



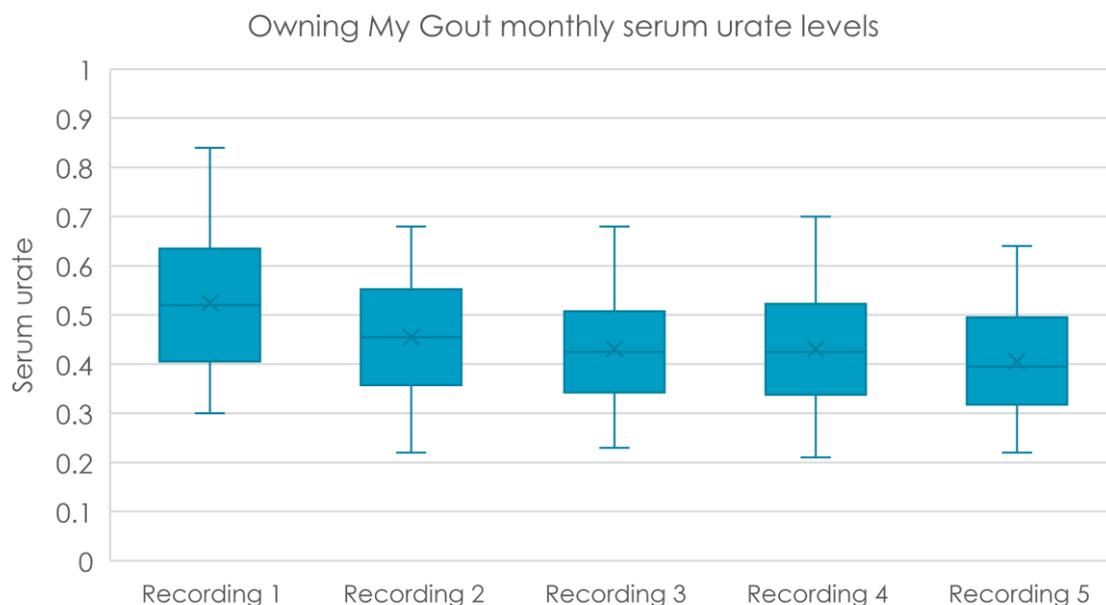
*Recorded as achieved SU<0.036mmol/L on their end of programme (second) measure.

Those 253 patients that succeed within the 91 days should have their maintenance dose of allopurinol entered in the data base. For the 196 enrolments with this entered, 300mg is the most frequent dose, but it ranges between 100mg and 600mg. Monitoring does not extend beyond this timepoint.

8.1.2 OMG clinical success

The data collected by OMG lists the month of the first and subsequent gout SU recorded and the result. The results show a gradual downward trend as SU measures reduce. This includes current enrolments so the numbers reduce because of people dropping out of the programme and because they may have only been enrolled a short time.

Figure 14: Monthly serum urate levels



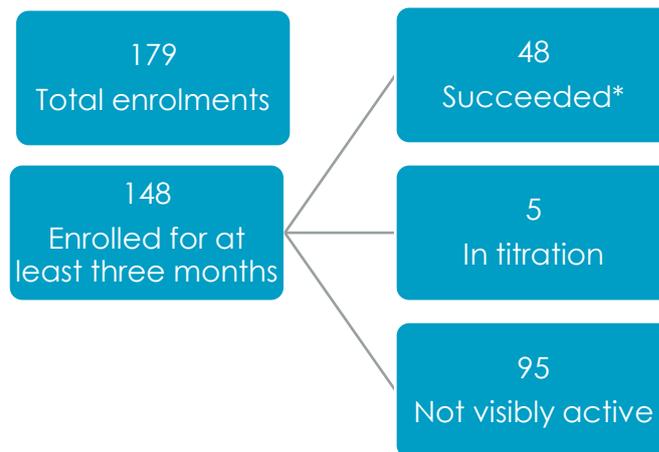
Of the 148 people on OMG at least three months:

- 71 people (43%) had achieved SU <0.36mmol/L at some point in time.
- **48 people (29%) had SU <0.36mmol/L at their last recording and had maintained this for the previous three months. This is the programme definition of success.**
- For those achieving the target serum urate levels, half of them took between three and seven months¹⁹ (median 5.3 months) to reach it for the first time.
- Of the 148 enrolments that had begun more than three months ago, 5(3%) were continuing with titration and the remaining 95(64%) were not visibly active in the programme.

These numbers are displayed on the following diagram for clarity. We have introduced the category of enrolled for at least three months for analysis only and to support some degree of comparison with Gout Stop.

¹⁹ Not including three people who never had a reading above 0.036mmol/L

Figure 15: Owning My Gout enrolment flow



*Achieved SU<0.036mmol/L for three consecutive months

8.1.3 Clinical success summary

The different programme structures, timeframes and data recording limit the scope for comparative analysis. We have tried to present a broad picture of their achievements in terms of clinical success with the data available. These data sets identify the following:

- Three to four enrolments in ten have either achieved their serum urate or were progressing towards it (in titration) after three months on the programmes.
- There is a relatively high rate of drop out or lack of visible data for around six or seven total enrolments in ten.
- The time it may take for people to achieve the desired SU can be many months, certainly more than the three months Gout Stop measures success. Expecting success within a short window of time may disincentivise patients (who need longer to titrate to a long-term dose of allopurinol) and not highlight the real success of the programmes (which is about transitioning people onto long term allopurinol).
- Common measurement models and minimum data collection would facilitate the sharing of results and learning about what works and for whom across different programmes.
- Additionally, clinical success should be considered achieved after three months of SU <0.36mmol/L. Programme measurement models and incomplete data sets mean this is not easily evidenced. Neither programme has collected to data that evidences the transition to long term allopurinol and gout management, though OMG is currently extending its monitoring timeframe.

8.2 Promoting equity

Key points: Both programmes demonstrate they are equitably reaching Māori and Pacific peoples. Enrolment profiles show both programmes exceed the needs-based proportion of Māori and Pacific peoples in their districts. Non-Māori /Non-Pacific peoples are more likely to maintain engagement with programmes and more likely to achieve SU success.

In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes²⁰.

This is how the Ministry of Health defines equity. Gout is an equity issue. The HQSC Atlas of Healthcare Variation identifies the higher prevalence of gout in Māori and Pacific peoples as well as their poorer access to appropriate medication and management. As such, gout has also been identified by PHARMAC as a priority condition for improving access equity to medicines. PHARMAC defines medicine access equity as:

The absence of avoidable, unfair or remediable differences in funded medicine access among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other means of stratification. Medicine access equity means that everyone should have a fair opportunity to access funded medicines to attain their full health potential, and that no one should be disadvantaged from achieving this potential. In this context, some groups may require additional support to access funded medicines than others.

Gout is a Te Tiriti issue. The principle of active protection brings a responsibility to promote and achieve equitable health outcomes for Māori and understanding gout within a Māori model of health.

This section analyses the reach, participation and outcomes of the programmes, with an equity lens.

8.2.1 Reach through enrolment

To be equitable, Māori and Pacific should be able to access services in proportion to their need. Across New Zealand Māori are twice as likely, and Pacific peoples three times as likely, as non-Māori non-Pacific peoples to have gout. Access rates that reflect this higher level of need in an equitable system, i.e. are weighted to show prevalence of need, provide a more accurate measure of equity of access.

Both programmes have demonstrated high proportions of their Māori (Gout Stop) and Pacific (OMG) communities in their enrolment profile. Equitable reach needs to consider the needs in the population rather than just the ethnic profile. Table 8 and Table 9 present data that shows a simple adjusted population burden of disease calculation. This is calculated by weighting the demographic profile of the DHB with the prevalence of diagnosed gout in those DHBs from the 2016 Gout Atlas of Healthcare variation. This compared to the ethnicity of those enrolled on the programmes.

Table 8: Northland needs-based prevalence and reach

Ethnic group	DHB % pop	DHB Gout Prevalence	Simple burden of disease weighting	Gout Stop enrolment	Difference
Māori	33.9%	12%	48%	63%	14%
Pacific	2.1%	10.4%	3%	5%	2%
NMNP*	64%	6.5%	49%	33%	-17%

*Non-Māori / Non-Pacific ethnicities

²⁰ <https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity>

Figure 16: Equity of reach into key populations

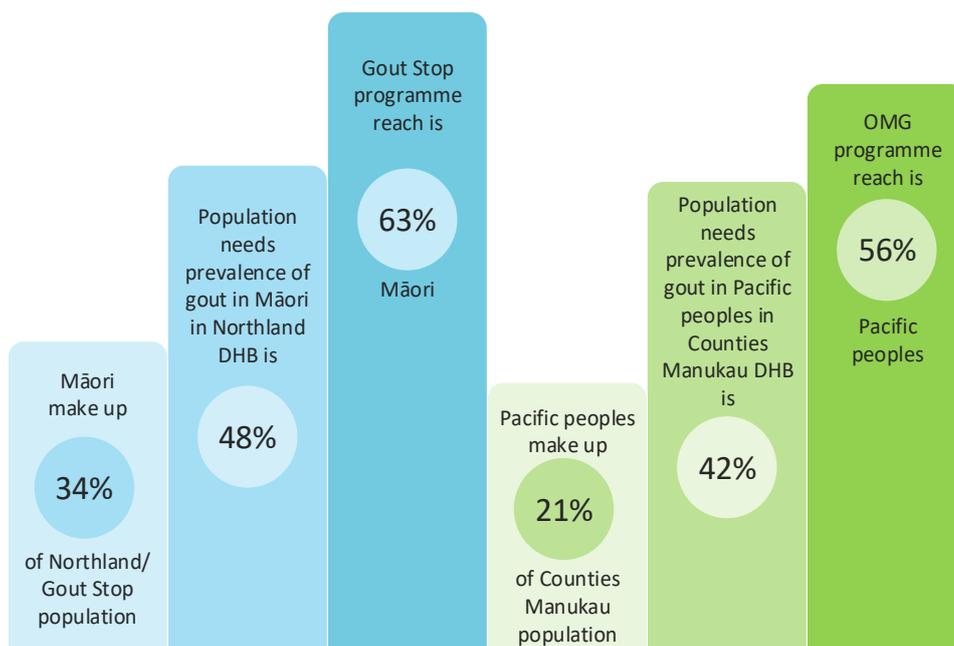


Table 9: Counties Manukau needs-based prevalence and reach

Ethnic group	DHB % pop	DHB Gout Prevalence	Simple burden of disease weighting	OMG enrolment	Difference
Māori	15.7%	10.6%	21%	25%	5%
Pacific	21.1%	16.2%	42%	56%	14%
NMNP	63.2%	4.8%	37%	19%	-19%

*Non-Māori/ Non-Pacific ethnicities

Figure 17 illustrates the scale of these differences and shows both programmes are promoting equity of reach into its prominent high needs populations. OMG also promotes equity of reach for Māori (exceeding weighted prevalence by 5%).

8.2.2 Equity of benefits

To benefit from the gout programmes (and experience the impact of those benefits), patients must participate in the programme long enough for benefits to be realised.

Gout Stop programme data showed that of the 1070 exited enrolments, the number of Pacific peoples is relatively small so should be interpreted with care.

- Non-Māori/Non-Pacific were much more likely to complete the programme (83%) than Māori (53%) or Pacific (57%).
 - Non-Māori/Non-Pacific were likely to achieve target SU (50%) than Māori (39%) or Pacific (30%).
- Non-Māori/Non-Pacific were only slightly more likely to still be engaged in managing their SU (succeed or still in titration) at the end of the programme (72%) than Māori (66%) or Pacific (56%).

Table 10: Ethnic comparison of Gout Stop programme outcomes

Data	Māori	Pacific	NMNP	Total
Exited enrolments	709	47	314	1070
Number completed programme	375	27	260	662
% of exited that completed*	53%	57%	83%	62%
No completed successfully**	132	7	114	253
% of all exited that completed successfully	19%	15%	36%	24%
Titration post 90 days	102	7	58	167
% of all exited that were in titration at 90 days	27%	26%	22%	25%
Number succeed or still in titration	234	14	172	420
% of all exited succeed or still in titration	33%	30%	55%	39%

*Collect all four packs ** achieve target SU

OMG data is not as straightforward to interpret to identify equity of participation. To explore equity patterns, we have analysed the ethnicity of people who have had less than four monthly SU recorded readings with those who have had four or more.

Table 11 presents these results and shows that:

- Non-Māori/Non-Pacific were more likely to be engaged in the programme for four or more months (49%) than Māori (53%) or Pacific (49%).

Table 11: Owning My Gout data ethnicity of participation for four or more months

	Māori		Pacific		NMP	
	n	%	n	%	n	%
Less than 4 readings	83	47%	176	51%	76	35%
4 or more readings	92	53%	171	49%	144	65%

For OMG 48 people had been on the programme more than three months and had a SU <0.036mmol/L recorded on their last three recorded entries. The ethnicity of these people is identified in Table 12 and this view of programme success shows that Non-Māori/Non-Pacific people are more likely to succeed than Māori or Pacific people. We do note that this is a limited view of success and is used to illustrate differences in benefits experienced by different ethnic groups.

Table 12: Owning My Gout entry data by ethnicity

Ethnicity	Māori	Pacific	NMNP	Total
Number enrolments	40	89	35	164
% of all enrolments	24%	54%	21%	100%
No. achieved target SU	7	26	14	48
% of ethnicity entered	18%	29%	40%	29%

8.2.3 Equity summary

Usual care, as evidenced by the Gout Atlas is highly varied in practice and isn't working well, particularly for Māori and Pacific peoples. These programmes work differently to reduce barriers and improve access to care and benefits of appropriate gout management. Both programmes are strong in terms of reaching Māori and Pacific peoples in their district, even considering the higher prevalence of need, their reach is strong. Once enrolled, both programmes are benefitting other ethnic groups more than Māori and Pacific peoples.

Differences in ongoing participation is not likely to do with the cost (as the GP visit and initial prescription change has been paid on entry) but the range of factors that are stronger barriers to engagement for Māori and Pacific.

It is beyond the scope of this evaluation to interpret the higher success rate in terms of SU at programme completion for Non-Māori/Non-Pacific (five in ten) compared to Māori (four in ten) and Pacific (three in ten)²¹. The OMG programme highlighted the increased length of time it takes some people to reach this SU and it cannot be expected, even with adherence, that all would reach the desired SU in 91 days; it is not long enough. Gout Stop success at 91 days would be more accurately reflected in terms of those who have reached SU or are still engaged/in titration on the programme at 91 days. These results show that they are impacting equity in a greater way.

As these two programmes (and other programmes) review their data and adjust delivery to improve reach, participation and clinical outcomes for patients, improvements should be considered not only for the programme as a whole, but with this equity lens applied to it also so that ongoing improvements are reducing, not exacerbating, inequities that exist.

8.3 Building health literacy outcomes

Health literacy outcomes for providers (relating to gout, local processes and building health literacy) have been identified from the providers interviewed. These generate the health literacy outcomes for patients (relating to understanding gout causes, the need for medication and the personal benefits for them of managing it long-term). These outcomes are not easily captured and the lack of direct patient feedback in this evaluation limits the degree of insight into the component about how health literacy was built with patients.

In this report programme leads, and other stakeholders, talked about education being given, or provided, to patients. Education components of programmes are designed to build health literacy in providers and patients.

²¹ Small numbers of Pacific peoples mean this should be interpreted with caution

Early in the evaluation we identified that outcomes about how patients' health literacy was built throughout the programmes were not quantifiable, and it was suggested participation be used as a proxy measure for this, assuming the more health literacy that was built with people, the more likely they were to persist with the programme. It has become clear that this is more complex and not a linear relationship; such assumptions are overly simplistic. The evaluation can offer insights into health literacy outcomes from the interviews completed; however, these were mostly provider interviews. The insights did concur with themes that have been evidenced in the literature around gout programmes, but it is not an extensive, nor likely complete, reflection of health literacy outcomes.

Stakeholders highlighted the aspects of messages that were critical to understanding and managing gout. These include:

- The need to replace old beliefs about gout with new information.
- That gout is not their fault and that Māori and Pacific peoples have a genetic predisposition because of the way their bodies metabolize urate.
- That diet is a trigger of an acute gout attack, not a cause.
- Gout is a long-term chronic condition and medication is needed for life to manage it.

"I suppose [the most helpful thing is] just learning about what gout is, I mean we've all heard this myth that only people who are alcoholics get gout, or that people who eat a lot of seafood get gout or rich food. But I don't eat rich food or drink. And so, after being explained what it was...I was able to get a bit more of a clue about it." (Client)

For patients the building of health literacy - repeated and consistent messages by people they trusted - was important too. This consistency has been supported by the professional development of providers and use of the same gout education booklets.

Providers who gave feedback on their learning about delivering the programmes valued the following aspects:

- Understanding gout prevalence, the scale and of inequity of non-optimal treatment was a motivator for those keen to promote the health of their communities.
- Skills to support the building of health literacy of patients emphasized the need to acknowledge existing beliefs about gout and understand patient learning as an incremental process.

"I ask them, 'can you tell me what you know already about gout?' and most people say, 'it's because I eat the wrong things'. I say, 'yes, that's what we used to think but we now know that's not the case'." (Gout Stop Pharmacist)

More thought (and resource) is required if gout programmes are going to capture learning outcomes for providers of gout programmes and the patients participating, either as a developmental check, quality improvement measure or a more systematic process.

8.4 Community outcomes

Operating at scale has helped to increase the capacity and social capital of the Northland community to promote gout treatment. This is by creating informal gout community champions and heightened awareness and health literacy in respect of gout by pharmacists, general practice and whānau.

The benefits of gout programmes extend beyond those participating. This is because the programmes are raising awareness of gout and addressing outdated beliefs about its cause and treatment. This can be seen as an increase in the capacity and social capital of communities and was evident particularly in Northland where the gout programme is district wide.

During our site visits and interviews we identified the creation of informal gout champions who were spreading the programmes messages about gout in their communities, workplaces and whānau. These were people who had been on the programme and who were sharing and using their experiences to encourage others to learn about the condition and seek appropriate treatment. While not surprising, this is not an explicit intention of the programmes.

"I'm working in a residential home ...and I had a young man who got a swollen foot. And I said, 'oh that looks a bit like gout'. So, I got him to go to the doctors and he got the gout tablets, but he wasn't taking it regularly and the gout kept coming back. So I actually said to him 'you need to be taking this every day, cos it will stop swelling' and so on. So by the information that I've learnt, I've been able to pass it on to him. I've really been on top of him about taking his meds since." (Gout Stop Client)

The encouragement of community organisations and workplaces to include gout awareness is highly positive as this will help shift wider societal attitudes about gout and, over time, provide a more conducive setting for health seeking. This may be more achievable through national and district wide programmes, rather than small-scale programmes as broader community understanding and acceptance also has a part to play in the success of gout programmes.

"Whānau are the people who support the individual, and if they're getting the same messaging then you're able to get rid of the old wives' tales. You need to educate the whole family and they will spread their knowledge and understanding to their networks and so on." (PHE staff)

The heightened awareness of gout in pharmacies involved in the programmes is evidenced by some examples provided in interviews. These included a more proactive response to OTC purchases of Voltaren, and the challenging of GP prescriptions to treat gout that aren't following programme protocols.

"The pharmacy I go to, if you want to buy [Voltaren], it they invariably get the chemist to come out and talk to you" (Gout Stop client)

These two examples suggest that gout programmes can support the creation of a self-monitoring primary care community that is better positioned to support people with gout.

9. HEALTH SYSTEM CONTRIBUTIONS

The value chain created by the programmes enables the logical assumption that the programmes have contributed to the benefits for patients and communities. The programmes have also contributed to the broader health system by promoting integrated teamwork, addressing health equity, reducing the burden of gout on the sector through a management focus, and providing good value for the resource required locally.

In addition to contributing to outcomes for patients and communities, programme benefits can be considered as contributions to the health sector more generally. The following themes have been identified as the key contributions of the gout programmes to the broader health system.

9.1 Promoting integrated teamwork

The gout programmes have provided a mandate for collaborative interdisciplinary teamwork in terms of day-to-day programme delivery and development. This integrated teamwork and role enrichment can be personally and professionally satisfying as well as an efficient way of using health roles. It can help maximise existing health workforce capacity and effectiveness.

The gout models of care design addresses barriers to working at top of scope identified in the literature such as hierarchical practices, siloed service delivery, conflicting or duplication of services and lack clarity of others' roles²². The gout programmes have well-articulated pathways that draw on multi-agency and inter-disciplinary collaboration that extends from the non-regulated workforce to rheumatology specialists. One of the strengths of these models is the clear but connected roles each plays in the gout pathway.

Strengthening this contribution: There is potential to deepen this contribution with more non-regulated roles, such as Health Coaches, being used in primary care. Ensuring gout programmes are well connected to other primary care pathways (especially those related to other metabolic syndrome conditions) will also increase the benefit to patients. Where education is the responsibility of more than one provider organisation it's advisable to have a system to check this occurs and patients don't slip through.

9.2 Pro-equity clinical practice and design

Gout is an equity issue. As this report has discussed, the barriers to accessing gout treatment, especially long term ULT are multiple and include both structural and personal factors. The programmes are promoting equity by

- Demonstrating strong reach into Māori and Pacific populations with the highest prevalence of gout.
- Recognising and addressing barriers to engagement through building knowledge and skills in clinical staff that includes cultural competency and understanding biases, building health literacy and gout treatment. In Northland the prescribing rate of NSAIDs for gout reduced²³

²² <https://www.tepou.co.nz/uploads/files/resource-assets/scope-it-right-literature-review.pdf>

²³ HQSC Atlas of Healthcare Variation <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/>

- Providing a pathway that reduces cost and time barriers to access (such as needing to frequently visit the GP or have blood tests) were thought to be of greater benefit to Māori, Pacific and others in the most deprived socio-economic quintiles.

Strengthening this contribution: Gout Stop had funding available to cover GP visits and prescription costs where this was a barrier, but this funding was not well used. This suggests a systematic application of subsidies (not for all, but for those experiencing this barrier the most) would be more effective at removing the cost barriers that prevent programme participation.

Taking time off work or to travel to general practices was also a barrier identified. Off-site and virtual delivery may also improve the accessibility of general practice for initial diagnosis and prescription, as may greater availability of labs for the more comprehensive blood tests required to monitor kidney function (eGFR).

The programmes provide a standardised approach that has potential for further differentiation for different patient groups and needs, for example, targeted follow up for younger Māori or Pacific men who don't complete the programme as well as working collaboratively with Māori and Pacific organisations.

9.3 Reducing the disease burden through prevention

Gout is a form of arthritis that can impact people's health, quality of life and participation in society in the short term (through painful flares) and, more significantly, without preventative management, longer term damage and disability can be caused. The personal and societal costs of gout are high; the Deloitte Economic analysis that was completed for Arthritis New Zealand in 2018 calculated 4850 disability Adjusted Life Years (DALYs) were lost because of gout

The programmes are contributing to preventing future loss of quality of life and disability through:

- Building the health literacy of patients and professionals about the long-term chronic nature of gout and the ongoing damage of high SU in the body (with and without flares).
- Reaching people in the younger age group. More than a third of people in both these programmes were aged under 45.
- Gout Stop included raising awareness, enabling messages to reach wider communities and those not engaged with general practice.
- Reducing the shame associated with gout by acknowledging historical beliefs and providing accurate information about gout's causes and long-term effects. These messages will take time to become established in communities.

Strengthening this contribution: Investment in raising awareness on a national level would provide a foundation for localised initiatives and generate conversations within whānau and communities, further encouraging informal gout champions that can reach into communities and help drive generational change.

9.4 Providing good value

Both programmes are providing good value for money locally. This is a general statement that reflects the programmes are good enough to justify the resource used for them. These are not expensive programmes to provide and represent, in the words of a funder, "a big bang for your buck".

- Gout Stop is a permanent care pathway across Northland DHB. Pharmacies are paid for new enrolments and completions.²⁴
- OMG has secured Counties Manukau DHB funding to increase from six to 22 pharmacies. Pharmacies are paid \$27.70 for each contact. Pharmacy costs include pharmacy time (for building health literacy), blister pack, consumables for BeneCheck © meters and overheads for IT and blood test quality control.
- The practice nurse time for oversight and building health literacy is not funded but fits within their existing role.
- Interdisciplinary teamwork may relieve pressure from GP shortages.

Strengthening this contribution: Having strong baseline evidence about gout prescribing and management practices helps programmes to evidence their positive impact. Programmes need to monitor people into the phase when they are persisting with long-term medication to demonstrate complete effectiveness.

A value for money analysis could consider:

- Reduced primary care demand.
- Reduced hospitalisations due to gout.
- Reduced use of emergency department and after-hours services for gout.
- Reduced loss of work time.

²⁴ Cost/payment information was not available for the evaluation .

10. PROGRAMME LEARNINGS AND IMPROVEMENTS

The two programmes have developed iteratively and will continue to do so. The following improvements were identified by stakeholders associated with the specific programmes and they raise important considerations for all gout programmes:

Gout Stop

- Pharmacists receive two payments, one on entry and a second on successful programme completion. A pharmacist reflected on the effort that went into encouraging participation and suggested a third payment option for 'exit with effort' be considered where the programme has not been completed but ongoing effort into follow up has occurred. This would need some thought to manage in practice. We did not speak to enough pharmacists to determine if the current payment structure was a disincentive to pharmacists to persist with patients, they felt would not complete the programme.
- All stakeholders identified the value of the community reach and raising awareness function provided by the kaiāwhina. Having more time and resource to raise awareness and follow-up outside health settings was a commonly identified improvement.

Owning My Gout

- Ongoing collaborative learning sessions with programme leads and participating pharmacists. These were a feature of the programme during the pilot phase and provided an ongoing opportunity for collaborative peer to peer problem solving, additional professional development, reflection and programme development. The sessions represent the commitment to the kaupapa of the work and emphasise its purpose beyond the effective dispensing of medication.

"Come and understand what the core of this service is and be inspired by people who have done well and build relationships out of your siloed environment and sit with other GPs, nurses and pharmacies around the same table" (OMG Lead)

- A suggested development related to an e-portal for patients, ideally one that could display changes in SU in a chart. While some patient groups may engage with, and benefit more from, this option than others, the e-portal would enhance the self-management tools available.

10.1 Lessons learned

Some learnings that are not reflected elsewhere in the report may be useful for others setting up or enhancing programmes to consider. These are lessons learned by these two programmes and shared for the benefit of others.

- OMG used a validated patient centred outcome measure in an effort to capture the personal impact and benefits for people. This wasn't easily or well used in practice and required lot of pharmacy time to support completion. A tool that is simple, visual and can be self-completed by those with low literacy and a range of first languages was identified as what is needed. Identification of such a tool is required and there are generic quality of life type tools available but would need some instruction, particularly for first time use.

- Gout Stop initiated a pathway from the emergency department (ED) by providing free vouchers for people who had presented with gout to see a GP for follow up. This didn't work well as the effort required to maintain a profile for the programme in the fast-paced department with high staff turnover was too great for the programme to sustain. This is not uncommon with ED based programmes. ED is a valuable setting for gout intervention, if the gout programme is well established district wide and the ED programme is sufficiently resourced, supported internally and sustained.
- Both programmes identified that medically complex patients, including those with tophi, (crystallised monosodium urate crystals within the subcutaneous tissues or joints) were more likely to be managed by a rheumatologist than on the standard gout programmes. Patients with tophi were uncommon. Tophi are a feature of chronic gout that has been untreated and can become disabling. In designing a gout programme or pathway consideration needs to be given to those patients the pathways do not serve but may not have to incorporate the complexities patients with tophi may present.
Gout Stop initially began recruiting and educating people to become formal community champions. This was hard to sustain with available resources and local stakeholders feel the organic generation of champions (in families, workplaces and the community) that occurs through individual involvement in the programme or health awareness raising, is working well.

11. INFORMING FUTURE ROLL OUT

The gout programmes have enabled the identification of critical factors for programme success. These relate to the components of the programme that are delivered (building provider and patient health literacy, key gout resources, easy access to medicine and raising awareness), and enable the programme to be delivered (a common programme framework and measurement model, systems to provide access to the right medication, share information, collaborative leadership, and sound planning and improvement activity). These need to be amended and be sensitive to the context in which they are implemented. It is recommended that programmes are set up with a view to long term sustainability. This will require resourcing and leadership at national, district and organisational levels.

Drawing on the experience of these two programmes and the contributions of stakeholders during our sensemaking session, has enabled core components of gout programmes to be identified alongside factors to consider about implementation. These are presented here to support the design and roll out of future programmes. This is represented as a guide, as programmes do need to reflect their local context and needs.

11.1 Common programme framework and measurement model

Working with two different data sets that record programme activity differently and interpret programme completion and success differently has highlighted the benefit a common measurement framework for gout programmes would provide.

Such a framework would support and monitor people not just to the achievement of SU <0.036mmol/L but beyond, so these rates are maintained and the transition to persisting with taking long-term medication has been maintained for 12 months. As people can take many months to achieve the desired SU, we propose that programme success is considered not within a fixed timeframe but as long as it takes for a person to achieve target SU for 12 months.

A measurement model that will identify key measures, common definitions and minimum data field collected will support programmes to learn from their data, share learning and track improvement with some consistency.

Implementation considerations

- Development of an agreed minimum data set. We propose this includes:
 - NHI and demographic information (prioritised ethnicity, age and gender).
 - Record of client permission to use/share their data for quality improvement.
 - Date of activity and date of SU readings.
 - The pharmacy dispensing and the general practice and GP generating the prescription.
 - SU and gout prescriptions dispensed.
 - SU measures until SU <0.36mmol/L has been stable for 12 months.
 - A record of how knowledge and skills have been shared, and where provided e.g. provided at the pharmacy (or not) for each contact.
- Ability to extract the data set as a whole (including demographic information).
- Protocols for collecting and sharing data. This could include the extraction of programme data to a secure common data vault for aggregation and reporting in

dashboard format would support dissemination and use of learning across gout programmes.

- Protocols for standard analysis to enable benchmarking for learning. This would include:
 - Consistently applied working definitions for success at different stages. For example, goal 1 achieved could be SU <0.36mmol/L for the first time, goal 2 maintaining that for three consecutive months, goal 3 and goal 4 and concordant when SU <0.36mmol/L for 12 months and allopurinol has been dispensed.
 - Consistently used numerators and denominators- for example the numbers of those achieving as a percentage of all enrolments.
 - Use age and ethnicity grouping consistent with the HQSC's Gout Atlas and analyse results to determine.

11.2 Systematise easy access to medication

The medications for gout are not new. These programmes used a Standing Order (OMG) or a preloaded pack option (Gout Stop). Systematising prescribing removes the need for patients to frequently visit their GP (saving time and costs) and makes the process easier and quicker for GPs, who only have one prescription to make. Some of these broader system barriers to accessing medicine are identified in the PHARMAC driver diagram. This is attached in Appendix 2.

Implementation considerations

- Building prescription packs into PMS systematises prescribing. In most DHBs there is likely a range of PMS in use, requiring software development that is more than a local need. MedTech has already developed and delivered this capability so could be a first choice for roll out.
- Standing Orders for prescriptions must meet the Ministry of Health guidelines 2016 (<https://www.health.govt.nz/publication/standing-order-guidelines>).
- Options will need to account for people with diabetes and impaired renal functioning.
- People need to be trained to use BeneCheck ©. The meters are a one-off cost (approximately \$72 retail) and the consumables (test strip and latex gloves) cost approximately \$2.20 per use. This provides opportunities for different funders to support initial, equipment and ongoing costs.
- Roles and responsibilities of all health workers on the gout pathway need to be understood by all, for the programme to work well and provide a cohesive experience for patients.
- Tracking the gap between those people prescribed medication and not collecting the first prescription will provide more information on accessibility to medication and if any introduced subsidies make a difference.
- BPAC guidelines recommend that prescribers provide a “pill in the pocket” for managing future flares²⁵ and should be considered within the broader prescription package.

²⁵ <https://bpac.org.nz/2018/gout-part1.aspx>

11.3 Building knowledge and skills in providers

Often described as workforce training or education, this component is about building awareness and skills in primary care and individual practitioners so they better able to support people with gout to self-manage. Content includes gout knowledge and best practice, the local process for gout pathway as well as cultural competency. Training also includes knowledge and skills to build health literacy in others to support self-management. Using the HQSC's Ask Build Check²⁶ framework that asks what people know, or want to know, builds on their knowledge incrementally and checks that new information is clear, is recommended as it emphasises the providers' role in contextualising information and building understanding and activating individuals, rather than simply providing standard education to all.

Implementation considerations

- The importance of ongoing training and learning for providers, rather than being a one-off event.
- Encourage shared learning as this fosters a common purpose and supports the professional trust and connections that are important to make local delivery work.
- An online resource has been developed, the Community Pharmacy Gout Management Service Training, and is available on demand at https://www.psnz.org.nz/Event?Action=View&Event_id=282. This resource may be used by health providers as a starting point to develop resources. This online training would need to be complemented by collaborative face to face sessions to generate the interdisciplinary working relationships to consolidate and sustain delivery.
- GP gout education is happening via Professional Education sessions and is an opportunity to introduce this broader knowledge and skill building (e.g. how to have a conversation with a young man in his 20s who has chronic gout which is impacting all aspects of his life), rather than focus on the clinical management of gout in isolation.
- Complimentary use of rongoā.
- Capturing evidence of the outcome of programmes in terms of increased knowledge and skills to self-manage.

11.4 Building knowledge and self-management skills in patients

Gout programmes are about behaviour change and are not simply a prescribing and dispensing mechanism. Patients need to understand about their gout and their persistence to take long term medication encouraged through trustworthy and relatable delivery of information. These two programmes have used pharmacists to build health literacy as well as a kaiāwhina (Gout Stop) and practice nurses (OMG). Having roles with dedicated time to spend building health literacy with patients is important to deliver this individualised support.

Implementation considerations

- Receiving consistent messages from different health workers is powerful.
- Use of non-regulated workforce roles as relatable sources of credible information.

²⁶ <https://www.hqsc.govt.nz/our-programmes/reducing-harm-from-falls/projects/ask-assess-act/>

- Requires a shift in thinking for some professionals about building health literacy (rather than solely education) as a dynamic process rather than a single transaction.
- Different approaches may work better for different patient groups and reduce the degree of drop out.
- Including whānau in the building of health literacy process.
- Developing mechanisms to account for the delivery and quality of health literacy being built with patients and whānau.

11.5 Gout resources

There are many patient resources available about gout, included the resource developed by the New Zealand Māori Pharmacists. Feedback suggested relatable resources that were highly visual were engaging for a broad range of patients. These programmes used the Stop Gout booklet 'the brown book' and the version developed by the Māori Pharmacists' Association 'the green book'. These resources are easy to read, visual and identify the minor role of diet in the creation of high uric acid. Not all resources convey this so clearly and understanding these things enables long standing beliefs and shame associated with gout to shift. Building health literacy with resources that are accessible for Māori and Pacific was said to contribute to programme effectiveness. If health workers refer to the same gout information resource, this is simpler for the patient, makes it more likely the messages will be understood and be seen as credible.

Implementation considerations

- Local agreement about what will, and won't, be used for gout information.
- Development of resources that reflects the community and their specific circumstances e.g. in a range of Pacific languages.

11.6 Raising awareness

Raising awareness that reaches into communities can share the key messages about gout causes and treatment and begin to break down the beliefs that perpetuate whakamā (shame) that is a significant barrier to effective treatment. Well-designed awareness raising activities can effectively reach people not engaged with primary care and well as whānau who can influence health seeking behaviour.

Implementation considerations

- Synergy between any national and local activity and resources.
- Tailoring to different target groups (e.g. Pacific peoples and younger working people (under45)).
- Reaching beyond health settings, into workplaces and other places where people naturally gather.
- Developing a mechanism for enrolling on the gout programme for those not engaged with primary care.
- Providing information about the gout programmes and who can help.

11.7 System to share information

Health workers need to be able to communicate securely about patients on the gout programme. This includes enrolment on the programmes and for Gout Stop, consent for contact by the kaiāwhina, SU as they are tested and titration information. Gout Stop used faxes and phone calls to transfer information and communicate about patients. OMG

developed an online secure system that has limited capability. The health workers supporting people on the gout pathway need to talk with each other and intelligent Information Technology can enable this.

Implementation considerations

- Phasing out of fax machines this year.
- Avoiding double handling of information.
- Pharmacies use a range of patient management systems which may prevent the development of a single software solution.

11.8 Collaborative leadership

Need to have funder representation, pharmacy and primary representation as well as a link to and support from tertiary rheumatology services. The group required to establish and provide strategic guidance may be different from the operation group providing oversight. Programmes take time to set up and manage. Dedicated time is required for leaders. These will be champions for the programme and will need to actively manage and drive the programme locally.

Implementation considerations

- Involving people with a passion to get the work off the ground and who have the networks and credibility to inspire action in others.
- Consider ongoing oversight of programmes and how leadership will work beyond the initial start-up phase.
- Representing key professional areas and inclusive representation of local health providers including iwi health providers.
- Presents opportunity for co-design and co-production of local services.

11.9 Plan for initial and ongoing implementation

A planned approach to roll out that allows the gout programme to be scaled up as a structured quality improvement framework

Considerations

- Capacity building in quality improvement methodology and data analytics may be required.
- Identify populations with greatest need and design an approach that is sensitive to the requirements of different populations.
- Identify and address where possible the institutional and structural barriers in the local context.
- Resourcing for planning and collaborative quality improvement.
- Aligning systems with existing structures and processes where possible.

11.10 Supporting effectiveness and sustainability of gout programmes

Identified improvements and considerations for the design and implementation of gout programmes have emphasised the need to approach delivery as a longer-term investment rather than a short-term project or pilot. Delivery of gout programmes will be supported by resourcing of action at national, district and organisational levels and consideration of the following:

National level

- Ensure the National Community Pharmacy Agreement sufficiently reflects the requirements of collaborative gout programme delivery.
- PHARMAC to review mechanisms that make access to gout medicines easier.
- Require DHBs with high prevalence of gout to develop targets relating to improved access to appropriate medication and reduced inequity of access and outcomes.
- Support the development and use of a common measurement model for gout programmes that reflect best practice and support and track patients over 12 months onto long term allopurinol.
- Support the development of infrastructure that enables safe data sharing and learning across gout programmes in New Zealand.
- Facilitate the development and dissemination of simple and standard gout resources that address inaccurate beliefs about gout.
- Health professional training provides a culturally sensitive introduction to gout.

District level

- Introduce targets in terms of people appropriately accessing medication as well as a reduction in the needs-based equity gap between Māori, Pacific people and others. This may be through the annual planning process, for example, and actions to reduce variation in equity of outcomes.
- Promote the accessibility of lab testing, especially for those living rurally, without transport and with daytime commitments.

DHBs may have a role in facilitating and endorsing the use of standing orders. This would be within the context of gout programme leadership and require collaboration across all levels of the health system.

Organisational level

- PHOs and general practices can create their own expectations and targets around people appropriately accessing medication as well as a reduction in the equity gap between Māori, Pacific people and others.
- Review use of existing funding sources and their potential contribution to gout programmes. Examples include Innovation funding, Services to Improve Access funding (SIA), Long term conditions funding streams as well as population-based funding for Pacific, Māori and high deprivation populations.
- Systematically fund GP and prescription costs for groups where this is a barrier to accessing support for gout.
- Embed gout programmes into organisational systems such as patient management systems (monitoring and decision support), e portals and long-term conditions portfolios.
- Connect pathways so those on gout programmes are connected to other relevant health programmes and vice versa.
- Succession planning for programme leadership.
- Consider the context of delivery and how this will shape the design and roll out of gout programmes. The two programmes featured in this evaluation both had a critical mass of their target populations. In other parts of New Zealand these populations are more dispersed. Providers encountering very low numbers per pharmacy or GP practice may not be viable.
- Asian populations have specific clinical management needs that need to be considered.

12. SUMMARY

Gout is treatable, its long-term damaging effects are preventable. The medication is effective and available. People can live pain free, socially and economically productive lives with ULT, yet nationally, less than half those who should, are provided with access to ULT.

The two gout programmes subject of this evaluation have demonstrated ways of implementing programmes in ways that begin to address the barriers to treatment for their communities. The programmes have strong enrolment reach into their high needs communities. Māori and Pacific are benefitting clinically from these programmes; however, non-Māori and non-Pacific people are more likely to benefit as judged by the timeframe and success measures used by these programmes.

The provider and patient health literacy components of the programmes are a key point of difference from usual care. Building knowledge and skills through health literacy is important to destigmatise gout and encourage and enable people to access care. Broader actions to increase accessibility of primary care for Māori and Pacific peoples and those economically deprived will facilitate greater access to the services and supports needed to enhance their health and wellbeing. Achieving more equitable gout outcomes will require some programme differentiation to respond to varied needs of participants and potential participants.

These programmes are low cost and deliver benefits to people and contribute positively to organisations involved and the changing landscape of the health sector. The programmes are not an instant panacea to all the barriers to initial and ongoing treatment but have provided real world learning to inform the roll out of gout programmes. This has enabled the identification of core components of programme design and insights into the implementation considerations in different contexts.

From a synthesis of the evidence collected for this evaluation it is recommended that programmes use a consistent framework that has agreed working definitions of programme success and monitors patients until their SU have been below 0.036mmol/L for 12 months. Shareable and comparable data will better enable learning and improvement across the gout community.

Gout is a significant health issue for New Zealand, an equity issue and a Te Tiriti issue. Delivering gout programmes provides value to the health sector as well as communities and patients. Programme implementation and outcomes can be framed through clinical management, prevention, equity of access and outcomes, workforce development and/or quality improvement lenses.

13. APPENDIX 1: ABBREVIATIONS

Table 13: List of abbreviations used in the report

Abbreviation	Meaning
DHB	District Health Board
ED	Emergency Department
eGFR	estimated glomerular filtration rate (measures creatinine, a waste product in blood to measure kidney function)
GP	General practitioner
HQSC	Health Quality and Safety Commission
NSAID	Nonsteroidal anti-inflammatory drugs
OMG	Owning My Gout
PHARMAC	Pharmaceutical Management Agency
PHE	Primary Health Entity
PMS	Practice Management System
SU	Serum urate level
ULT	Urate lowering treatment (medication such as allopurinol)

14. APPENDIX 2: PHARMAC'S DRIVER DIAGRAM

AIM

