



WHANGANUI

# Whanganui Gout Stop Programme Evaluation

Final Evaluation Report

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**Whanganui Regional Health Network**

With support from Health Solutions Trust as part of the  
Whanganui Regional Health Research Collaborative

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# 1 Executive Summary

## 1.1 Introduction

Gout arthritis (gout) is a chronic, long-term, treatable condition that disproportionately affects Māori and Pacific peoples in terms of genetic causes, earlier onset, severity, and burden of disease. Gout can be effectively managed in primary care; however, the identification of gout and uptake of management services provide barriers to effectively supporting the population suffering from gout.

Whanganui Regional Health Network (WRHN) has commenced development of a local Gout Stop programme (GSP) to address the high rates and inequity of gout in the Whanganui DHB region. The Whanganui GSP builds on previous Gout programmes in Northland and Counties Manukau. The GSP is intended to be a whole of system approach and has involved activity across three main components: general practice, community pharmacy and Kaiāwhina / community engagement. The Whanganui GSP was launched in November 2020.

## 1.2 The delivery and achievements of the Gout Stop Programme

The delivery of the GSP is across the whole Whanganui rohe but most of the GSP engagement has come from a small group of community pharmacies, general practices and Whanganui Accident and Medical (WAM). Health providers have a large role to play in supporting patients to enter the GSP and also on the completion of the programme.

Health literacy appears to be a key component in the pathway to well managed gout. Understanding of gout was considered a contributor to people accessing the health care system for their gout and completing the GSP. Food triggers tended to be well described by patients but understanding the nature of gout as a long-term condition, the genetic causes that disproportionately affect certain ethnicities, and the role of long-term medication in prevention varied. Multiple patients described stopping their preventative medication once the gout attack had stopped. The delivery of gout initiatives, whether at the individual or community level, should focus on developing health literacy.

The GSP demonstrated equity in its reach, completion, and clinical outcomes. More than half of the patients that engaged with the Gout Stop programme were Māori, but the reach also extended beyond those recorded as being in the GSP as there was a 25% increase in the number of Māori receiving regular allopurinol from general practice across the rohe. While there was a slightly smaller proportion of Māori at the target serum uric acid (SUA) level after the programme, the average reduction in SUA was greater for Māori than non-Māori.

## 1.3 Conclusions and considerations for an implementation guide

The early adopters of this programme demonstrated that the GSP is effective in improving the quality of life of Māori with gout. The challenge for future collaborative LTC programmes is being able to roll-out a programme with buy-in from all providers. Getting the implementation right is the key to programme reach and success. This could be supported by sustainable funding for implementation, national activities to build awareness, and integrated IT systems that better enable information sharing and collaboration.

The Whanganui Gout Stop Programme is one example of collaborative LTC programme that is making a difference. Their experience has informed some recommendations for getting the implementation right:

- **In the initial stage of establishing a collaborative LTC programme**, start from a place of co-design with all stakeholders, including consumers. Give careful consideration to the skills, competencies and roles included when establishing the leadership and implementation team. Build equity into the programme at all stages starting from defining the programme aim.
- **When designing a collaborative LTC programme**, use planning models and tools that work for your team to ensure you can communicate how your programme activities will achieve your programme aim. Ensure that the health providers involved are able and supported to deliver the activities in the plan, and that required resources are secured. Also plan what indicators are meaningful for stakeholders to enable feedback with a learning and improvement culture.
- **When delivering a collaborative LTC programme**, use any tools and resources available to encourage provider activity. This includes establishment of champions, directing Cornerstone activities towards the topic of gout (or programme LTC in focus), including Health Improvement Practitioners (HIPs) and Health Coaches in routine pathways, and provision of regular feedback on progress.

## 2 Introduction

### 2.1 Why Gout Arthritis?

Gout arthritis (gout) is a chronic, long-term condition that causes joint pain and swelling. It is caused by too much uric acid in the blood which turns into sharp crystals in the joints. If left untreated gout can cause serious damage to joints, kidneys, and quality of life.

However, gout can be effectively managed in primary care through the use of uric acid medicines and blood tests to monitor serum uric acid levels. The key to preventing gout attacks is lowering serum uric acid (SUA) levels to below 0.36 mmol/L.

Gout is an equity issue as it disproportionately affects Māori and Pacific peoples. There are genetic causes to gout that mean there is a higher prevalence, earlier onset and severity of gout for Māori and Pacific people where they experience a greater burden of disease. Despite the higher burden of disease, the identification and utilisation of management services in primary care is lower. This provides an inequitable barrier to effectively supporting the population suffering from gout. These inequities in rates of best-practice gout management result in higher rates of avoidable hospitalisations for Māori and Pacific people. Not only does this difference represent a poor health outcome that is unjust and avoidable, but it impacts on quality of life, ability to engage in mahi, with whānau, and culture.

The Whanganui rohe has a high prevalence of gout arthritis in Māori and poor management. Based on the Health Quality & Safety Commission (HQSC) Atlas of Healthcare Variation, in 2019 Whanganui District Health Board (WDHB) had 6.4% of the population with gout but this consists of 9% for Māori and 9.8% for Pacific peoples (compared to 5.6% for non-Māori, non-Pacific peoples). Note that for WDHB, Māori make 27.4% compared to 4.0% for Pacific peoples<sup>1</sup>. However, less than half of all gout sufferers in Whanganui were regularly receiving preventative medication and this rate was decreasing (WRHN, 2019). In 2017/18 it was estimated that 130 ED admissions were due to gout arthritis, illustrating the medical consequences from poorly managed gout arthritis (WDHB, 2019).

### 2.2 What do we already know about Gout Programmes?

In February 2020, Arthritis NZ, PHARMAC and HQSC funded Synergia to evaluate two gout programmes operating in New Zealand:

- Owing My Gout – A community pharmacist and nurse-led collaborative model piloted in Counties Manukau. GPs issue standing orders for community pharmacists to prescribe gout medication. Together the practice nurse and pharmacist titrate medication and build patients' health literacy.
- Gout Stop programme provided by Mahitahi Hauora PHO in Northland – The programme is based on a 91-day model of collaboration between GPs, community pharmacists and Kaiāwhina working together to improve accessibility to medication

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<sup>1</sup> StatsNZ. Ethnic group (total grouped responses) for census usually resident population count in Whanganui district Health Board in 2018.

and health literacy. This is the programme that informed the Whanganui Gout Stop programme.

These programmes both achieved equitable levels of programme enrolment but challenges maintaining participation. The programmes were less likely to retain Māori, Pacific, and younger people which contributed to lower rates of clinical success for these priority patients.

The Synergia evaluation identified core components of gout management programmes as being easy access to medicines for patients, activities to build provider and patient health literacy, accessible gout information and awareness raising. Key enablers to delivery of such programmes were systems to provide easy access to the right medication and share patient information, collaborative leadership, a common gout programme framework and measurement model, and sound planning and ongoing improvement activity.

### 2.3 The path to starting a Gout Stop Programme in Whanganui

The Whanganui Gout Stop programme was launched in November 2020 but the journey started in 2018 when Arthritis NZ demonstrated the poor performance of WDHB Gout care based on the HQSC's Atlas of Healthcare Variation. At the time, management of gout was not a strategic priority for the DHB or primary care. However, it was acknowledged that it needed to be a focus area.

Primary care then did some early work to improve the management of gout. The Whanganui Regional Health Network (WRHN) provided support with a PowerBI dashboard illustrating gout data in general practice and disseminated awareness communications via their Collective Comms group and Health Matters publications. One practice implemented a continuous quality improvement (CQI) project and implemented a clinical audit. This was successful in reducing the number of patients with a gout diagnosis who did not have their serum uric acid levels tested in the last 12 months. During this CQI project, it was also identified that there needed to be a clinical update for GPs/nurses on gout. Best practice treatment and management for gout had changed over recent years and there needed to be a greater understanding of the impact of genetics on gout, especially in younger Māori and Pacific males. The process and outcome from this project were shared at a Whanganui Inter-Professional Education session and the clinical update facilitated by Arthritis NZ.

Gout was included in the WDHB 2019/20 annual plan as an equity outcome and a proposal was made to the Whanganui Alliance Leadership Team (WALT) to deliver a collaborative model of care to manage gout. It would be based on the previous Gout programme in Northland to include general practice, community pharmacy, and a community Kaiāwhina role. However, it was adapted to suit the local context and needs of the Whanganui population. The Kaiāwhina role would be jointly funded by WDHB and Arthritis NZ. From this the Whanganui Gout Stop Programme (GSP) was established.

Leadership, planning and delivery of the GSP was provided by a steering group, improvement team, consumer group, and a project lead. While the Northland programme provided a starting point, a co-design process was used to review and develop the services that would be provided as part of the GSP. The project was led by primary care with valued



contributions from Arthritis NZ, WDHB, general practices, community pharmacy, and health consumers with an experience of gout. This co-design process was supported by an equity workshop facilitated by Gabrielle Baker and Leanne Te Karu and has been embedded in the representation and activities of the implementation team.

#### 2.4 Reason for another gout evaluation

In June 2021, the Ministry of Health (the Ministry) contracted the WRHN to undertake an evaluation of their Gout Stop programme. The objective for the Ministry was to gain insight and evidence that could support the development of implementation guidance about doing LTC programme design differently to achieve equitable health outcomes that could be utilised nationally. It would build from the evidence already gained from the Synergia evaluation which included finding a significant group of patients disengaging around 6-9 months after starting the programme. The focus was on the transferability of the programme to other contexts, the patient journey and experience of the Māori population in the Gout Stop programme, including what can be done to maintain engagement or re-engage with people in the management of their gout.

### 3 Evaluation aims, objectives and methods

The aim of the WRHN evaluation is to conduct a process and outcome evaluation to provide insight and evidence for the Ministry that could support the development of an implementation guide/bundle with advice about doing LTC programme design differently to achieve equitable health outcomes.

The evaluation objectives are to:

- Explore the patient journey and experience as a result of the Gout Stop programme, particularly focused on the Māori population and specifically:
  - o How people become engaged and then enter?
  - o When and why people exit? And what can be done to re-engage those who drop-out?
  - o How to sustain changes in good management of gout?
- Explore the transferability of the programme to other contexts such as other LTCs or in other geographic locations, including consideration of:
  - o Barriers and enablers to establishing the programme and delivery of the programme?
  - o Opportunity for integration of Health Improvement Practitioners and Health Coach roles that are being rolled out nationally?
- Support learning and quality improvement cycles to maximise the quality and effectiveness of the Gout Stop programme.

This evaluation uses a mixed methods approach using quantitative and qualitative data sources and synthesis of this evidence to address the evaluation objectives. Specifically, this evaluation drew evidence from:

- **Programme delivery data** recorded on the TUKU referral management system. This system collected information recorded by community pharmacy, general practice, Whanganui Accident and Medical (WAM) and Kaiāwhina on new referrals to Kaiāwhina and new enrolments on the Gout Stop programme. The system also allows activity such as education consults, dispensing and SUA testing to be recorded and for patients to be discharged. As this was a new system for community pharmacy there are some limitations to the quality of data recorded on this system. This limitation was mitigated by requesting community pharmacy to review the programme data recorded for their pharmacy. Descriptive statistics were undertaken to explore the engagement with and level of delivery of the Gout Stop programme.
- **Clinical data** recorded within the practice management system (PMS) of WRHN general practices. Descriptive statistics were undertaken to identify changes in the population with regular allopurinol prescriptions (proxy for gout as there are limitations with the recording of gout diagnoses within this dataset), serum uric acid testing and SUA test results for patients involved with the Gout Stop programme.
- **Key documents** from delivery of the programme, including the equity hui feedback.

- **Key stakeholder interviews** with people involved in funding, leading and implementing the Gout Stop programme. There were six stakeholder interviews conducted from October to December 2021.
- **Patient interviews** were conducted with 13 patients, with 11 being recorded and transcribed and 2 having interviewer notes only. All patients were Māori and had a gout diagnosis recorded at a practice in Whanganui that had good delivery of the Gout Stop programme. They were conducted from February to September 2022 by an interviewer of Cook Island Māori ethnicity until data saturation was reached. Not all patients interviewed were enrolled on the Gout Stop programme as there was difficulty getting engagement and consent from Māori on the Programme. This means that interviews may not represent all the perspectives of the most hard-to-reach patients but maintains a strong focus on equity and understanding the patient experience for Māori that was important to the aims of the programme and this evaluation. Patient interviews were thematically analysed using a general inductive approach that supports a focus on the evaluation objectives while allowing flexibility for themes to arise from the data (Thomas, 2005).

## 4 The Whanganui Gout Stop Programme

The Gout Stop Programme is a 12-week gout management programme. It centres on a model of collaboration between general practice, community pharmacists and Kaiāwhina, working together to improve accessibility to medication and health literacy. The delivery of the programme consists of a number of different activities to reduce barriers that disproportionately affect Māori in achieving good gout management:

- **Kaiāwhina support available to all patients, with a focus on Māori and Pacific people.** This is to help address any barriers that a person is encountering on their journey; whether it is navigation, advocacy, education, or strategies to self-manage that work with their life.
- **Communication, information and education for communities,** including through employers, faith-based and other communities. This is to address the myths and stigma attached to gout which are barriers to talking about gout and accessing help.
- **Two primary care consults that are free to patients that meet eligibility criteria** (Māori, Pacific, and/or CSC card holder) to initiate their Gout Stop journey and a three-month review. This is to remove the primary care cost barrier to commencing good gout management.
- **Funded blister packaging for medications** as part of the 12-week Gout Stop programme. This is to remove the cost barrier of a solution that makes it easier to take daily medications.
- **Expanded role of community pharmacy to include gout education consults and point of care serum uric acid testing.** This is to enable the health care system to support people where they first present for care and to improve health literacy through education and engaging people in their care by seeing SUA levels.
- **Education, training and programme support for general practices, community pharmacy, and other health care providers** that encounter gout patients who may not be well managed, e.g. WAM. This is to address the barriers from myths and misunderstandings that exist around gout, and system barriers to equitable delivery such as inconsistent provision of care, and culturally appropriate engagement and messaging.
- **Localisation of gout arthritis in Community HealthPathways** to enable access to consistent clinical advice about key education points, the clinical pathway for management, and the availability of the Gout Stop programme.
- **Provision of data and feedback to general practices** for individual patients via dashboard and PowerBI report, and population level feedback with an equity focus to track their success on process and outcome measures. This is to create transparency and understanding around the issue and make it easy to act in ways that promote good gout management for Māori.

The programme logic model for the Whanganui Gout Stop Programme is illustrated in Figure 1 and Figure 2 provides a flow chart demonstrating the patient journey through the Whanganui Gout Stop Programme.

Figure 1: Gout Stop programme logic model

Programme aim: To improve quality of life of Māori living with Gout Arthritis. It will demonstrate success by achieving equitable outcomes for Māori compared to non-Māori in the district and by delivering a programme that is designed for and with Māori.

### Context

- Gout arthritis is a treatable long-term condition.
- Estimated 40% of people living with Gout arthritis in Whanganui are not accessing general practice.
- High rates of OTC NSAIDS and acute presentations at pharmacy and urgent care.
- Māori experience higher prevalence of gout arthritis yet are less likely to receive best-practice gout arthritis management.
- The Whanganui region has an above average Māori population, high prevalence of gout arthritis and low capacity within general practice.
- Arthritis NZ is leading a national campaign to improve the management of gout arthritis in NZ.
- There is evidence of effective gout arthritis programmes from Northland and Counties Manukau.
- PHARMAC focus on gout
- MoH focus for LTC annual planning

### Inputs

- 1.0 FTE Kaiawhina.
- Allocation of Services to Improve Access special projects funding.
- Funding to remove barriers at urgent care.
- Adaptations to contracts with community pharmacy.
- Gout Stop 3-month programme design.
- Pharmacy education programme from Midlands Health Network.
- Gout arthritis guide for general practice education and patient audit.
- Gout arthritis indicator on patient dashboard.
- Prescription packs.
- Standing orders.
- Gabrielle Baker pro-equity focus
- WRHN Programme leadership, improvement team, resources, education, comm's and evaluation
- Infrastructure development cross-system.
- General practice and WAM GOUT advanced form.

### Activities

General practice:

- Support GP to undertake patient data audit and recall.
- Same day appointments for acute presentations (practice discretion).
- 2 appts SIA funded by WRHN for high needs patients.

- Provide patient education and resources.
- Three-month GOUT STOP prescriptions
- Lab forms direct to laboratory.
- Follow up appointment and prescribing at end of 3mth programme – maintenance or titration of dose.
- Commencement of group consults for gout management.
- Upskilling of clinical team and provision of tools and resources to support programme

#### Pharmacy:

- Pharmacists credentialing programme and team cultural education (Mauri Ora training).
- Provide patient education and resources.
- Enrol patient education and resources.
- Enrol patients on Gout Stop Programme.
- Point of care testing, monthly visits.
- Prescription charges for three months are covered.
- Refer patients to Kaiawhina.
- Re enrol if patient not met target at end of 3mths
- Data collection and referral – TUKU training.

#### Kaiawhina:

- Outreach visits for patient education and reduction of patient barriers to engagement and management.
- Point of care testing.
- System navigation support.
- Advocate for patients.
- Provide/facilitate opportunities for education/upskilling providers, NGO's and community as identified.
- Māori consumer engagement and programme input.

#### General:

- Referrals from WAM, Iwi providers and others to Kaiawhina.
- Communication campaign to destigmatise and dispel myths.
- Developing local resources to raise community awareness.
- Provide evaluation feedback loops and patient stories.
- Cross-system comms & education of clinical teams.

#### Outputs

- High needs patients with gout arthritis are identified by general practice, pharmacy, WAM, and Iwi providers.
- Patients with gout arthritis access the Gout Stop programme and get two appointments, three-month prescription, education and support.
- Accredited trained pharmacists.

- Practices, pharmacy, Kaiawhina and stakeholders receive evaluation feedback and patient stories.
- Pharmacy data collected systematically and can be extracted for learning.
- General practice claiming system in place.
- Iwi providers trained in medications for gout management.

### **Short-term outcomes**

#### Patients

- Māori patients receive regular uric acid testing.
- Increased medication adherence of Māori.
- Increased health literacy, key messages – genetics, benefit of preventive medication.
- Māori develop personal skills to manage gout.

#### Workforce

- Providers have greater awareness and understanding of the inequities of gout.
- Māori patients are actively recalled and supported to manage their gout.
- Pharmacists have increased role in gout management.

#### System

- Increase Māori patients receiving allopurinol.
- General practice data shows increased % of Māori patients with good gout management.
- Community has good understanding of gout and where/how to seek support if needed.
- Māori consumer feedback informs programme change.
- Māori providers are resourced to support gout patients in the community.
- Learning about transferability of the approach.

### **Medium-term outcomes**

#### Patients

- Māori patients have fewer acute gout attacks
- Māori have increased self-management skills with better control of their gout
- Whānau make lifestyle changes to improve gout management.

#### Workforce

- Māori receive timely treatment and management of their gout.
- Equitable prescribing of preventive medications for Māori patients in treatment of gout

#### System

- Reduced use of OTC NSAIDs for gout by Māori patients.
- Improved Māori health literacy about gout
- Facilitates national learning about programmes to address gout for Māori.

- Facilitates learning and delivery of approaches to improve quality of care for other LTCs for Māori.

### **Long-term outcomes**

#### Patients

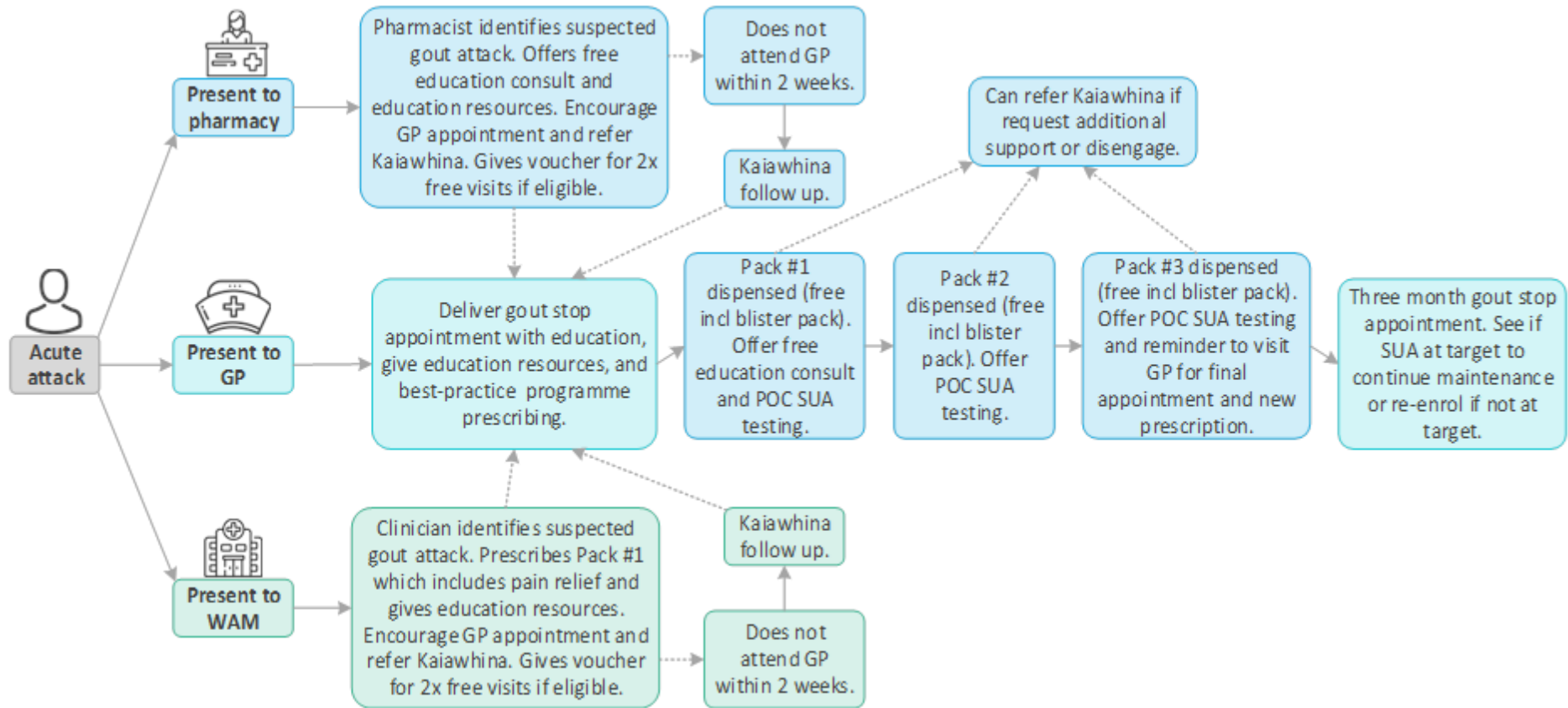
- Improved quality of life of Māori with gout.
- Improved whanau wellbeing.

#### System

- Cultural shift in treatment of Māori patients.
- Reduced number of Māori presenting acutely for gout in WAM and ED.
- Improved health outcomes for Māori with gout.
- Sustainable programme embedded to identify and treat Māori with uncontrolled gout early.



Figure 2: Patient journey/s through Gout Stop programme



## 5 The patient journey and experience of the Gout Stop programme

### 5.1 How do people become engaged and enter?

A total of 114 unique patients were recorded as having engaged with the Gout Stop Programme in the 17 months from commencement of the GSP in December 2020 to the start of May 2022. Over half of these patients (61%) were Māori which indicates the target group is engaging with the Programme. Table 1 illustrates the engagement with the Programme and Kaiāwhina by ethnicity.

Table 1: Engagement with Gout Stop programme and Kaiāwhina by ethnicity

	Kaiāwhina only	Both	Gout Stop only	Total engaged
<b>Māori</b>	30	9	30	69
<b>Pacific</b>	3	2	6	11
<b>Other</b>	7	3	24	34
<b>Total</b>	40	14	60	114

Interestingly, participants in general appeared to find involvement at the pharmacy level more beneficial in their gout management than attending their GP. There appeared to be a sense that the role of the GP was purely to prescribe the medication for gout, while the visits to the pharmacy provided more than that.

*“Well my pharmacy visits are for my gout and I just go there. And all the GP does is give us pills, medication. That’s it.”*

GPs, however, tended to be the first port of call for a diagnosis of gout. Participants appeared to feel that GPs held a level of power over their experience of gout and what they were entitled to. Despite this, there was an expectation that GPs would provide gout sufferers with information about how best to manage their condition.

*“I would expect the doctors to be the ones to tell me what I should be doing or shouldn’t be doing. You know? It’s sort of their job, isn’t it?”*

#### 5.1.1 Converting engagement to action

This engagement data also suggests that while there is a high rate of engagement with Māori, there is lower conversion to enrolment on the GSP. Table 1 shows a high number of Māori engaged with Kaiāwhina only (and not Gout Stop programme). Based on the Gout Stop Programme pathway, this suggests that Māori are more likely than those of other ethnicity to be identified outside of the GP setting (either community pharmacy or WAM) and have not yet enrolled in the Gout Stop Programme with their GP.

The GSP has been effective at reaching its target audience when they have touchpoints with the health system. The next step is to support progress through the Stages of Change (Prochaska & Velicer, 1997), from pre-contemplation to action where they enrol on the Gout Stop programme. This will take time and, while education consults are a good start, additional strategies may be required. The involvement of Health Coaches in care could support strategies that support progression through stages of change.

### 5.1.2 Getting active programme adoption by health practitioners

Health practitioners had a large role to play in patients' awareness of and entry into the GSP. Among the gout patients interviewed for this evaluation, a number were not aware of the presence of the programme. Awareness of the GSP appeared to be related to whether or not a health practitioner had informed them of the Programme. This demonstrates the need for health practitioners in all settings to take an active role in communicating about the programme in addition to gout education. Although GPs are a key point for providing information and enrolling people on the GSP, some patients describe being diagnosed with gout and that was all that happened.

*"I didn't see anything about that [Gout Stop Programme]. The doctor diagnosed, he said okay, I think his words were 'well it sounds, it looks to me like you have gout'. That's how it went."*

There is variation in the GSP activity across different community pharmacies and general practices. This means patients are receiving a different level of access to best-practice care depending on where they present. Table 2 shows where the referrals have come from with a small number of sites making the biggest difference (note that some patients have multiple referrals):

- There are 15 community pharmacies in Whanganui, seven have recorded any GSP activity, but 74% of Gout Stop enrolments (55 of 74) come from just two urban pharmacies.
- These pharmacies are closely located to the two practices that have made direct referrals to Kaiāwhina. This would suggest the GSP gets best engagement and entry when both the practice and pharmacy are actively involved – it can't be carried by one health practitioner alone.
- Whanganui Accident and Medical identified a high number of people with suspected gout coming to them for acute care that could be directed to the GSP.

Table 2: Source of Gout Stop Programme enrolment and referrals

Source site	Gout Stop Programme	Kaiāwhina	Grand Total
Pharmacy A	2		2
Pharmacy B	19	1	20
Pharmacy C	2		2
Pharmacy D		1	1
Pharmacy E	36	4	40
Pharmacy F	4	1	5
Pharmacy G	11	4	15
Whanganui A & M		24	24
Kaiāwhina		3	3
Practice A		15	15
Practice B		1	1
<b>Total</b>	<b>74</b>	<b>54</b>	<b>128</b>

This variation in adoption by health providers is to be expected in the early stages of a new programme. The Diffusion of Innovation Theory (Rogers, 1962) indicates that new ideas will be trialled by a minority of early adopters before the majority. The Gout Stop programme can leverage the successes achieved by these early adopters to appeal to the majority who prefer to see evidence of success to convince them to change. It should be noted that the GSP was being rolled-out in the middle of the Covid-19 pandemic which was a challenging time to ask health providers to adopt new programmes while the Covid response made even usual business difficult to maintain.

#### 5.1.3 Access to general practice

The accessibility of general practice has an impact on the accessibility of the GSP. This includes ensuring that care can be delivered in a way that is appropriate to the patient, taking account of preferences for *kanohi-ki-te-kanohi*. While the GSP was delivered in the context of the Covid-19 pandemic, the issue of telehealth was raised by an interviewee, with the view that it is not always an appropriate way of engaging with patients.

*“Much to my distress, and I have had an appointment with her three times, each time it’s been on the phone. And face to face would be... She is trying to limit me. You know, a lot of people seem to think you can do everything over the phone, but I’m one of these people who actually think that you can’t do medicine over the phone. You need to be looking at the person.”*

#### 5.1.4 Patient understanding of gout

Participants varied in their understanding of what was going on for them in the early development of gout. For some participants, they were completely aware of what was happening to them. For others, gout was something that they had never heard of or considered. For those who recognised the initial symptoms of gout, there tended to be a family history of gout and exposure to *whānau* or others with gout had primed them to recognise the symptoms.

*“I knew what it was ‘cause my brothers have lived with it for years and yeah, just got the same thing.”*

For many patients, the myths and poor understanding about gout can pose a barrier to accessing gout care. Patients described not recognising the symptoms or beliefs which led to denial that the problem could be gout. Commonly held beliefs include it being “an old man’s disease” and being caused by lifestyle factors.

*“If something did flare up, I’d be conscious about it but not quickly jump onto it, and say I had either broken a toe or broken a finger.”*

*“I just turned around and said, ‘nah, I don’t suffer from gout’. I meant that, you know, [at] that younger age.”*

#### 5.1.5 Influence of friends and *whānau*

Friends and *whānau* tended to have an influence over what people believed and felt about gout. Participants either described *whānau* influence as a positive part of their gout journey

(e.g., in helping them identify the issue or giving them insight into gout management) or stated that it played a negative role in their experience of gout. An interesting finding was that participants who had whānau with gout often held the belief that getting gout themselves would be inevitable. For these people, it was not a surprise when they started to experience symptoms of gout or were informed that that was what they were experiencing.

*“Well yeah, I’ve heard that it is hereditary. And you can’t do anything about that eh? If it’s in your genes, it’s in there.”*

Responses from friends and colleagues could reinforce unhelpful stereotypes about gout. In cases, patients described situations in which myths about gout were being perpetuated. For some, there was an element of whakama (shame) as a result of the way that friends and whānau responded to the person’s gout. This appeared to be due to a feeling that their friends and whānau were making fun of them for having gout or were making light of what they were experiencing.

*“It was around my 39th birthday, ‘cause I remember my brother laughing at me... You get it from your friends, ‘oh you’re getting old’ or something, I dunno. Yeah all that sorta stuff and it’s like yeah it’s funny and blah, blah, blah, but it’s not that funny.”*

*“I went to work with this really, really sore toe and got to work and I talked to the other guys... and they all said to me, ‘what have you been doing this week?’ And I said ‘oh, three parties in a row’, and they said ‘you’ve got gout!’ And I said ‘what? What the, what, goat?’ I had never even heard of it. And so the guys explained what it was.”*

For others, there appeared to be an element of comradery around sharing the diagnosis of gout, which had the ability to impact choices around food and alcohol use. Participants described incidents where there was a sense of sharing the consequences of choosing to eat certain foods or drink a certain amount of alcohol, whether this involved them personally, or they saw it occurring with others around them.

*“Some of my cousins and some of my aunties and uncles, they go hard... Oh they just, we all go, ‘ooohh man, this is going to hurt in another couple of days’. But they’re prepared to go through that pain.”*

## 5.2 When and why do people exit?

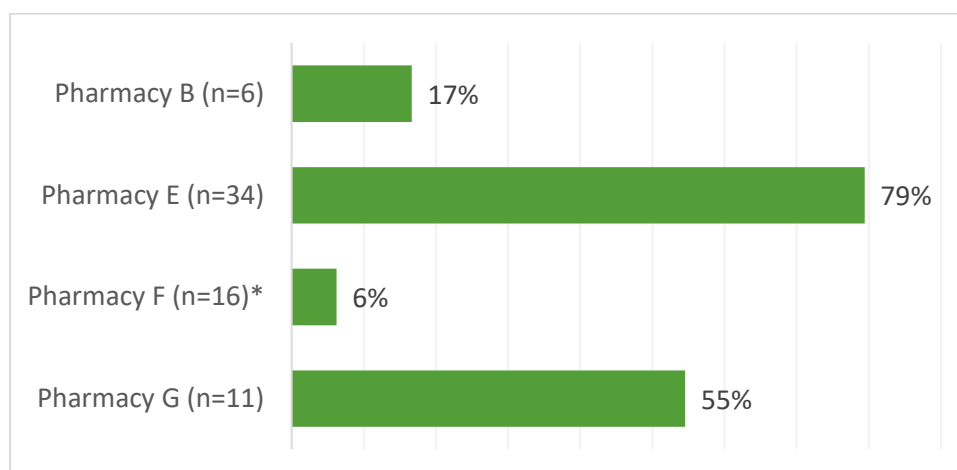
Just over half (51%) of people completed the Gout Stop programme. Data on exit status was available for 67 of the 74 patients enrolled on the GSP and is illustrated in Table 3 below. It demonstrates that completion rates for Māori reflect those of the total population but Māori who exit are more likely to exit earlier than others (but also more likely to restart).

Table 3: Completion rates and exit points along the Gout Stop Programme

Population	Completion	Exit before pack #1	Exit after pack #1	Exit after pack #2	Restarted after exit
Māori (n=37)	19 (51%)	1	13	4	2
<b>Total (n=67)</b>	<b>34 (51%)</b>	<b>2</b>	<b>19</b>	<b>11</b>	<b>2</b>

The biggest factor influencing exit rates appears to be the implementation from the health provider (Figure 3). Pharmacy E is co-located with a general practice, has good levels of implementation, and the highest completion rates (and is the provider for the two patients who restarted after exit). Pharmacy G with above average completion rates was also one of the providers with a higher level of implementation and close relationship to a nearby general practice.

Figure 3: Completion rates by pharmacy



The importance of the education consult provided by pharmacy is also suggested by the performance of Pharmacy F. This provider had 4 patients recorded as being enrolled on the GSP but when confirming their service data, there were additional patients they had not recorded. These additional patients had been supported with the GSP funded free prescription, free blister packs and SUA testing but did not receive an education consult from the pharmacy. None of these patients had completed the programme which indicates the education consult to build health literacy is a key component for successfully improving gout management.

Pharmacy E reflected on how they successfully manage delivery of the programme:

*We are very fortunate to be next door to a GP practice who support the Gout Stop Program, plus we actively promote the GSP and get customers on board. Mostly our scripts come from this GP practice, already identified as being for Gout Stop. We do not have many requests for OTC medication.*

*The patient has immediate access to a pharmacist, who runs through the program, and delivers an education package. We ask if they would like it blister packed, which we encourage if it has reducing prednisone, though*

*they also have the option of bottles. Priority dispensing and/or blister packing means the patient doesn't leave without their medication and an understanding of how to take it.*

*When they have left, we enter them into our system to ensure they get a text reminder each month to return and collect further medication before they run out. We continue text reminders after this as well to ensure they continue getting a supply of medication. Anyone we notice falling through the cracks we can refer to the Kaiawhina to follow up with.*

*We really believe in this program. It's great to show the patients their decreasing uric acid levels as they increase their allopurinol. It's something visual, alongside their decreased gout attacks. One example is of Mr A, a Māori gentleman, who has slowly increased from 50mg daily over 4 months, is still increasing and still coming regularly to collect his medication with the text reminders.*

The data suggests it is what providers do, rather than any patient factors that is the biggest reason for exit. The ability to develop health literacy appears to be a key causal pathway to exit. Other barriers to completion were also discussed by patient interviews. It should be noted that the people who exit the GSP are also difficult to engage in evaluation interviews and as a result, these themes are not specific to patients who exited the programme.

#### 5.2.1 Access barriers

In the Whanganui rohe, while there are traditional access barriers with a wide geography and few transport options, it was other access issues that were most raised by patients. There was a common perspective that there is a lack of access to doctors (both for routine gout management and in a gout emergency). Patients spoke of how this lack of access for routine gout management meant that their gout needs were often superseded by other medical issues that arose, which required more urgent conversation with the GP. This was compounded by the fact that appointment times were believed to be too short.

*“Just getting hold of GPs or practitioners is becoming a real mission. And everything that is not absolutely critical is getting pushed down the priority list. And unfortunately, that's got consequences. Means guys like me, I drop them off the bottom basically, where we have legitimate needs that need to be discussed, but gout?”*

The consequence of being unable to see a GP for routine gout management was reported to be the inability to ask questions about the person's gout management plan.

*“Where are we at? Where are we going next?’ Or such interesting things as ‘are my medications correct at this time?’ which is a big thing with me ‘cause I'm taking about 12 different ones.”*

Participants also described a lack of choice in being able to access the care they prefer. There was discontent around being redirected to see a nurse. For some, this was not around

the fact that the person was a nurse; rather, there was a level of unhappiness that there was no chance to see their doctor. For others, it was insinuated that the opinion of a doctor is more trustworthy than the opinion of a nurse. Some participants were adamant that they wanted to see their GP for their gout-related care.

*“I’m not super happy going to the doctors anymore because you never get to see your doctor. You see a nurse. They have a yak to you. They go and have a yak to the doctor and then come back with a diagnosis and give you a script and away you go.”*

Discontent was also raised around the issue of telehealth, with the view that it is not always an appropriate way of engaging with patients (see section 5.1.3).

Māori patients continue to have poor experiences when accessing health professionals which influences their future engagement with the health care system. Some interviewees reported experiences leading to feelings of shame and discrimination. This appeared to be due to a sense that the doctor was blaming the patient’s lifestyle for the flare up or that they were being treated as if the gout episode was their fault. In addition, these participants either personally felt that they were wasting the time of the medical staff or that the doctors felt that they were wasting their time.

*“No the doctor, he was pretty arrogant... He goes ‘just imagine what it’s doing to the rest of your body, you know?’... He says ‘it’s your lifestyle choices.’ He said, ‘it’s the alcohol you’re drinking.’ And that’s first of all what he blamed.”*

*“Most probably in his mind he thought ‘I’ll be better treating my patients that try to take care of themselves instead of someone that doesn’t take care of themselves.’”*

Participants reported that accessing medication was very difficult if you were outside of Whanganui and usually required attending the nearest Emergency Department, which was extremely time- consuming and frustrating. People discussed their frustrations around having to spend long periods of time trying to access medication that they already knew they needed, and were already being prescribed.

*“Medical centres don’t accept outside people. And especially when you’re from out of town, it’s pretty hard to get some healthcare.”*

*“Fortunately I have an understanding GP and they very often are happy to let me have a three month supply of the meds that I need so I’ve got the entire period covered. But if there’s an emergency comes up, like if I get a really bad case of gout and I urgently need some prednisone, then I’ve really got to work hard to get that.”*

It was suggested that there was a need for a national record-keeping system, which would allow doctors to have access to their records for expedience of prescribing gout-related medication.



*“Well it’s basically getting off their duffs and doing what they have said that they were going to do about a National IT records system that anybody can access from anywhere. And making sure that the medical assistance is truly portable.”*

### 5.2.2 Attitudes towards medication

For some participants, there was a reluctance about being on long-term medication. For some of these people, this was due to a resistance about using medication or ‘drugs’, while for others, this was based on preconceptions about the effects of medication, after hearing how it had affected friends or whānau.

*“I didn’t wanna go on the Allopurinol, because I just don’t like being on medication... so I did lapse, to be honest, on the drugs. And I kinda go, ‘cause I didn’t wanna be on them, I didn’t want to be on daily drugs.”*

### 5.2.3 Health literacy and understanding of gout

For some participants who were prescribed Allopurinol there appeared to be a lack of health literacy where they may not have understood the reasons behind taking this as a long-term gout medication. This group appeared comfortable taking their Allopurinol during flare ups but did not seem to recognise that they were supposed to be taking in between gout episodes.

*“When I got gout again, I’d get more pills and they were giving me gout pills when I was getting my prescriptions, you know. Even when I didn’t have gout.”*

*“Oh no, once the gout went, that was it, I stopped the tablets.”*

*“I wasn’t even aware that you could stop gout. I’m very conscious that I laugh, I’ve been told that look you’re going to be taking allopurinol for the rest of your life. I took that to mean I’m always going to suffer from periodic expressions of gout.”*

### 5.3 What can be done to re-engage people with their gout management?

Follow up with patients should be proactive and respectful of their right to make choices about their own care. Where they may choose not to engage with the GSP, patients need to be aware of easy and judgement-free pathways to re-entry. For the Whanganui Gout Stop Programme, this proactive follow up and re-entry contact is available through the Gout Stop Kaiāwhina. An example of how patients can self-refer to the Kaiāwhina is illustrated in the brief case study below from the Gout Stop Kaiāwhina:

*Self-referral came though, he was at WAM and spoke with the receptionists who gave him the change your life booklet and Kaiāwhina contact details. The client called the 0800 number, and I gave him an education consultation and free GP voucher and referred him back to his GP. The client was happy to hear about the Gout Stop Programme as his gout has been poorly managed for years. He did take Allopurinol but*

*stopped taking it for 6 months and tried changing his lifestyle. But he has continued to get multiple flare ups. Now he feels it is time for him to get his gout under control. He is confident now after investing more time into learning about the condition and has a better understanding.*

As health literacy is a large barrier to engagement, repetition of consistent messaging will support re-engagement. However, this will not be an immediate process and will take time for trust and understanding to develop. There are many existing beliefs about how to cure gout and patients may go on their own journey to self-manage their gout and learn from experience before they are ready to engage with the messages from their health professionals.

*"I got on the phone to my brother and I got the Apple Cider Vinegar business. And he just goes, oh try that, you know, and drink heaps of water, piss it out. But I did go the chemist because that stuff wasn't necessarily, wasn't doing the job."*

Educating trusted community leaders and encouraging conversations can also support re-engagement. For one patient, it was the motivation from another acute attack and the experience of talking to their kaumatua about their shared experiences with gout that helped them to engage with lifelong preventative medication.

*"It's easier to stay on if you know you're going to get it again I think, so I did lapse, to be honest, on the drugs. Because I didn't want to be on them, I didn't want to be on daily drugs. But then I got gout again and so I kind of know that I'm going to be on it now, that's just it. A bit of, like I've talked to my matua, who's also got it. And, just knowing that he's got it and he's going to be on allopurinol all the time, and struggles to take it every day. But it'll keep me on it to know that, you know I can yarn to him about it."*

#### 5.4 How can we sustain changes in good management of gout?

Gout can be managed and sustained when primary care is delivered well. Good delivery of primary care works to develop health literacy and address access barriers in a way that responds to the cultural background of patients. For patients that relied on Allopurinol to keep their gout under control, it appeared to be well managed.

*"I'm on medication that I take daily to get the uric acid down. And they've been awesome. Absolutely awesome... Has really stabilised my gout, to the point where I don't think I get it. I don't want to be so bold in saying that, but I haven't had an episode for quite a long time. Or since I've been taking these pills."*

*"So Allopurinol is just part of the daily routine. So yes, since about the year 2000 I've been on Allopurinol."*

#### 5.4.1 Building health literacy

It became evident from interviews that, where gout-related health literacy levels were low, participants were less likely to make the changes required to manage their gout well. Some participants reported that they were not always provided information about their gout at the time of initial diagnosis and, for some, it took many years to really learn about the condition. Thus, it became clear that there is a need for good gout-related education to be provided to all gout sufferers and that it should not be assumed that because they have previously already been diagnosed with gout, they have been provided with adequate levels of information.

*“But she kinda mapped it out a little bit clearer for me, in that, you know it’s, because of my genetics I’m probably going to get gout. And continue to get it if I don’t get on the Allopurinol.”*

*“They put me in hospital and they filled me up with pills and stuff over 24 hours and everything came right. And then they were going to prescribe me some gout pills and I said no, I’ve still got some. I don’t need them, I’ve got some. And the nurses say how come? And I said well when my gout felt better I stopped taking them. And they said that was probably the reason that I kept on getting it again. Because I wasn’t finishing the medication they were giving me. And I’d stop as soon as my gout felt better. And then I ended up in hospital.”*

All health professionals have a role to play in developing health literacy. Pharmacists were seen as a valuable source of gout care in the Whanganui Gout Stop Programme, and the interviews illustrate that patients look to their general practitioners as experts that should be providing them with trusted information. Participants acknowledged the benefits of being provided with adequate information about their gout. This included how to identify triggers of gout and the best options for gout management.

Beliefs around the role of food and alcohol in gout episodes were very strong and appeared to shift only when the participant had received gout-related education. A consequence of these strongly held beliefs appeared to be the belief that there was a level of irresponsibility when a person experienced a flare up, due to the fact that they had chosen to eat or drink something they knew would lead to an episode of gout.

Participants spoke of needing to learn to trust that, by following their treatment plan, their gout could be better managed. Within this, was an acknowledgement that decisions around their treatment plan (e.g., medication) needed to be based on whether or not it was working for them.

*“Like I was very skeptical about this medication that I was taking, but look I’ve had 12 months of it and look, I can’t, it’s fantastic. It’s kind of changed my life.”*

#### 5.4.2 Primary care processes

General practices can support sustainability by ensuring best-practice data recording and information set up within their practice management systems. In particular, having a diagnosis of gout recorded and recalls for ongoing testing enables best-practice care to be delivered. The GSP found a number of patients that were prescribed allopurinol but did not have a gout diagnosis recorded on their medical record or recalls for serum uric acid testing to ensure the correct dosage was being prescribed. Correct recording is beneficial for all long-term conditions managed in primary care and also enables good information about the disease burden, in addition to the access, equity and effectiveness of care provided.

There are also broader issues to improve access to care and medication when patients were out of town (e.g., if they travelled for work or were visiting friends and whānau in other areas) as in section 5.2.1.

#### 5.4.3 Cultural considerations in the delivery of care

Providing culturally appropriate care that gives patients greater choice will help improve the relationship with health care professionals to create a safe space where management of gout can be sustained. In particular, patients talked about the recent changes (post-Covid) to being offered virtual medical appointments instead of face-to-face appointments. It was felt that virtual appointments were not always a culturally appropriate way of delivering healthcare and that being unable to see a doctor face-to-face was problematic for some. Patients described differences in the quality of their care and in their ability to understand issues around their gout management when they were able to see their GP in person.

*“Well, I’m thinking that you are Māori, and with ethnicity and with my understanding, the whole communication thing is very, very strong. And it’s greatly limiting if you can’t see someone’s expression. Even down to the way they hold themselves, so even just looking on a screen is not quite the same thing as being in person.”*

*“Then the second visit to the doc was in person and that was, you know, obviously much better just being in person.”*

### 5.5 Key points to improve the Gout Stop Programme

#### 5.5.1 Building greater awareness

There was a high level of patient support for the idea of a Gout Stop Programme. Patients learning about the GSP during interviews talked about how it would have been beneficial, and some indicated they were going to talk to their GP and whānau about the GSP. There were different motivations present for wanting to participate in the GSP; some wanted to have a safe space to talk openly about gout, to be connected to others suffering from gout for emotional support and education, for others access to free medical care was the main reason. This level of support and motivations to engage with the Programme illustrates that awareness is the main barrier to enrolment. Therefore, it is important for GPs and Pharmacists to be made aware of the importance of introducing patients who present at their services for gout.

*“I’ll talk to my GP next time I see her about that Gout Stop programme. I’ve never heard of that, so I’ll talk to her about that. She didn’t mention it.”*

*“[My reason for joining the Programme was] Largely because there was two free doctor visits in it, to be blunt.”*

#### 5.5.2 Support more providers to actively provide the gout stop programme

The role of health practitioners in making the programme work and achieving its goals is critical. They play a key role in communicating about the programme so that people enter. They also develop health literacy for patients and have a key role to play in whether patients complete the programme. Part of this may occur through diffusion of innovation and shared learning of what works now that there is evidence of the programme delivery in Whanganui. Gout should also be considered in the establishment of localities and how this locality approach can enable providers to work collaboratively to address LTCs.

#### 5.5.3 Greater Programme definition

There was a sense that participants would like to take part in a gout-related programme, but that the programme as it stands is not obvious or defined well enough. Participants described it as providing a couple of additional free visits to a GP and having access to free medication. There appeared to be confusion about what the programme actually provided them, and it became clear that the programme is not well described to people during the enrolment stage. In addition, while some participants were aware that their gout-related doctor’s appointment was free of charge, they did not feel that the consultation really focused on the issue at hand. There is a need for more accurate and detailed information about the programme to be provided to patients, so that they are aware of exactly what they will receive and how long the programme will last.

*“Cause literally, I’ve just been to the doctor and I was like, ‘oh, this is just really a doctor visit’. Yeah it was about gout, but it was about other stuff as well.”*

*“Yeah it doesn’t feel, yeah I wouldn’t call it a programme. It literally gives you, it’s a bit of structure to give you some, to encourage you to actually treat the issue.”*

In addition to communication to improve definition of the programme, structural changes could be made to the delivery that set it apart from standard care. From patient interviews, there is strong support for the development of a gout group, which patients with a gout diagnosis could attend. This would provide people with additional emotional support, due to feeling that others in the group understand what they are going through, in addition to advice around how to manage different emerging issues.

## 6 The outcomes achieved from the Gout Stop programme

### 6.1 Patient level outcomes

There has been an improvement in clinical outcomes demonstrated for the patients engaged with the Gout Stop programme. For the 74 patients who were enrolled in the GSP (with Kaiāwhina or programme only), the serum uric acid test results recorded within the practice management systems were analysed<sup>2</sup>. At both the aggregate level (Table 4), and when narrowed to the pre-post matched pairs (Table 5), there was a substantial improvement in SUA levels. In addition, this improvement was greatest for Māori.

Table 4: Aggregate level analysis of change in serum uric acid levels for patients enrolled in the Gout Stop Programme

Population	Pre-programme SUA	Post-programme SUA	Post-programme number at target
Māori (n=39)	0.468 (n=38)	0.387 (n=32)	15 (47%)
<b>Total (n=74)</b>	<b>0.455 (n=64)</b>	<b>0.386 (n=61)</b>	<b>30 (49%)</b>

Table 5: Pre-post level analysis of change in serum uric acid levels for patients enrolled in the Gout Stop programme

Population	Mean change	Proportion of patients with reduced SUA (desirable)
Māori (n=30)	-0.107	73% (22)
<b>Total (n=53)</b>	<b>-0.089</b>	<b>77% (41)</b>

These patient outcomes represent substantial changes to their quality of life. Patients reported the physical impact of acute suffering, influence on whānau, and the emotional impacts of gout. For most patients, the pain was described at a level where it was difficult to manage and impacted on their ability to do everyday tasks, sleep, and work. Ability to spend time with whānau was affected. Both physically unable to participate in sports with their children because of the pain they were experiencing and less time with whānau due to having to spend long periods of time trying to get their gout under control. These impacts, and the stigma associated with the disease, contributed towards feelings of low self-worth and shame.

*“I know a lot of older people have suffered during this whole Covid thing because they’ve been cut off from their mokopuna. And, you know, as an older person, that’s one of your basic reasons for existence. Is the little ones, and the contact with little ones. And when you don’t have that, what have you got? The temptation to just roll up and say well fuck it! And*

<sup>2</sup> WRHN has access to the serum uric acid levels recorded in the practice management system (PMS) of WRHN practices only. This means some patients do not have pre and post results due to; not being enrolled in a WRHN practice, not have a result in the PMS before enrolment on the programme, and/or not having a result in the PMS after starting the programme.

*that's it, it's over. There's nothing left and just fade away. And I've been working in that sort of headspace for the last 30 odd years."*

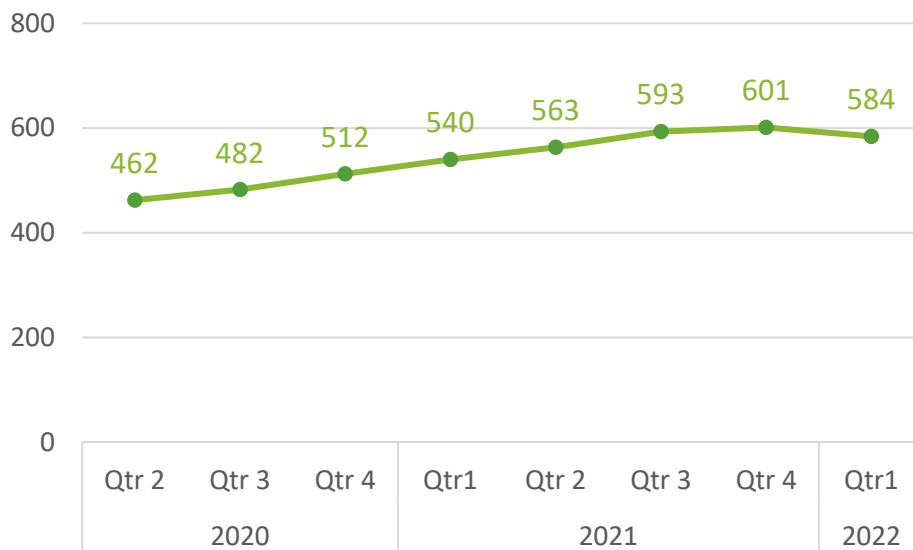
The results of the Gout Stop programme are also spreading across whānau. The Gout Stop Kaiāwhina reports a brief case study below where two sons are learning from the progress of their dad:

Followed up the family of 3 dad is still managing his gout well. The sons are starting to follow suit. Both have been back to their GP in [rural town] and both are now on 300mg for Allopurinol. So far, no flare ups.

## 6.2 Improved access to gout health care

The Gout Stop Programme has successfully increased the number of Māori who are accessing preventive medication for their gout in primary care. While there were only 39 Māori enrolled on the Gout Stop programme, there were 69 with any engagement with the programme (e.g. received an education consult), and an increase of 122 Māori (25%) being prescribed regular allopurinol (Figure 4). This illustrates the work of raising awareness and educating health providers has had a greater impact on equity of gout management care than just that represented by GSP enrolments.

Figure 4: Māori receiving allopurinol at least twice within a 12-month period



There are many pathways that may have contributed to this wider improvement in access to gout care for Māori. Building of health literacy about gout is likely to be shared with wider whānau for them to seek allopurinol. Equally, education and awareness-raising activities from the gout Kaiāwhina may be leading more people to ask for preventive medication. Educating health providers may also be changing their clinical practice to improve access to preventive medication without the administrative process to formally enrol patients on the GSP.

## 7 Themes in exploring the transferability of the programme establishment and implementation

### 7.1 Co-designing not copying

The importance of taking a co-design approach was highlighted by key stakeholders. Having an equity goal and examples of previous programmes were a useful starting point to establishing the programme. The co-design process was a key enabler in ensuring the programme would meet the needs of the local context. This process included starting with an equity workshop which had representatives from funders, management / implementation, providers, and consumers. As well as ensuring the programme design and delivery was adapted to meet local needs, it also supported a shared understanding and buy-in across different groups.

Principle of co-design was also embedded in the design and functions of the GSP steering group and implementation team. This included having diverse interests represented in both groups and a core function of the implementation team was consumer engagement for the GSP. In this way, the ongoing programme adaptations, resources, etc are designed with input from funders, doers and consumers. For example, consumer engagement established principles of engagement to improve the experience of all gout patients in Whanganui when using the health system or facing health messages (Appendix 1). Ensuring the co-design approach is kept when transferring the programme to other areas (rather than direct copy of the 'product') will support their successful integration in the new landscape.

### 7.2 Getting the right programme implementation team and leadership

Having a multi-disciplinary team with diverse skills, experiences and relationships was perceived as a strength of the programme. It supported easy access to knowledge and feedback from different sectors. For example, having a pharmacist representative was helpful to inform new programme agreements with community pharmacy that would fit with their existing reality. Members who represented and connected to stakeholder groups enabled this diversity to be included without making the implementation group too big to be manageable. Fortnightly meetings were regular enough to keep the team moving together in the same direction.

Leadership of the programme and implementation team was non-clinical and primary care based. This leadership by a health promoter was seen as essential to ensuring the GSP took a wellbeing approach that was focused on building health literacy and reducing barriers to care and self-management. The WDHB has provided support and maintained visibility throughout the project but otherwise devolved control to primary care. The primary care control has meant the programme benefits from existing relationships with general practices. It was perceived that this approach from DHB was easier due to the smaller size, flexibility, and connections of the DHB.

### 7.3 Achieving practice leadership and buy-in

The Whanganui GSP has found that the changes needed in general practice are bigger than just adding programme resources and processes; building knowledge and shifting culture is also required for successful delivery of the GSP by a general practice. Providing a quality



gout consult involves sharing a different message to the lifestyle change message that many clinicians are used to sharing for gout. Another common problem identified in primary care is where patients are left on the same dose of a preventive gout medication when they don't receive a blood test and follow up.

Nurse champions have been proactive in providing practice leadership to support change where they are available. Nurse champions are also used successfully to support other projects in primary care. The challenge is to have a nurse champion who is passionate and able to take on the leadership role. This will help the wider team buy-in to adopt changes such as the new prescribing regimen, using an advanced form for PHO funded gout consults, and clinical audit of patients with gout.

Several general practices have used equitable gout care as their continuous quality improvement (CQI) project for Cornerstone. This has provided additional motivation for practices to focus on adopting the GSP and monitoring their process and outcomes. It also provides benefit to practices where they get PHO support towards their CQI project e.g. data being provided to practices.

#### 7.4 Role of HIPs and Health Coaches in team-based care

There is potential for the Health Improvement Practitioner (HIP) and Health Coach to become valuable parts of general practice delivery of gout care. Health Coaches would have a role in supporting health literacy and self-management, which could include the provision of group consults for gout. Gout is mentioned in the training received by Health Coaches, but a stakeholder queried whether they would also benefit from completing the same Midlands training received by community pharmacists.

There are some particular contexts in which it was felt that HIP and/or Health Coach involvement would benefit patients with gout:

- Support the building of health literacy for patients who may be pre-contemplation to encourage progress through the Stages of Change. This would be particularly beneficial when patients are not yet fully engaged with the Gout Stop programme.
- Work to support behaviour change for patients where the health care process appears to be best practice, but the patient is not demonstrating the expected clinical outcomes.
- Where a patient is struggling with the psychological impacts of a new LTC diagnosis (especially at a young age) and/or the psychological impact of acute attacks impacting other aspects of their wellbeing.

The challenge with use of HIPs and Health Coaches is about how the new roles have been established within a general practice. This includes the relationship with the practice and how they are integrated as a normal part of team-based care. In Whanganui, both roles are based in the general practice (and employed by the general practice in most cases) and patients can be introduced to either role by any member of the practice team. In other regions this delivery model may differ, for example the Health Coach may be more external to a general practice or there might be an additional community support worker role.

Communication of the purpose of different roles can also be a challenge to using HIPs, Health Coaches and community Kaiāwhina effectively. In Whanganui, there has been some confusion about how the Kaiāwhina role fit with the general practice as there was very little relationship at the start of the GSP. Where the Health Coach is used as a key part of gout management, there may be less need for general practice to have a direct relationship with the Kaiāwhina – allowing for more community engagement work.

#### 7.5 Kaiāwhina workforce

At the time of starting the GSP, WRHN was at the beginning of establishing a Kaiāwhina workforce. This has resulted in the GSP being impacted by WRHN learning about what it takes to develop, support and best utilise this workforce. One stakeholder commented that this role may have been better suited to be employed by an organisation that already had an established Kaiāwhina workforce. This would include Kaiāwhina leadership, professional support, and flexibility as part of a Kaiāwhina team. This workforce development may already be established in other regions and should be considered when deciding where a Kaiāwhina role is employed.

The GSP had a two-month vacancy for the Gout Kaiāwhina position which provided both a challenge and opportunity. The original Gout Kaiāwhina resigned to take up another opportunity and it proved difficult to recruit a replacement with multiple rounds of recruitment before the next Kaiāwhina was employed. This provided a challenge to continuity and momentum where a minimum level of activity was maintained by the WRHN implementation team. However, it meant less resource for community engagement activities. However, it did provide an opportunity for WRHN to re-think the structure of their Kaiāwhina workforce and break down silos. While there is a dedicated Gout Kaiāwhina, there is also an increased team approach with connection to the long-term conditions outreach team and other Kaiāwhina roles.

Despite these challenges, the Kaiāwhina role has been a valuable part of the team. They have different skills including a non-clinical understanding of wellbeing, some lived experience with gout, and strengths in engaging Māori.

#### 7.6 Making a different role work for pharmacy

Overall, it was considered that the GSP was well received by pharmacy. Stakeholders considered that the WDHB is already proactive in terms of increased use of community pharmacy for health initiatives, including funded emergency contraceptive pill and rehydration services. All community pharmacies had at least one pharmacist who completed the Midland training to deliver gout education consults.

However, there has been variation in the degree to which different community pharmacies then deliver the GSP. A small group provides an excellent service with the GSP dispensing, education consults, serum uric acid level testing, and will communicate with general practice to query a prescription if they think a dosage may not be correct for a patient. Some do not appear to be delivering the GSP and many provide some aspects of the programme. The serum uric acid testing appears to be one of the activities where it has been more difficult to get pharmacy uptake. This testing is valuable in both reducing barriers

to care and building health literacy to achieve the goal of improved equity. The GSP stakeholders want to find a way to maintain access to this for their population. The benemeters used to measure serum uric acid also test for diabetes and cholesterol which would support translation of the model to other LTCs using the same testing tool.

Considerations for adaptation included smaller increments of activity and funding. One stakeholder considered that spending 15 minutes for a pharmacist education consult was too much time off the floor for a pharmacist within the way community workforce operates. This is also illustrated by some of the pharmacist feedback that they were not including all their education consults in their invoicing as they were delivering brief education and not sure it was sufficient to be invoiced as an education consult. Adaptation to involve pharmacy assistants in delivering the education consults could also be considered. The stakeholder also thought payment for specific activity rather than programme milestones would support greater GSP activity by community pharmacy. This would also provide a financial incentive to have complete recording of activities provided by community pharmacy.

#### 7.7 Integration of information systems

Several challenges to the GSP are linked to lack of flexibility and integration between information systems. These included; MedTech prescriptions need to be pre-set for each medicine for each individual user rather than pre-set regimen in a facility, prescriptions are not marked as 'Gout Stop', making it difficult for community pharmacy to identify who should be enrolled on the GSP, community pharmacy systems are disconnected causing difficulty in automatically populating data when enrolling or sending data back to general practice e.g. sending back a serum uric acid level reading taken at community pharmacy.

The GSP implementation team have attempted to find solutions, however their experience is that these have not supported utilisation or sustainability. Writing 'Gout Stop' manually on a prescription requires the clinicians to remember an additional step, is not sustainable, and not compatible with e-prescriptions. Adding extra systems for pharmacy to complete which can send notes back to the general practice inbox were not well utilised. Investment in IT infrastructure across the system would benefit a number of programmes that aim to provide collaborative, system wide responses to health care. Different IT projects are already underway and would benefit from including community pharmacy within their scope.

#### 7.8 Competing priorities

There were a number of competing priorities for the Whanganui health care sector that present a challenge to engagement in the GSP. One of these competing priorities was the disruption from COVID-19. The pressure on the workforce to provide both COVID-19 and influenza vaccinations, and the need to increase infection prevention measures in the way care is provided has left primary care short staffed.

The unusual origins of the programme also resulted in the GSP being added on to the WDHB priorities. It was not an original focus, but the WDHB could see the need for an equity focus

on gout, so it was added to the strategic plan and other things were changed. This resulted in a less strategic view to commissioning by the WDHB.

The foundations of the GSP needed to be pulled together from different places. There were some useful resources to pull together; the blueprint from existing gout programmes, the clinical audit that had been done. However, some bits were still being developed or pulled together including review of gout education resources and the local development of a Kaiāwhina workforce.

#### 7.9 Monitoring progress and impact

Monitoring can support sustainability of programmes and motivate change.

Recommendations from the equity workshop included independent and ongoing monitoring of the GSP. The WRHN have data monitoring and provision of feedback as a routine role of the programme team. This has focused on simple process and outcome indicators with an equity lens that are targeted towards general practice (example in Appendix 2). This has demonstrated changes in activity from practices after actively showing them their monitoring data.

It is important to integrate the narrative story around quantitative monitoring data rather than looking at indicators in isolation. For example, an increase in the identification of gout may contribute to percentage process and outcome indicators looking worse. But identification is a good first step in the provision of good gout management. The Health Quality & Safety Commission's Atlas of Healthcare Variation can also provide useful information in interpreting and understanding gout data.

## 8 Conclusions

### 8.1 Early adopters were successful in improving quality of life for Māori living with gout arthritis

The reach of the Gout Stop programme in engaging patients into the programme was focused on the health care providers which adopted the full delivery of the programme early. While some other providers delivered some activity, a smaller group of providers accounted for most of the programme engagement. However, within these early adopters, the reach of the programme appeared equitable with engagement with a high proportion of Māori patients.

For those patients engaged in the programme, the evaluation found that it was successful in improving the management of gout for Māori within Whanganui. Patients also described the impact that management of gout made across all aspects of their hauora to improve their quality of life.

### 8.2 Creating systemic change is more than just another programme

A key learning from the experience of implementing the Whanganui GSP is that creating change is about more than just a programme or an additional role. The wider work from the Gout Stop implementation team was successful in improving the access to gout management in primary care for more patients than those who were enrolled in the programme. A focus on providing an additional service to individual patients is useful as a 'band aid' to improve management and outcomes for patients for whom the mainstream healthcare system has not worked. And meeting the needs of these patients is important to support our equity goals. However, a team approach to educate and change the culture of the workforce and public discourse can create a sustainable system that is enabling of equitable management of gout where fewer people need a 'band aid'.

This system change includes a focus on cultural safety and a change in the relationship between Māori and the health system. Patient interviews indicated that there is still work to do in improving the cultural responsiveness of our primary care services. Some current work supports this focus, including the increased use of a more diverse workforce in primary care such as Health Coaches, Kaiāwhina and Kaiarahi (connectors). Progress towards the goal of cultural safety and participatory relationships with Māori in all aspects of the health system will support the equity outcomes for gout and more areas of health and wellbeing.

Specific to gout, the narrative and understanding around gout needs to change. When myths are busted for health care providers, patients, whānau, and communities, there can be less stigma and more open communication. It can be easier to talk about, seek support, come to terms with a diagnosis and to involve whānau in care. This includes involving Māori communities, with whānau and kaumatua involved in this conversation.

### 8.3 National considerations to support collaborative model of care programmes for LTCs

There is a lot that can be done regionally but these programmes will also benefit from national support. An integrated IT system would enable patients to access care wherever

they go. When developing integrated and shared care IT projects, it is important that all health system providers are included to support the collaboration in collaborative models. This includes community pharmacy.

Local efforts to build awareness can be supported by national health promotion campaigns. This requires national leadership to prioritise and plan communication campaigns that regions would be unable to implement on their own. With sufficient notice, regions can leverage this investment to maximise the value of regional programmes.

#### 8.4 Considerations for an implementation guide for collaborative model of care programmes for LTCs

There are existing programmes that aim to improve the management of gout and other LTCs across the country, of which the Whanganui Gout Stop programme is one. This means there are numerous examples of programme delivery, but it does not mean that project planning and project set up should directly copy an existing model. In the initial stages of establishing a collaborative programme for LTCs, it is recommended that:

1. **Programmes start from a place of co-design** where funders, providers and consumers are brought together as equal stakeholders. This will enable a shared understanding of the background from different perspectives, and shared buy-in to a programme aim and objectives that are meaningful to the interests of all groups involved.
  - A consumer perspective is crucial as the intended beneficiaries of a programme. Ensuring the planning addresses their perceived needs and including them throughout the programme implementation will be a valuable resource to a successful project.
  - Providers are key to enable the implementation of the programme. As demonstrated by the Whanganui Gout Stop programme, the success of the programme was limited by the spread of the delivery by health care providers. This would suggest that the wider number of providers can be involved, the wider the programme is likely to be delivered from the start.
2. **Equity is built into the programme at all stages**, and this starts when defining the project aim. The Gout Stop Programme aim was explicitly about improving outcomes for Māori due to obligations under Te Tiriti in addition to the equity gap for Māori within Whanganui (despite the gout impact for Pacific peoples nationally, Whanganui has a very small Pacific population). Different regions or programmes may have additional equity considerations to build into their programmes.
3. **Careful consideration is given to establishing the leadership and implementation team** for the programme. An implementation team needs a mix of skills and competencies.
  - Different skills and competencies considered important for the Gout Stop programme included leadership, management, analytical, communications, consumer engagement and group facilitation, clinical knowledge and networks with general practice and primary care.

- Programme leadership delivered by a non-clinical role based within primary care was considered a strength as it ensured close relationships with primary care providers and communities, and ensured different models and perspectives were prioritised in programme delivery.
- Clinical expertise remains an important part of the implementation team to give credibility and trust to health providers that it is based on a robust clinical pathway.

When designing the LTC programme:

4. **Use planning tools** to help ensure the programme reflects your context and values and works for your region. Choose the tool/s that are most intuitive to your use, the important part is to be able to communicate how the programme activities will deliver outcomes that achieve your programme aim.
  - Fishbone diagrams were used by the Gout Stop programme in the early design stages to articulate what is currently going wrong from different perspectives and where activity can be delivered to have the most impact.
  - A logic model was used by the implementation team to communicate the intended delivery and outcomes of the programme.
  - Process mapping was used to communicate steps in the programme that needed to be delivered by different health providers – including the activities and documentation required at different stages of the patient journey.
  - Be clear on the level at which you are intervening and make the programme clear at different levels. For example, the Whanganui Gout Stop programme would have benefitted from separating the patient programme intervention and the system change interventions to enable greater definition of both complementary components.
5. **Encouraging and enabling providers to deliver the activities is a key factor for success.** The reach and completion rates require providers to be on board and this leads to achievement of outcomes. This works best when there is a collaborative relationship between different providers supporting the same patient population (often closely located general practice and community pharmacy). Other barriers to provider delivery should also be addressed in the co-design of the programme with providers.
6. **Be clear on the programme resources required** and plan to have quality, capacity and sustainability in the procurement of these resources.
  - Several gout education resources for both consumers and health providers have been developed. They have been peer-reviewed and provide the benefit of nationally consistent messaging.
  - For employment of human resources, ensure there is sufficient leadership, professional support and development for the role/s to thrive. It takes organisational capability and capacity to provide this and ensuring this is already proven reduces human resource risks to implementation.
  - Consider if scarce resources are essential to delivery as capacity and time will be a challenge to delivery. For example, when collaborative programmes

include community pharmacy, can it make use of pharmacy assistants to reduce the need for a pharmacist?

- An ongoing commitment from funders to deliver the programme as part of business as usual will help to give confidence to providers and consumers.

7. **Plan what indicators are meaningful to stakeholder groups** and keep it simple – process and outcome with an equity lens is suggested. Plan how these will be measured and actively communicated. Feedback, learning and opportunities for adaptation should be built into the programme delivery to give funders confidence that sustainable resourcing will lead to progress against the objectives to which the funding is intended.

When delivering the LTC programme:

8. **Establish champions** in health providers, typically general practice but also other providers, to provide practice/organisation leadership and buy-in.
9. **Consider how you can leverage existing general practice requirements such as Cornerstone** to make equitable LTC management a practice priority that attracts attention and resource.
10. **Consider how new HIP, Health Coach and other roles can be included** in 'routine pathways' for LTC management, regardless of the model in which they have been established in a region. This includes introductions for new diagnoses, unmanaged gout, and psychosocial impacts from gout attacks.
11. **Provide feedback to encourage provider delivery** as provider activity is the biggest contributor to outcomes.



## Appendix 1: Principles of engagement for gout consumers

### Gout Consumer feedback

These principles are the core things that came from the feedback from gout patients themselves. Actively utilising these principles will improve the experience of all gout patients in the future. They can be demonstrated in small ways but make a big difference to the experience of gout patients using the health system or consuming health messages.

### Principles of Engagement

**Keep it whanau based.** Overwhelming feedback from our consumers has been that gout is not an individual disease state. The implications of this, particularly an acute flare up are felt by the entire whanau. Therefore it is important to keep this conversation whanau based and involve more people than those with the condition only.

**Be cautious about whakapapa and gout connection.** Remember to keep the conversation strengths based and do not imply or explicitly state that the whanau genes/whakapapa is to blame for their condition.

**One message per message.** When dealing with whanau, or with health messaging remember to keep it simple and give one message per message.

**Strengths based approach.** Keep the conversation strengths based/solutions based. What solutions are available to support the whanau to manage acute flare ups and meet the goals of the whanau?

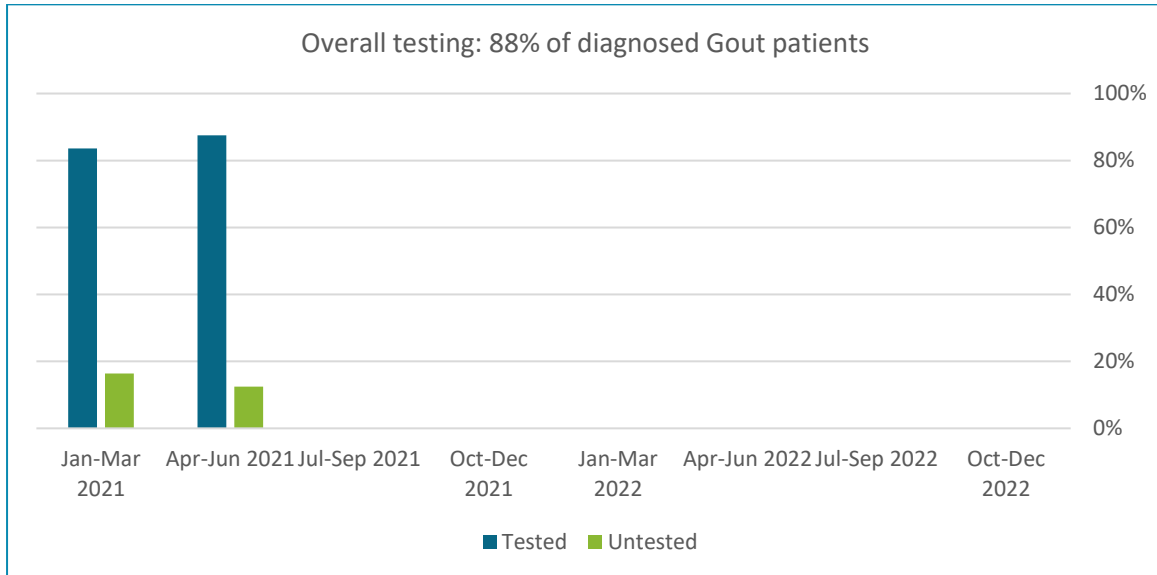
**Avoid blame.** It is important that when in a consultation with a gout sufferer or developing gout messages, that we avoid blaming the condition on the patient and focus on solutions and a strengths-based approach.

## Appendix 2: Example of practice data feedback

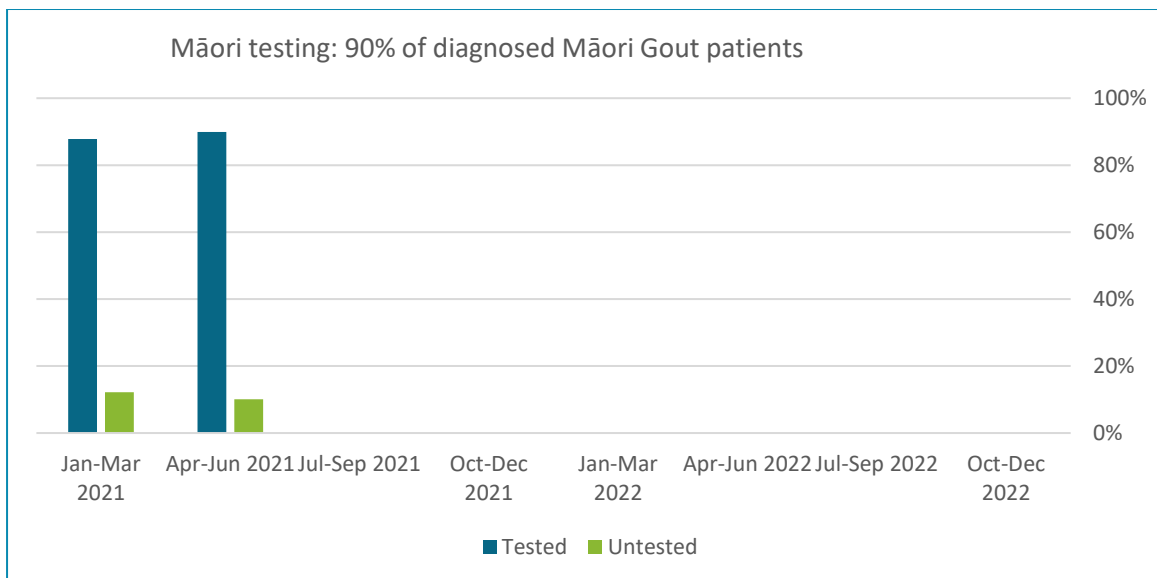
How well is Gout managed in XXX Practice?

Process – what proportion of Gout patients have had uric acid tested in the last 12 months?

Overall (all diagnosed gout patients): **88%**

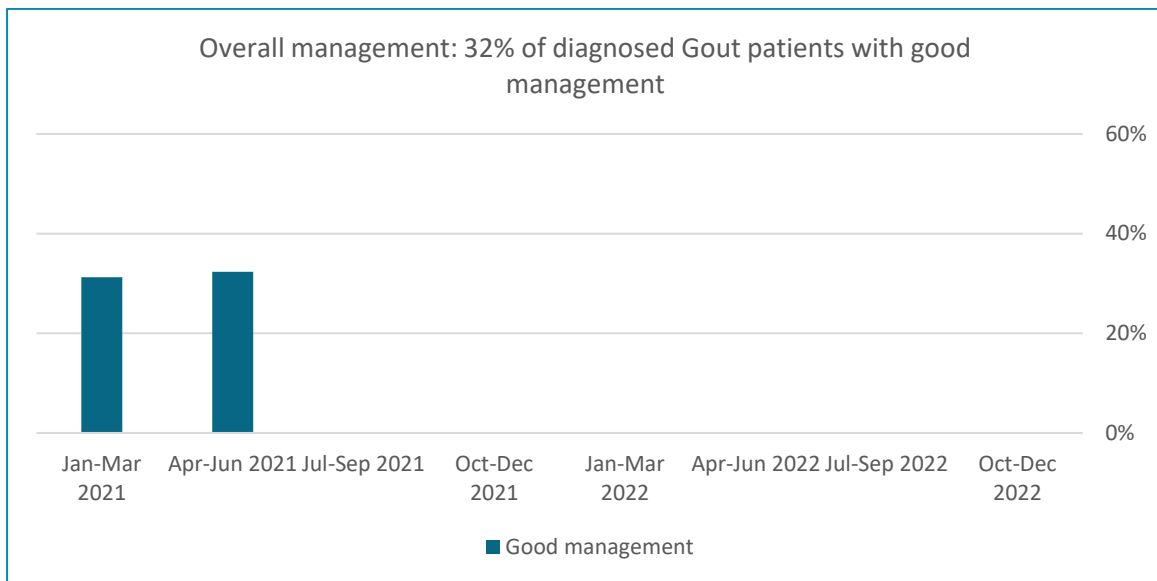


Equity: **+2%** difference

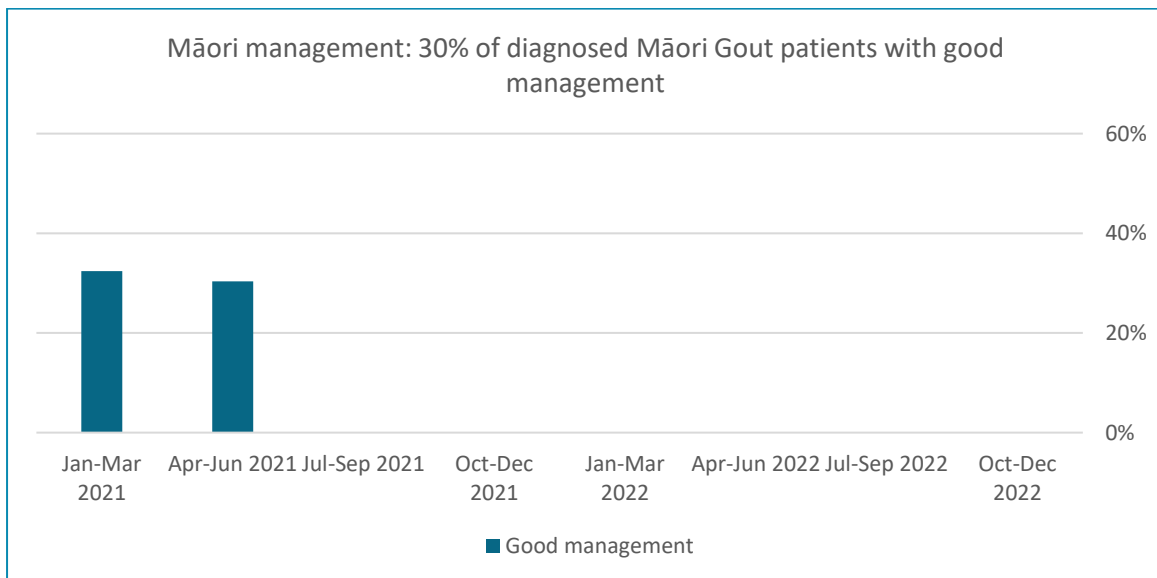


Outcome – what proportion of diagnosed Gout patients have good management (uric acid level <0.36)?

Overall (all diagnosed gout patients): 32%



Equity: -2% difference



Key points

- Audit for immediate difference
- Recalls for sustainable difference
- Classify correctly as LTC