SYNERGIA

Evaluation of gout management programmes Gout Stop and Owning My Gout

A summary of the evaluation report for Arthritis New Zealand and its partners (February 2020)

Introduction

- Synergia has been commissioned by Arthritis New Zealand and its partners PHARMAC and the Health Quality and Safety Commission (the Commission), to complete a process and outcome evaluation focused on Stop Gout and Owning My Gout (OMG). This will contribute to the evidence base of what works and inform District Health Boards (DHBs) and Primary Health Organisations (PHOs) about gout programme delivery.
- This is a summary of the evaluation report and designed for key stakeholders of the evaluation to present.
- Findings are based on evidence from the two programmes and a stakeholder sensemaking workshop.

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Gout

- **Gout is a form of arthritis**; a chronic condition caused by excess monosodium urate crystal deposition in and around joints, ligaments and tendons. Weight, impaired kidney function and genetic factors prevent the kidneys from eliminating urate.
- **Gout flares** cause painful inflammation and swelling, limit function and have a negative impact on quality of life. Flares are treated with steroids (such as prednisone) and non-steroidal anti-inflammatory drugs (NSAIDs, such as Voltaren).
- **Gout can be disabling but its effects are preventable** by long term urate lowering therapy (ULT, most commonly allopurinol), that reduces serum urate to a safe level, below 0.36mmol/L
- **Usual care** requires frequent GP visits and lab visits for blood tests to gradually titrate the dose of allopurinol over a period of months.

Gout in Aotearoa New Zealand

Barriers to effective management of gout …*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'. (Dalbeth, N. et al. 2016*)*

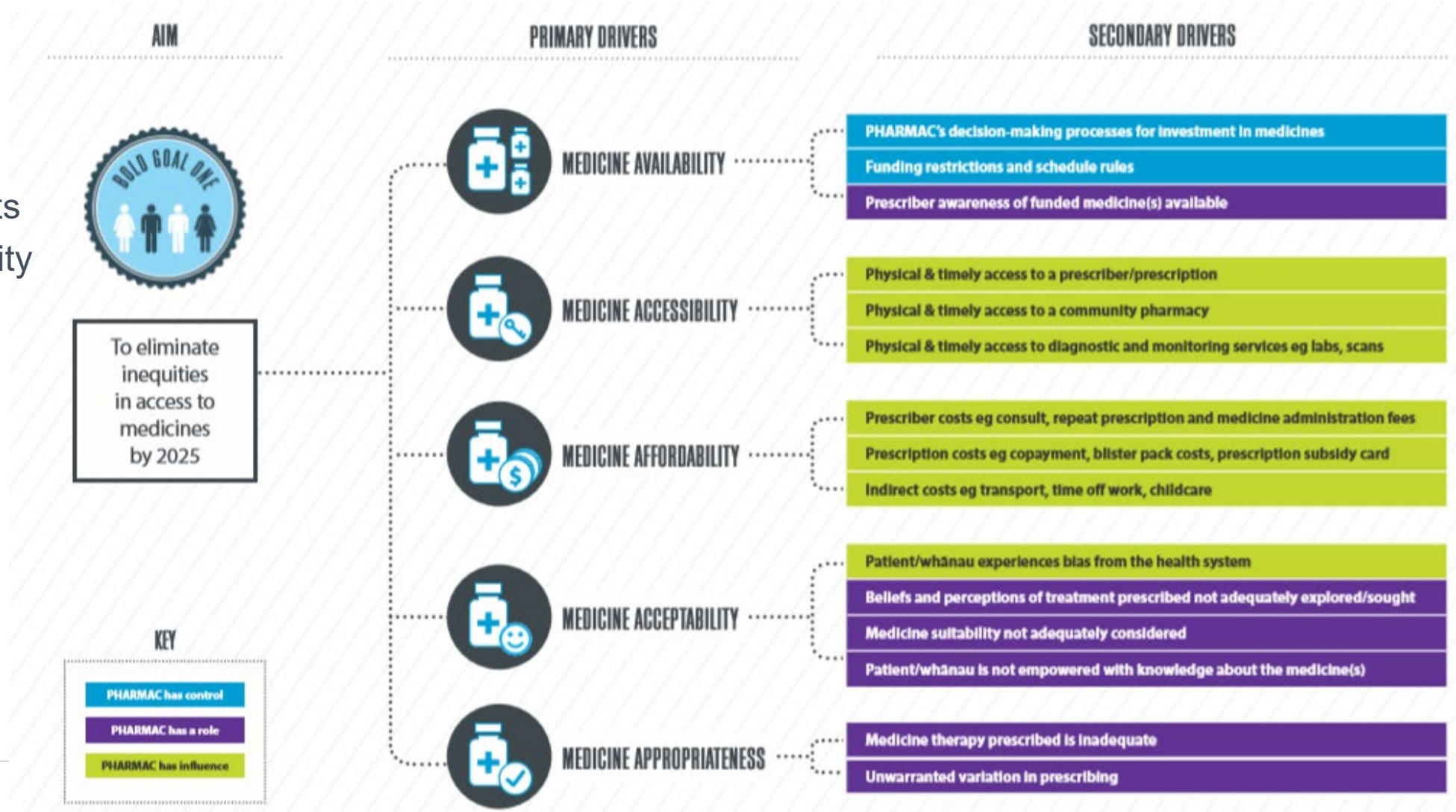
- Māori and Pacific peoples have two and three times the prevalence of diagnosed gout respectively, compared to people of other ethnicities. Māori and Pacific peoples also have poorer access to long-term medication to control gout*.
- Gout is a health equity issue and the health sector has obligations under Ti Tiriti o Waitangi to respond.
- Mahitahi Hauora PHE's Gout Stop and Counties Manukau Health's Owning My Gout programmes (OMG) begin to address some of the barriers associated with usual care. They have provided real world learning opportunities into programme design and delivery.

*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. **HQSC Atlas of Healthcare Variation

PHARMAC
TE PĀTAKA WHAIORANGA

medicine access equity driver diagram

PHARMAC has identified gout as a priority condition for its medicine access equity work programme and has an interest in understanding how these programmes facilitate and overcome barriers to access the funded medicines for gout.



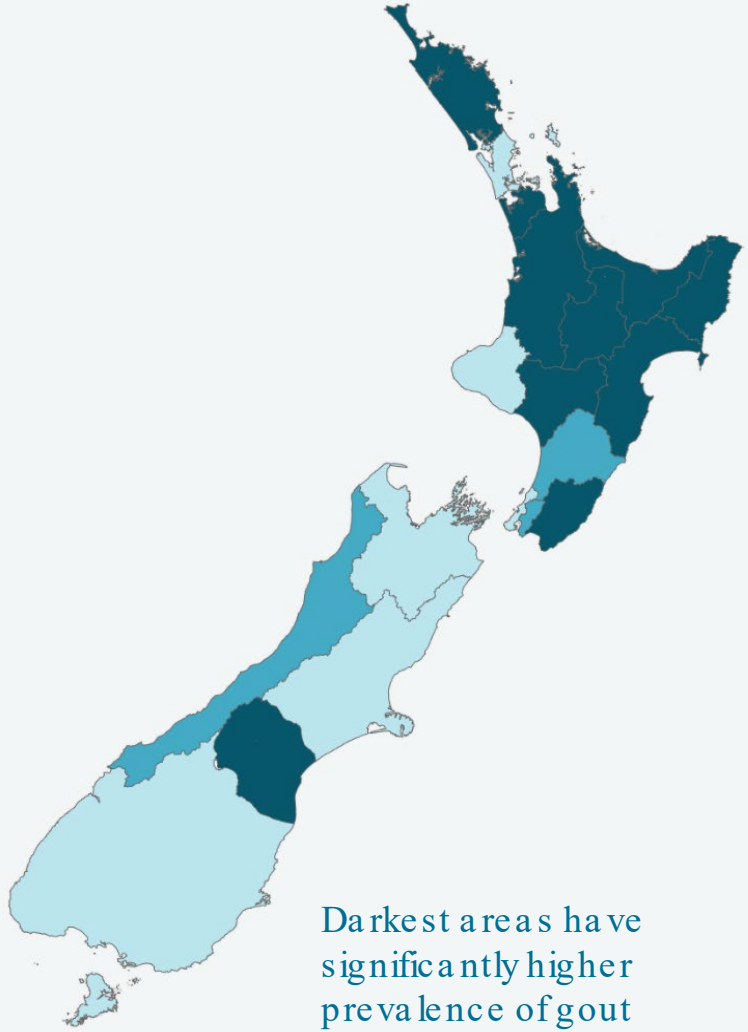
Atlas of Healthcare variation

The Commission's Atlas of Healthcare Variation shows sub optimal and unequitable access to appropriate gout medication across the country and for Māori and Pacific peoples.

Data includes:

- Prevalence of gout
- NSAID dispensing
- NSAID without ULT
- Colchicine without ULT
- Serum urate testing following ULT
- Hospital admissions due to gout.

https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/gout/



Darkest areas have significantly higher prevalence of gout

Evaluation of the two gout programmes

SYNERGIA

- Synergia has been commissioned by Arthritis New Zealand and its partners PHARMAC and the Commission, to complete a process and outcome evaluation focused on Stop Gout and OMG. This is to contribute to the evidence base of what works and inform DHBs and PHOs about gout programme delivery.
- Mixed methods design included:
  - site visits to interview programme stakeholders (7), providers (6) and patients (3)
  - analysis of programme data (Stop Gout, n=1536 and OMG, n=164 enrolments)
  - literature relating to the programmes
  - sensemaking session with programme and evaluation stakeholders.
- Data collection occurred in November and December 2019.
- Limitations from the small number of OMG programme interviews and patient interviews are identified.

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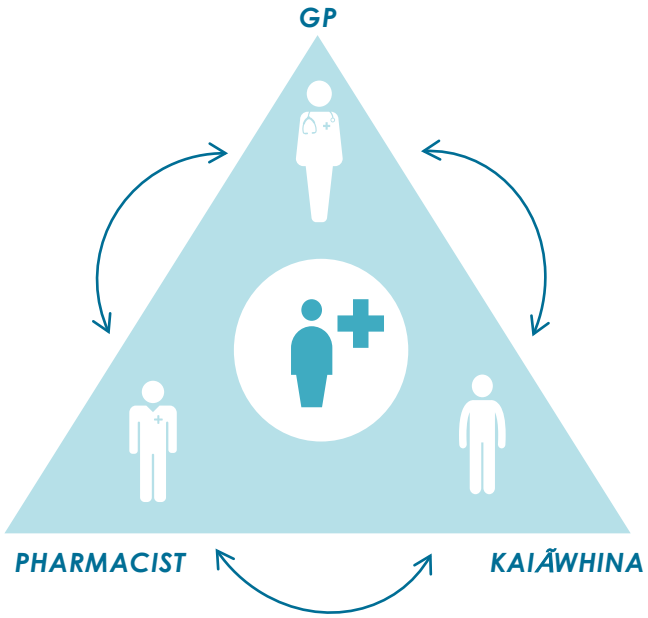
Programme design

Overview of the programmes informing the evaluation

Key features of the programmes

Gout Stop Programme



- **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 build health literacy.

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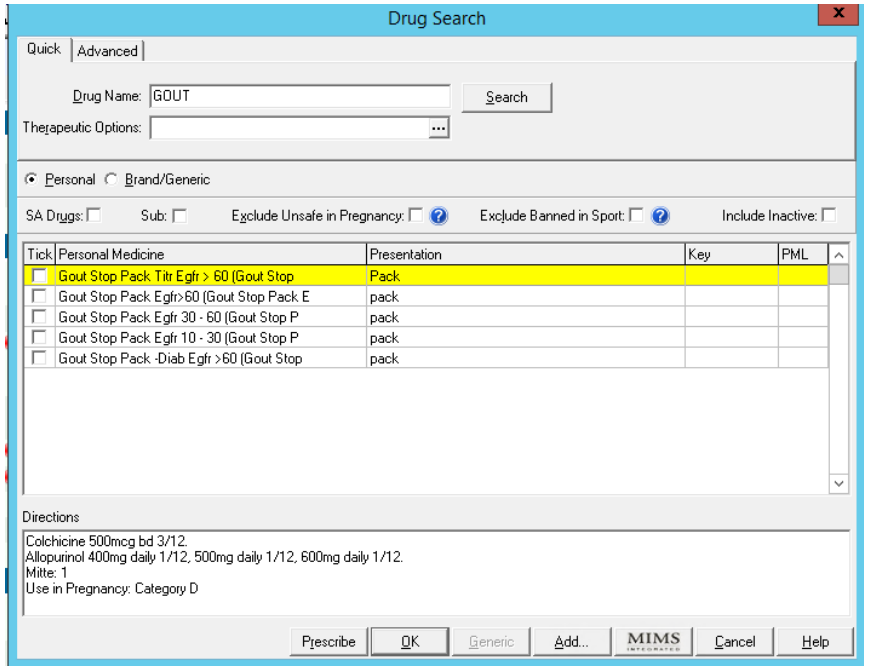
Gout Stop key features

- Pharmacists are paid for each enrolment and successful programme exit. Their role is to support adherence with medication through building health literacy and encouraging perseverance.
- Gout Stop is supported by a kaiāwhina role, originally provided by Arthritis New Zealand, but now contracted locally by the PHE.
- The kaiāwhina supports self management for patients. For most people, this is a telephone conversation a few weeks into the programme.
- The kaiāwhina is also engaged in gout awareness activities, including visiting workplaces and marae.

GOUT STOP PACK OPTIONS IN MEDTECH

The programme developed four “Gout Stop Pack” options for prescribers to select based on patients renal function and diabetes status. Packs consist of four prescriptions covering 91 days. Packs are built into MedTech and appear if gout is searched for.



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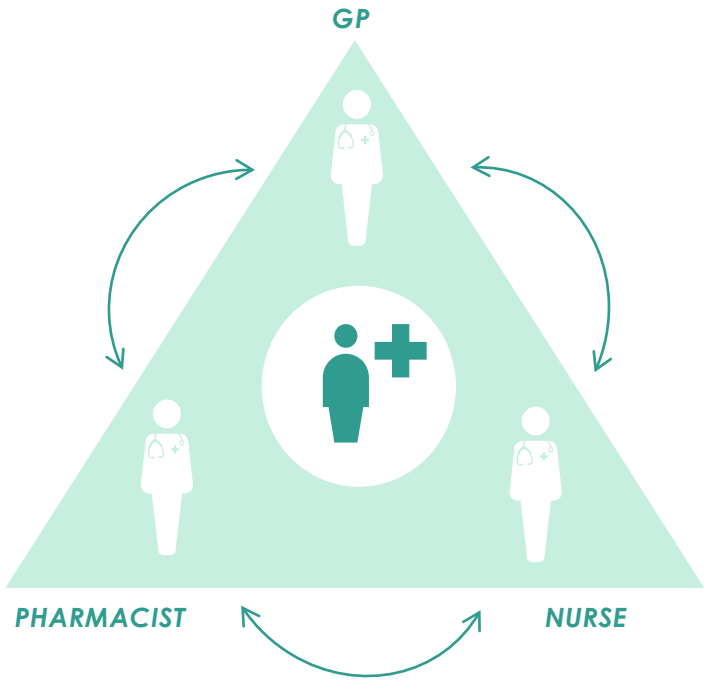
Owning My Gout programme



- **Owning My Gout** is a community pharmacist and nurse led collaborative gout management model in a pilot that by 2017 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.

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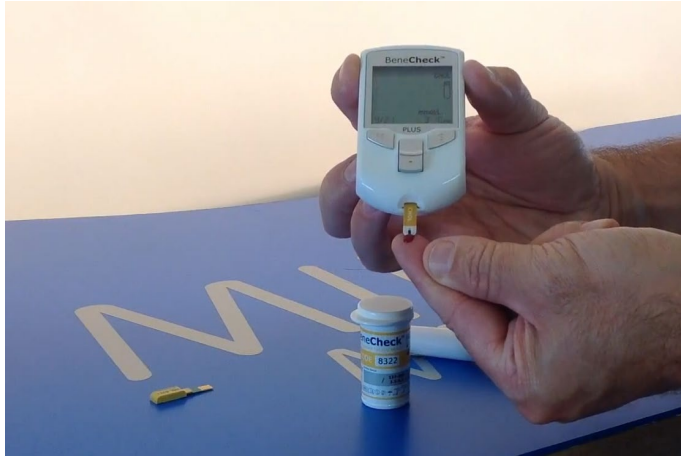
Owning My Gout key features

- Pharmacists to titrate allopurinol appropriately based on point of care testing results.
- Nurses can be the practice champion - oversee and manage the process/interface with pharmacy and provide education to patients.
- Electronic shared-care plan to encourage communication and information sharing between health professionals, and can include the patient.

MONTHLY BENECHECKS© FOR TITRATION

Patients visit their pharmacy once per month to check serum urate levels. Allopurinol is titrated for the patient using the results of the Benecheck©.



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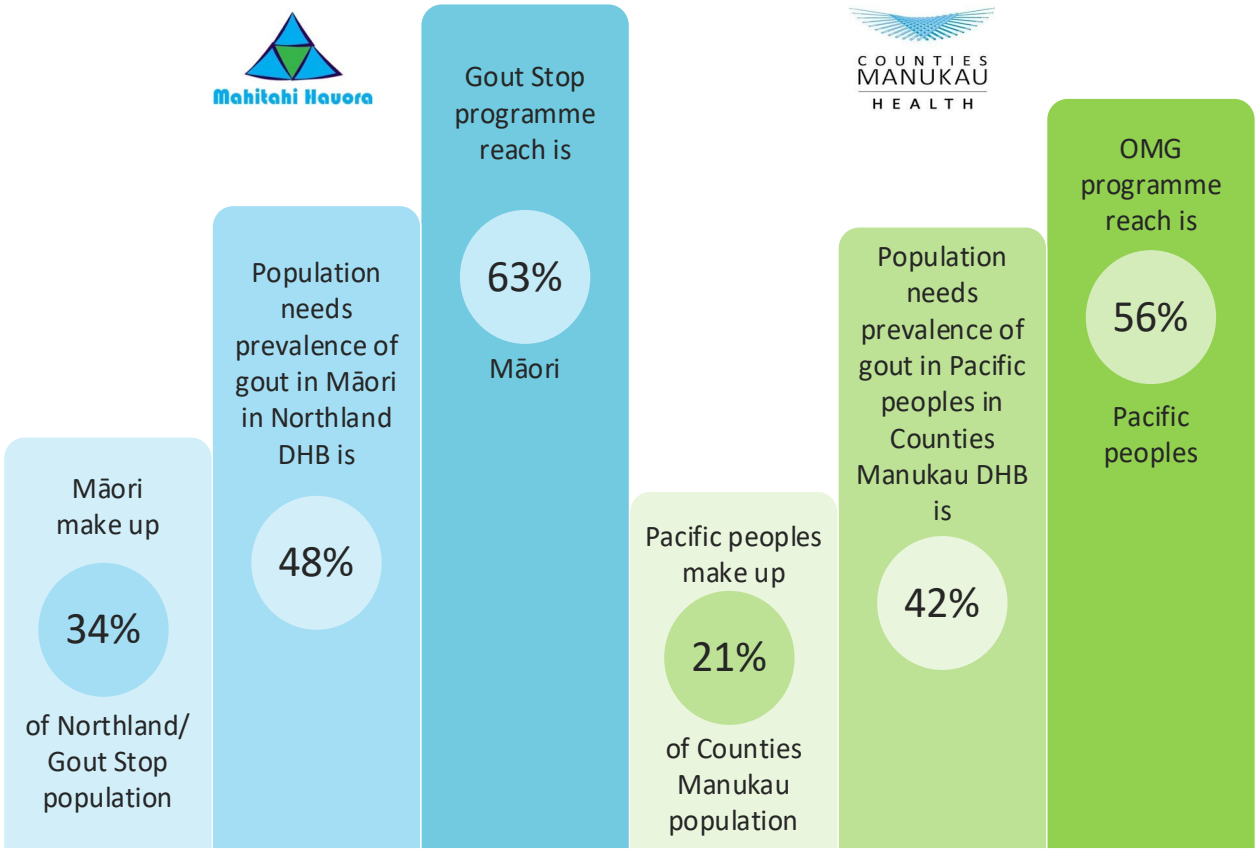
Delivering the programmes

Demography

Participation in the programmes

Influences on engagement and participation

Equity of access for Māori and Pacific peoples

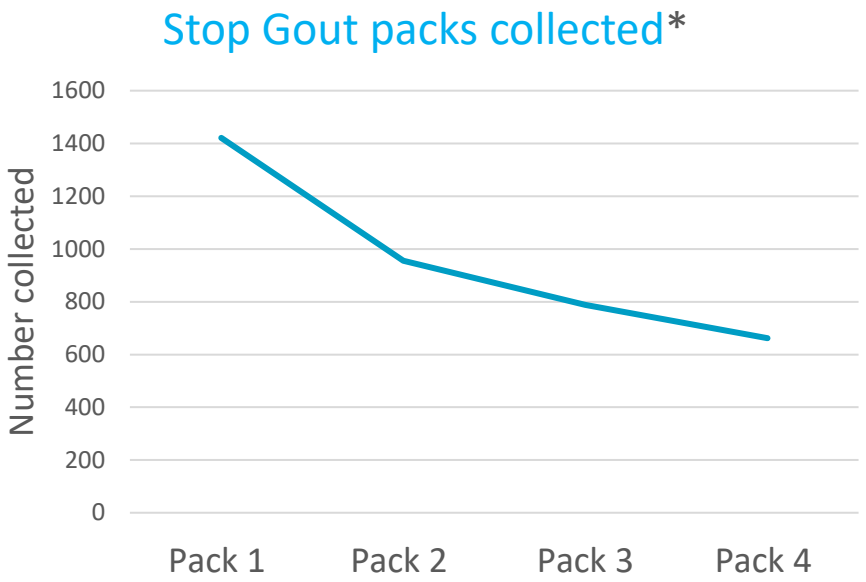


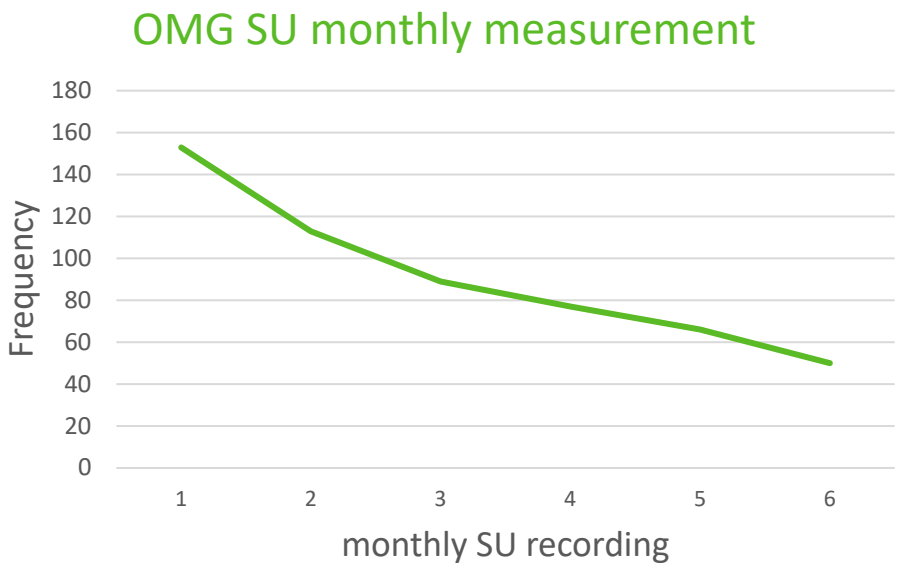
Programmes differ in scale but show similar enrolment trends:

- equity of access for Māori and Pacific (simple needs based population profile)
- a third or more aged under 45 indicated the huge preventative potential of programmes
- 8 in 10 enrolments are male, this was higher than expected.

Needs based prevalence calculated from Gout Atlas prevalence of diagnosed gout in each DHB by ethnicity.

Participation dips as the acute pain resolves





- Around one in four of those enrolled do not participate beyond the point where the painful flare fades. This pattern was reflected in provider feedback and programme data. Gout Stop data showed that Māori, Pacific and those under 45 were least likely to continue with the programme.
- Pattern to be anticipated by providers and highlights a time point and priority groups to focus quality improvement efforts.

* Have assumed pack collected for pack one where enrolled on programme but no date recorded

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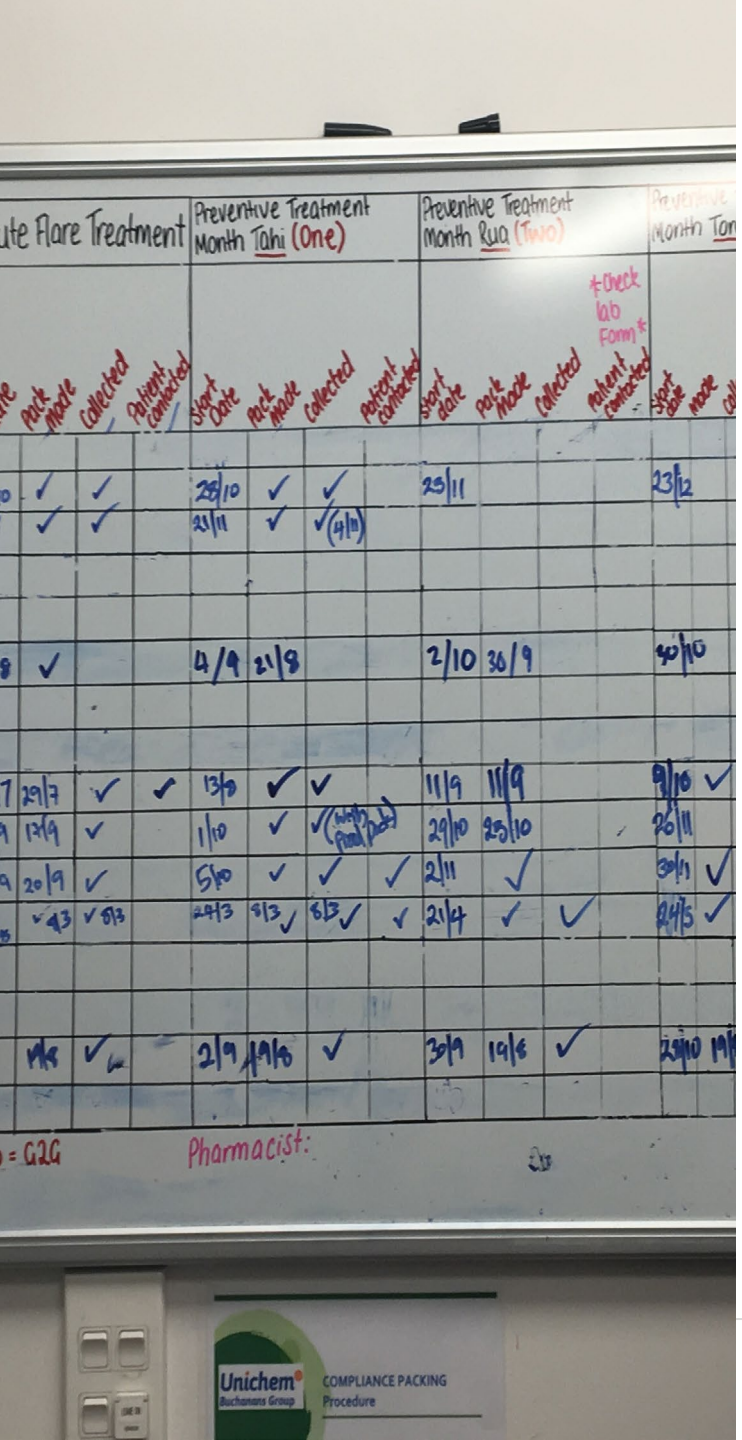


Encouraging participation

"We originally dispensed the two-week acute treatment prescription but we found 'Ah 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." (Stop Gout pharmacist)

"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)

Strategies to encourage participation included:

- pharmacists modifying dispensing mode and frequency to promote adherence
- pharmacist provides reminders where needed
- Gout Stop kaiāwhina phones patients as the first pack is finishing to encourage adherence.

Influencing patient participation in gout programmes

Barriers and enablers to accessibility

- Programmes remove the need to frequently visit the GP and have blood tests for the titration of allopurinol, saving time and costs for patients. This makes gout management more accessible than usual care. Barriers to gout management were still experienced by some, particularly Māori and Pacific peoples:
  - Generic patient barriers to primary care such as cost, travel and availability
  - Gout specific barriers for patients such as timely access to blood tests, use of over the counter pain relief options and the reduced incentive to complete the programme when pain fades.
- Pharmacists and general practices were more aware of gout management best practice and aware of barriers for Māori and Pacific peoples in particular. This makes gout management more accessible.

Influencing patient participation in gout programmes

Patient pre-conceptions can be a barrier to participation

- Well established but incorrect beliefs about the cause and treatment of gout.
- Whakamā (shame) associated with gout historically, especially in Māori and Pacific communities.
- Not understanding that gout is a long term condition and flares are a symptom.
- Not accepting the need for long term medication to manage gout.
- People already taking long term medication were more likely to accept need for daily medication to manage their gout than other groups.

Influencing patient participation in gout programmes

Building health literacy supports participation

- Needs to be built iteratively. Hearing the same things from different people reinforces learning.
- Key messages and information patients need were identified as:
  - Gout is a long term chronic condition not just flares
  - Māori and Pacific peoples have a genetic predisposition to higher levels of serum urate
  - Why medication is needed to control SU long term
  - Foods and drinks are not a cause of gout but can cause painful flares.
- Stakeholders identified health literacy in whānau and broader community as a supportive factor.

Community pharmacy provision

- Opportunity for community pharmacy role development. Pharmacists generally motivated to participate and work to top of scope.
- Contracts enable a degree of autonomy/flexibility re -dispensing to respond to local requirements.
- Online training available. This includes how to build health literacy with patients. Value from additional and ongoing shared learning.
- Pharmacists in both models play a significant role in building health literacy. Being available when needed and having private space can be challenges but pharmacists are well placed to engage with patients and whānau.
- Relationships and communication with primary care is important to success. Co- location with GP may facilitate good relationships but is not essential.
- Pharmacy funding may be an enabler. Leadership and commitment is also crucial to effective pharmacy delivery of gout management programmes.

"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)

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

General practice influences

- Gout Stop is district wide standard practice, reinforced through HealthPathways and collective understanding of Gout Stop as standard practice.
- OMG is a small scale pilot and working with willing general practices only.
- GP willingness to work alongside practice nurses and pharmacists is variable - pphilosophical, clinical practice and business reasons.
- No incentives for GPs– no gout specific targets and lots of other targets to focus on.
- Kaiāwhina a link between GP, pharmacy and patient for Gout Stop.
- PHOs could play a key role in supporting the uptake of gout malmanagement programmes.

"Some GPs think its bad practice not to see patients but they weren't seeing them anyway." (Owning my Gout GP)

"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)

Summary of participation in programmes

Patients experience a range of barriers both generic and specific to gout. Lack of pain and incorrect but powerful preconceptions about gout decrease motivation to participate.

Programmes demonstrated needs based equity of access for Māori and Pacific peoples but were less successful at maintaining engagement with them (especially younger people) as they experience more barriers to participation.

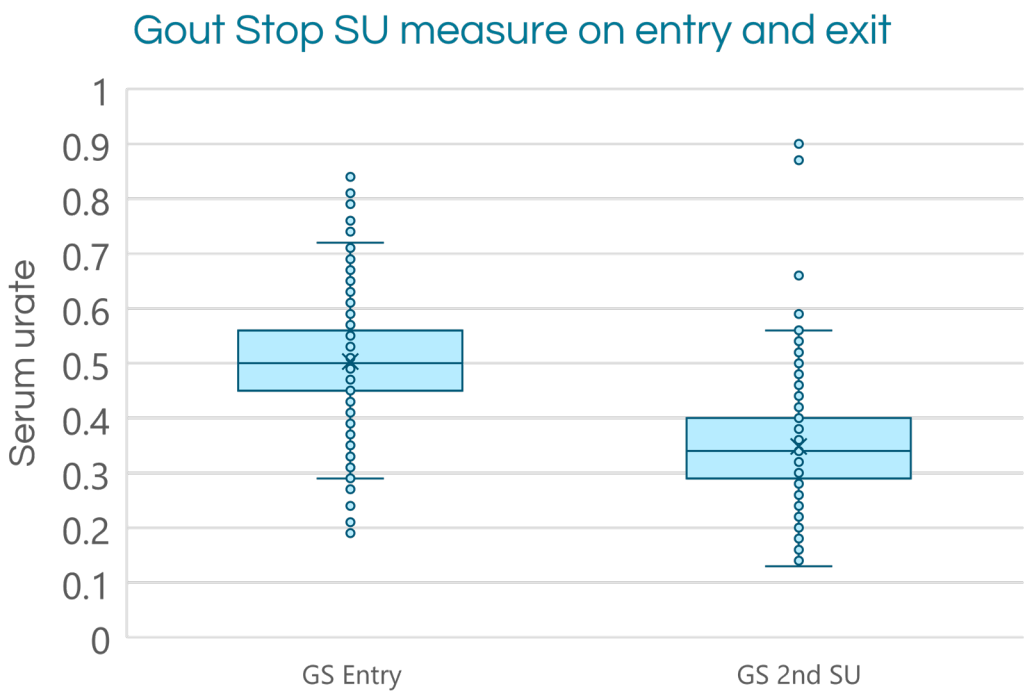
The programmes have not engaged with patients long enough to determine a successful transition to long term allopurinol; the ultimate programme aim that requires monitoring for 12 months once target SU level is reached.

Community pharmacists embracing working at top of scope; funding is an enabler but effective delivery requires real buy in. More mixed reaction from general practice - some champions, but others need convincing of process from clinical and business perspectives.

Outcomes

Outcomes for patients,
organisations and the system

Supporting clinical success: Gout Stop



Gout Stop four packs over 90 day programme
Enrolment on second flare in 12 months
Entry n=958, exit n=443

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 (collected all four packs)
- 253 (18%) reached the SU target and
- 167 (12%) continued with titration.

Non-Maori-Non-Pacific peoples who completed the programme were more likely to achieve target SU at programme completion (around five in ten) compared to Māori (four in ten) or Pacific peoples (three in ten).

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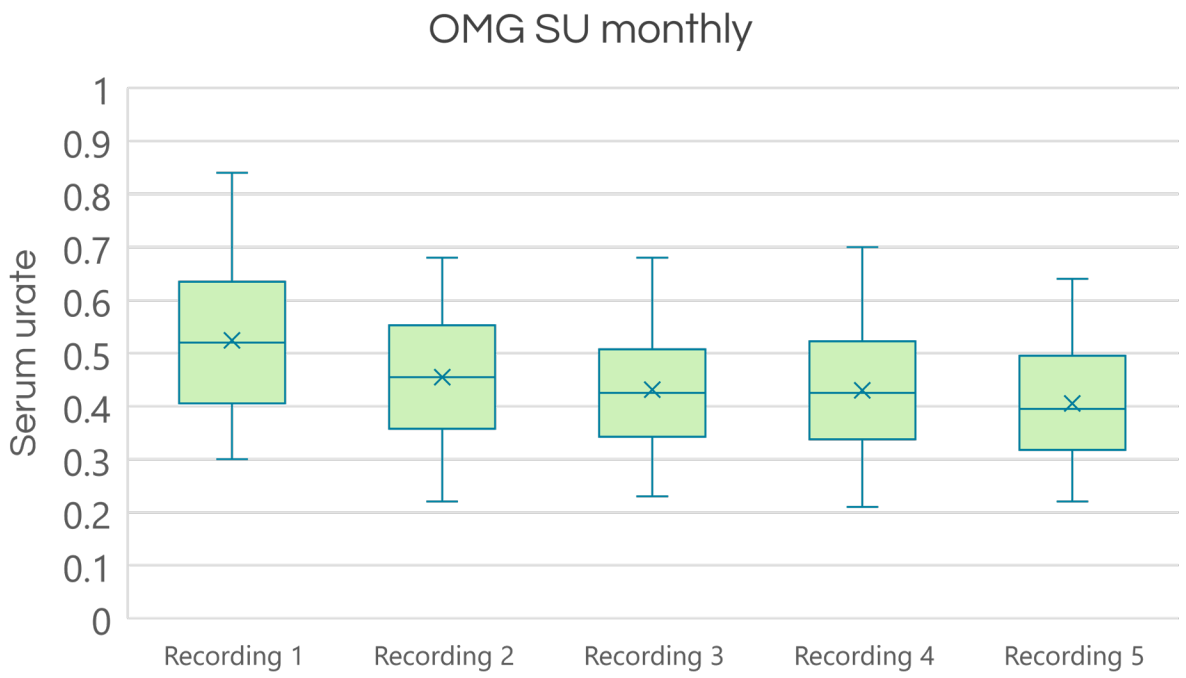
Supporting clinical success: OMG



- OMG recruitment through practice audit and acute enrolment.
- Monthly serum urate testing at pharmacy.

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
- it took around six months (median 5.3 months) for this SU to be reached
- a further 5 (3%) were continuing with titration.

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Building health literacy in providers and patients

Provider health literacy

- A health literate system provides quality services that are easy to access and gives clear and relevant health messages so that people can effectively manage their own health.
- Provider preparation included building of health literacy re updated gout clinical knowledge, local programme processes and knowledge to support building health literacy in patients.
- Providers had heightened awareness of gout, best practice guidelines and inequities in access and outcome of treatment.

Patient health literacy

- An iterative and individualized process using the Three Steps to Health framework is promoted by both programmes:
  1. Ask – what they know already and need to know
  2. Build – knowledge and skills incrementally
  3. Check - for understanding.
- The individualized and iterative building health literacy was identified as important to building understanding.

Building health literacy

“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.” (Gout Stop Client)

“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)

Outcomes beyond individual patients

- Increasing health literacy can have benefits beyond patients as whānau involvement can also increase awareness and understanding of the causes and management of gout.
- Awareness building acitiy in Northland reached people beyond health settings – e.g. at workplaces, marae, cultural and sports gatherings.
- Patients can become informal gout champions in their community and encourage others others to manage their gout.
- Informal gout management monitoring was occurring in Northland, with, for example, pharmacists querying prescriptions when local processes are not followed.

Outcomes beyond individual patients

"Whanau 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)

"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)

Adding value to the health system

The value chain created by the programmes enables the assumption that the programmes have contributed to the identified benefits for patients and communities. These programmes have also contributed to the broader health system by:

- promoting integrated teamwork (GP, practice nurse, community pharmacist, kaiāwhina and potential for other roles)
- contributing to a health equity work programme
- reducing the burden of gout on the sector through a management focus
- 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.

Summary of programme outcomes

The two programmes identify clinical success (achievement of serum urate <0.36mmol/L) differently. Around a third of participants on both programmes are achieving serum urate success.

Programmes do not demonstrate equity of outcomes for Māori and Pacific peoples within the timeframes and clinical success criteria. Tracking perseverance with long term allopurinol (best practice is 12 months from initiation) is a stronger indicator of successful gout management.

Reducing misinformation and shame associated with gout, greater awareness of best practice in pharmacy and general practice and informal champions created through programme participation all contribute to building community capacity for gout management.

Health system benefits include promoting integrated teamwork, addressing health equity issues, health gain from prevention while providing good value locally.

Supporting future roll out and improvements

Insights from the evaluation and sensemaking that can inform programme design, local implementation and sustainability

Programme components and system requirements

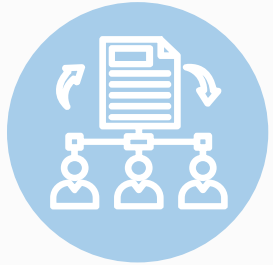
Systematise easy access to medication

Build knowledge and self-management skills in patients

Build knowledge and skills in providers

Raise awareness in communities

Collaborative leadership and delivery

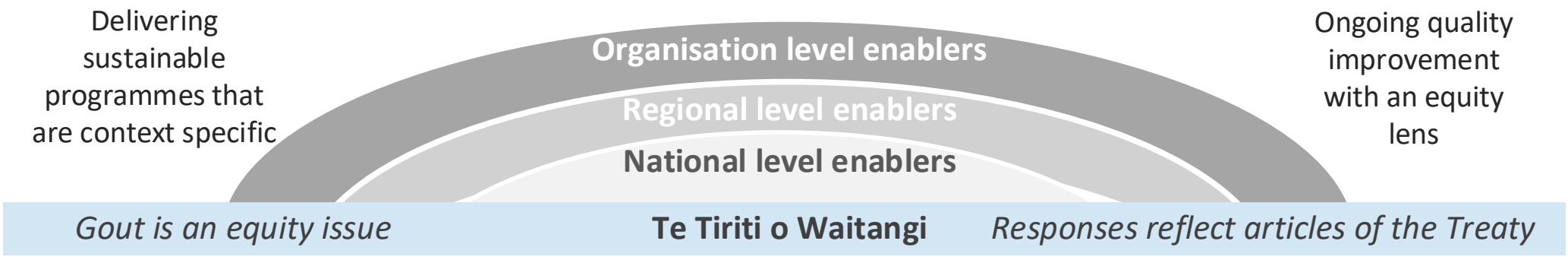


Common programme framework and measurement model

Invest in systems to share patient information

Enablers to implementation

- Enablers to implementation lie across the system; at national, regional and organisational levels.
- There are also context-specific enablers to implementing gout management programmes in primary care.



Policy and planning

Build capability and supporting infrastructure

Contractual arrangements

Acknowledgements

- Synergia acknowledges and thanks the evaluation stakeholders, programme providers and patients for their support with the evaluation.
- This summary is based on the Synergia report: Evaluation of Gout Stop and Owning My Gout management programmes: A final report for Arthritis New Zealand and its partners (28 February 2020).

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