**PROTOCOL**

**Pasifika intervention to increase uptake of urate lowering therapy for gout**

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# 1. Overview

**Title: Pasifika Intervention to increase uptake of urate-lowering therapy for gout**

Study period:3 years

# 2. Rationale

Gout is a commonly occurring arthritis caused by an inflammatory response to urate crystals in the joint. Gout flares are episodes of acute inflammatory arthritis, which are extremely painful, causing disruption to work and family life, with untreated hyperuricemia leading to chronic joint damage. Pacific people have over three times the gout prevalence of the non-Pacific non-Māori populations: 47% of Pacific men aged ≥65 years have gout, compared with 17% of non-Pacific non-Māori.1 Flares can be prevented through long-term urate-lowering therapy (ULT) such as allopurinol, which has considerable health and social benefits.2 Pacific people receive less regular urate-lowering drugs (35% versus 44%), and have nine times as many hospitalisations compared with non-Pacific non-Māori people3. Pacific people have earlier onset, higher flare frequency, more joint inflammation, greater hospitalisation rates and lower healthrelated quality of life than non-Pacific44. Māori rates fall between Pacific and non-Pacific non-Māori. Despite recognition of this under-treatment,4 regular use of ULT such as allopurinol among Pacific people remains low.5 6 Barriers to regular ULT use include understanding the need to take daily long-term medication; attendances for blood-testing for serum urate and for titrating the drug dose; obtaining regular three-monthly repeat prescriptions, and remembering to take daily medication.7

The Pacific People’s Health Advisory Group (PPHAG) comprises community members from a number of Pacific ethnicities and backgrounds, ranging from young people to the retired. The group was developed after Dr Tana Fishman (then a South Auckland general practitioner) and Ms Rose Lamont (Samoan teacher) received Patient and Clinician Engagement (PaCE) training in North America.8 9 PaCE is based on the premise that community engagement in generating research questions is necessary for evidence to be translated into best practice to improve health and well-being (the principle of co-design).10 A Pacific Practice-Based Research Network (PPBRN) was set up through the Alliance Health Plus (AH+) Primary Health Organisation (PHO), with designated research officers for each member practice. A research officer may be a GP, nurse, practice manager or administrator. Dr Ofanoa and Prof Goodyear-Smith have provided workshop training for both groups in Pacific methodology, and how to identify and ask relevant and important questions which might inform and change practice to benefit Pacific people.

The partnership group comprising members of PPHAG, PPBRN, AH+ and University of Auckland researchers is known as the Collective.

Both groups identified improving Pacific ULT use as the research question of prime importance for improved health outcomes Pacific people in South Auckland. This research proposal, based on participatory action research and co-design11, involves a partnership of researchers and end-users (community members, patients, clinicians)12 collectively involved in the design, conduct and dissemination of the findings of research. Research that is “carried out with and by local people rather than on them”3, is an effective means of reducing health disparities14. The collaboration extends beyond this specific project, for a long-term synergistic relationship, continuing to build on what has been learnt.15 16

The core principles of primary care are a patient-centred equitable approach, providing services that are available, accessible, and affordable.17 Services need to be comprehensive (caring for the whole person, not just a specific disease), continuous (maintained over time), and coordinated with other services.18 We add to this that the central tenet of primary care is effective relationships. Quality care depends on good communication between providers and patients, on acknowledging connections, and on engaging in collective decision-making. An effective intervention to improve Pacific uptake and maintain use of gout preventive medication needs to address all these primary care components.

# 3. Aims and Objectives

## Aim

Building on this knowledge, this study aims to develop, implement and evaluate a novel innovative intervention to improve the uptake of urate-lowering therapy (ULT) by Pacific patients with gout.

## The study objectives are

1. To determine ‘how big is the problem’ by measuring gout prevalence and management in Alliance Health Plus practices comparing Pacific, Māori, and non-Pacific non-Māori gout diagnoses, allopurinol prescribing and serum urate testing over a five year period, and also comparing with national and the three Auckland District Health Boards (DHBs) data (Phase 1).

2. To use a co-design approach to assess ‘what Pasifika think’ (Collective members including community members, clinical staff, PHO workers and other key stakeholders such as people with gout and their whānau) about possible initiatives to ULT uptake leading to design of a novel innovative and feasible intervention for South Auckland Pacific patients with gout, and a plan for its implementation (Phase 2).

3. To evaluate the implementation of the plan to see how well this intervention performs in the real world in a South Auckland context, including its feasibility and acceptability to relevant end-users (especially patients and health care providers), using an implementation science approach (Phase 3).

4. To prepare an implementation framework to guide future implementation roll-out in other New Zealand settings (Phase 3)

# 4. Study design and methodology

This is a mixed methods study using the Samoan research framework Fa’afaletui as a culturally appropriate framework for research with Pasifika participants. This approach focuses on the importance of considering different perspectives in research, including ‘people at the top of the mountain’ (for example, a national overview) ‘at the top of the tree’ (a regional perspective), who bring long- and middle-distance lenses to the issue, and the ‘man in a canoe fishing’, who is closest to the ‘school of fish’, and most affected by the problem (community members, patients, primary care clinicians).

The intervention will be informed by the stocktake of current New Zealand initiatives and international systematic review of interventions to improve uptake of URT undertaken by Masters in Health Leadership student Iqbal Gill. He found that the intervention types were educational campaigns, nurse or pharmacist-led programmes or multi-disciplinary team approaches. All took place in primary care or in rheumatology out-patients. None were community-led initiatives, and none were conducted outside of traditional healthcare settings.

# 5. Methods

There are three components this study. Iniital ethical approval will be sought from the Auckland Health Research Ethics Committee (AHREC) for Phase 1 and 2. Once the intervention has been designed, ethical approval will be sought for Phase 3.

## Phase 1: Quantitative assessment of Pacific gout health burden and treatment need

Observational times series study will use routinely collected data to determine the prevalence of patiens with gout,and the proportion of these who have their urate levels monitored with blood tests, understanding the need to take daily long-term medication and hence are prescribed ULT. We also wish to assess the proportion who get their prescribed nmedication dispensed and who receive regular (three-monthly) repeat prescriptionsas an indication of taking their daily medication. The measured urate level in the blood is also an indication of whether or not the patient hads been taking their ULT.

### Data sources

The secondary anonymised datasets used will be:

1. Alliance Health Plus (AH+) clinical data of the de-identified enrolled patient population.
2. Health Quality and Safety Commission national and regional DHB (Waitematā, Auckland, Counties Manukau) Atlas of Heathcare Variation – gout <https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/gout/> Data sources for the Atlas include the National Minimum Dataset; Laboratories Collection; Pharmaceutical Claims and PHO enrolment.

### Alliance Health Plus data

Routinely collected data stored by electronic health records and provided by the AH+ Primary Health Organisation (PHO). AH+ has a network of 40 general practices with a total of approximately 117,000 enrolled patients of all ages. The study denominator will be all people enrolled with AH+ who, at 1 October 2021, are aged 20 years or older and the numerator is the number of people diagnosed with gout.

The following variables will be obtained for individual visit data from the PHO:

* Patient identifier - AH+ will de-identify data and apply codes to replace NHI.
* Sex
* Date of birth
* Ethnicity - prioritised
  + Total Pacific (as a binary variable – any Pacific ethnicity reported Y/N)
  + Total Tokelauan (ethnicity group Level 2; binary)
  + Total Niuean (ethnicity group Level 2; binary)
  + Total Tongan (ethnicity group Level 2; binary)
  + Total Cook Island Māori (ethnicity group Level 2; binary)
  + Total Samoan (ethnicity group Level 2; binary)
  + Total Other Pacific Peoples (ethnicity group Level 2; binary)
  + Total Pacific Peoples not further defined (ethnicity group Level 2; binary)
  + Total Fijian (ethnicity group Level 4; binary)
  + Māori (ethnicity group Level 1; binary)
  + European (ethnicity group Level 1; binary)
  + Asian (ethnicity group Level 1; binary)
  + MELAA (ethnicity group Level 1; binary)
* NZ Deprivation (NZDep) index decile
* A current primary care-coded diagnosis of gout (binary)
* Date of gout diagnosis
* Number and date of prescriptions for urate-lowering therapy (allopurinol) in the period 30 September 2016 to 1 October 2021
* Number and date of serum urate tests requested in the period 30 September 2016 to 1 October 2021
* Number and date of serum urate test done (i.e. have results) in the period 30 September 2016 to 1 October 2021
* Serum urate test results in the period 30 September 2016 to 1 October 2021 (actual value in mmol/L)
* Hospital admission with the primary diagnosis of gout

### Analyses

Data will be analysed in R. We will use descriptive epidemiology to determine the prevalence of patients aged 20 years and over with a diagnois of gout by ethnicity (Pacific, Māori, and nonPacific non-Māori) and gender over the past five years. We will measure the percentage of the adult population diagnosed with gout by ethnicity (Pacific, Māori, nonPacific non-Māori), and the proportion who have had serum urate monitoring, and hospitalisation for gout. We will conduct sub-group analyses by age, gender and New Zealand Deprivation Index quintile (NZDep) and time series to determine trends.

For the national and DHB samples we will include disepensing of urate lowering therapy (eg allopurinol). For the AH+ we will include prescribing of urate lowering therapy (eg allopurinol).

The study population will be described according to gender, age, ethnicity, NZDep decile and whether or not they have a primary care-coded diagnosis of gout. Continuous variables (age) will be summarised as means with standard deviations and medians with interquartile ranges, and categorical data (sex, ethnicity, NZDep decile and gout) as frequencies and percentages.

The proportion of participants with gout will be compared by ethnicity, for sex and 10-year age groups.

Among participants with gout, the proportion with the following in 2021, 2020, 2019, 2018 and 2017 will be compared by ethnicity, for sex and 10-year age groups:

* prescribed ULT (allopurinol)
* dispensed allopurinol (if available)
* serum urate test requested
* serum urate test result

The frequnecy of ULT prescribed over the duration of the gout diagnois (wthinin the study period) will enable calculation of regularity of three-monthly prescriptions, giving inde

Among participants with gout and who have had a serum test result in the preceding 6 months, the proportion with and without serum urate of <0.36 mmol/L will be compared by ethnicity, for sex and 10-year age groups.

Differences in proportions between ethnic groups will be assessed using a generalised mixed methos model with binomial or poisson distribution.

### Data transfer and storage

Deidentified data from AH+ will be transferred via an encrypted USB memory stick and stored on a password-protected University of Auckland drive.

## Phase 2: Designing the intervention and developing the implementation plan

### Summary of the existing initiatives

The stocktake of Aotearoa New Zealand gout programmes, including those not published in the peer reviewed published literature, will be updated. These include Counties Manakau DHB Own My Gout; Northland DHB Gout Stop; Greenstone Clinic Doctor Bypass programme, and Papakura Marae pharmacist-led clinic. A comparison between the Own My Gout and Gout Stop programmes has recently been reported.

A concise, user-friendly summary of the types of complex interventions identified by the systematic review and the national stocktake will be produced to inform key stakeholders on what has already been tried, and what has been shown to be effective in different contexts. This will include visual reperentations for example in powerpoint presentations, posters or storyboards.

### Qualitative enquiry

The intervention will be designed through qualitative enquiry using nominal group technique where possible to ensure all voices are heard. At the beginning of the first workshop, the participants will be informed about existing interevntions and their degree of success, using the summary materials outlined above.

A series of workshops will be conducted with Collective members and other key Pacific stakeholders and community representatives to explore their views on interventions currently available, their perceived barriers to Pacific people taking ULT, and to brainstorm innovative alternatives. The final intervention will be designed through workshopping with the Collective.

### Sampling

Participants will be the current partners in the Collective (PPHAG, PPBRN and AH+and other identified key stakeholders) attending the design workshops.

• *Pacific People’s Health Advisory Group (PPHAG)*: This group comprises male and female community members aged in their 20s to their 70s, of mixed Pacific ethnicities (Samoan, Tongan, Niuean) with a range of occupations including nursing student, teacher, social worker, broadcaster and retiree. All PPHAG members will be invited to participate in the workshops and the project is open to their inviting others they judge can add value to the workshops.

• *Pacific Practice-Based Research Network (PPBRN)*: All PBRN research officers (who include general practitioners, nurses, and receptionists depending on the practice) from South Auckland practices in the Network will be invited to participate in the workshop/s. The research officers will be asked to extend the invitation to other practice staff members to participate, should they wish to do so.

* *Alliance Health Plus (AH+)* The clinical director, the nurse lead and any other AH+ relevant staff will participate in the workshops.

*• Other relevant stakeholders*: Invitations to participate will be extended to other relevant stakeholders such as community pharmacists, community members and/or others identified during the course of the study. This may include Pacific people with gout and their family / whanau members.

All participants will receive the Particiapnt Information Sheet and sign witten consent forms prior to the onset of the workshop.

Workshops will take place either in-person or via virtual means such as zoom, depending on availability, preferences, and COVID-19 Alert levels. On occasion, semi-structured interviews will be undertaken with key stakeholders who cannot attend workshops. Sections of the workshops may be audiotaped and transcribed or results may be collected on paper and through phtogrpahs of whiteboard workings etc. No induvial contributors to the collective decision-making will be identified.

### Conducting the workshops

The workshosp will take place in-person if at all possible, at a venue which best suits the participants. Pacific patients and families will be engaged using appropriate cultural processes and protocols. Talanga30 (interactive talk with a purpose) will be used to ensure two-way dialogue takes place when communicating with Pacific people.21

### Theoretical frameworks and analyses

The luva approach (presentation to others), as exemplified in the Kakala research framework.32 will be used to feed back the synthesised material to the collective group at a subsequent workshop. The novel intervention will be informed based on the Pacific peoples holistic view of health as in the fonofale model.33 This model addresses social, physical, mental and spiritual well-being, grounded by family, and overlaid by the Pacific cultural values of connectedness and collaboration, to create an innovative approach feasible to implement within South Auckland Pacific communities.

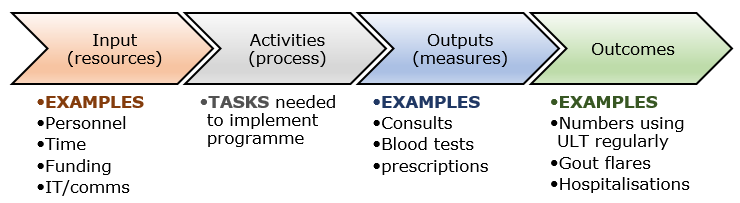
The data collected from both the workshops and interveiews will be collated and synthesised. Key themes may be identified and analysed in NviVo software using a general inductive approach.31Suggested interventions and intervention components will be discussed with advisers Prof Nicola Dalbeth and Dr Corina Grey to assess the feasiblity of the approach.

### Design of the intervention

Once an intervention has been drafted, the Collective will collectively refine it through workshopping and other digital communications with key stakeholders into a strategy that can be implemented in South Auckland. Factors to be addressed in the intervention include what components it entails (eg health promotion, education, prescribing, dispensing, serum urate monitoring, patient reminders, family/whanau involvement), who leads it (eg doctor, nurse, pharmacist, team, community-led), and where it takes place (eg health premises, community location) and any possible digital modes of delivery (eg app, txt messages).

### Implementation plan

A framework to map the intervention implementation will be developed. 34 35 A logic model of change36 (a graphic representation of the relationship between the intervention, the mechanisms of change, and behavioural and health outcomes – see Figure 1), will be created using an intervention mapping framework.35 The logic model will define the inputs (resources, investment needed to implement intervention); key activities (tasks needed to successfully implement the intervention); outputs (measures to be made to demonstrate that the activities have been undertaken), and short-term outcomes (changes which are expected to result).



***Figure 1 Logic Model of Change***

## Phase 3 Evaluation of the intervention implementation

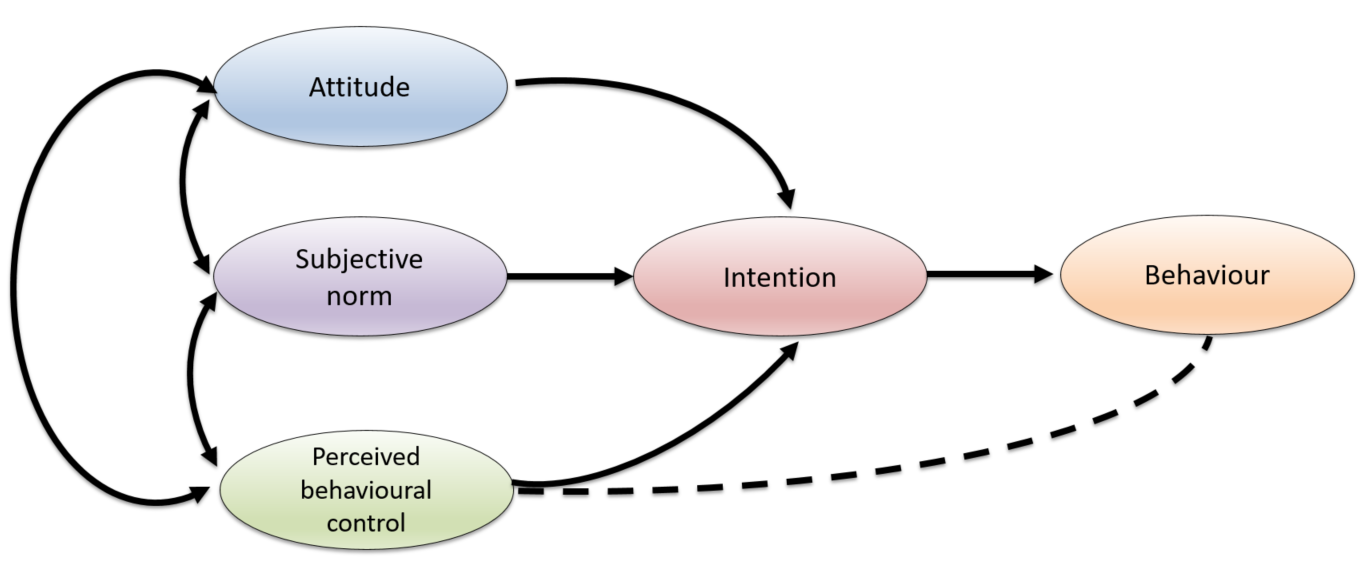
Precise details of the evaluation will depend on the nature of the novel intervention and its characteristics. The intervention will be evaluated over a nine month period (up to three three-month prescribing cycles for ULT).

### Study approach

This Phase will use an implementation science approach, which is a systematic study of the activities that facilitate the successful uptake of an evidence-based health intervention, in this case a strategy and programme to improve ULT amongst Pasifika with gout in South Auckland. The design of the evaluation of the intervention implementation will be underpinned by a theoretical framework34 and informed by behavioural change theory, whereby a person’s attitudes, personal or subjective norms, and their perceived behaviour controls (not doing what they think is wrong) shape an individual’s behavioural intentions, and hence their actual behaviours (Figure 2).37

Evaluation will focus on:

1. *Process* How components of the strategy are delivered or adapted, and how much they conform to the intended intervention components and principles. This includes acceptability and feasibility of intervention delivery.
2. *Mediators of change* Whether these components reduce perceived barriers, or enhance perceived enablers.
3. *Outcomes* How well the intervention assists patients to take regular ULT.



***Figure 2 Theory of planned behaviour***

### Data collection

1. *Process data* Measures will assess the feasibility of the implementation of the intervention including mechanisms to promote its use to patients with gout, its acceptability, and any enablers and barriers to its use. Patients will be invited to undertake in-depth interviews on their experience of their gout and its management; whether they used the intervention and the enablers and barriers they identify. Family members will may also undergo interviewing. The fonofale model33 will be used, exploring how well the intervention met patients’ physical, mental, spiritual, social, family and cultural needs. Acceptability and feasibility data will be sought from personnel involved in providing the intervention. This may be in the form of survey responses (eg Likert scale, free text or both); individual interviewing by phone or zoom, or through focus groups, depending on circumstances and participant preferences.
2. *Mediators of change* Potential data collected include numbers and frequency of intervention delivery, its duration, costings, events that facilitated or impeded its delivery, and other factors dependent on the nature of the intervention. Adaption to real-world circumstances requires a cyclical rather than a liner approach. Iterative changes to the programme delivery may be made in response to feedback and process data analyses during the evaluation period, to improve systematic uptake of the intervention.
3. *Outcomes* Individual patient data will assess before-after management of gout to determine preliminary effectiveness of the intervention. Data will include gout diagnosis based on Read code classifications as outlined in Phase 1 above; regular prescriptions of gout-specific ULT; serum urate testing results during the evaluation period; and hospitalisations for gout.

### Analyses

Analyses will be guided by an evaluation framework such as RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance – Figure 3).38 39 Translation of knowledge into practice requires engagement of all relevant stakeholders, behavioural change, and a flexibility of approach to adapt to real-world contexts. We will evaluate the influences on patient, healthcare professional, and organisational behaviours in the intervention setting to assess whether it can successfully reverse the evidence-practice gap. While the logic model and plan are presented as step-wise and linear, in reality implementation of a complex intervention requires an iterative co-design process, with audits of various components leading to cyclical changes and then being reassessed in a series of feedback loops, and end-users (patients and providers) engaged throughout the process.

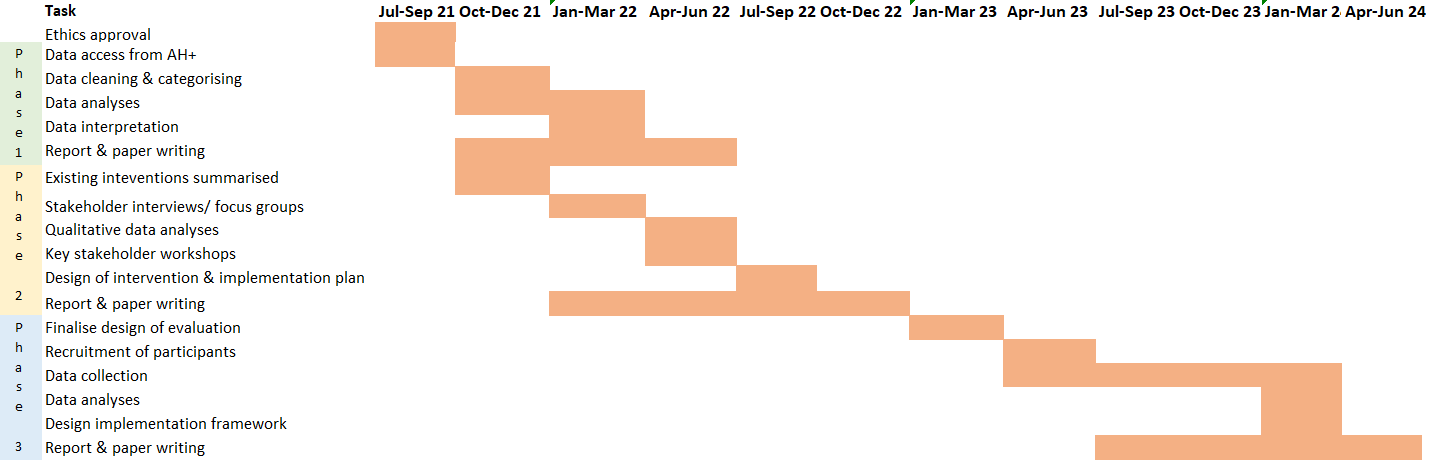
### Implementation framework

Finally a framework will be produced based on the Consolidated Framework for Implementation Research model (Figure 4),40 41 which may serve as a guide to extend the implementation to other settings, tailoring the processes and outputs to different contexts. This Framework provides a menu of constructs arranged across five domains (intervention characteristics, outer setting, inner setting, individual characteristics and process) that can provide a practical guide for systematically assessing potential barriers and facilitators, in preparation for implementing an innovation in a particular setting.40 This will serve as a guide for adaption and implementation of the intervention in other settings.

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***Figure 3 RE-AIM Figure 4 Consolidated Framework for Implementation Research***

# 6 Proposed gantt timeline



# 7 Dissemination of Results

The results of this study will be disseminated via many platforms. Firstly, study participants may wish to receive the findings. Hence, a brief summary will be sent to them via email or other relevant methods. Second, the findings will be presented at national and international conferences and will be published in academic journals.

# 8. Ownership of Data

The study will be carried out under the Pasific Health Section of the University of Auckland. The University of Auckland will thereby own the study results.

# 9 Research impact - benefits of this research

This study aims to enhance health and wellbeing for Pacific peoples, contribute to the creation of Pacific health knowledge and the translation of the research findings into Pacific health gains, and build capacity and capability of the Pacific health research workforce.

The objective of the project is to design a novel innovative and feasible intervention for Pacific patients in South Auckland with gout, to increase their allopurinol use. An intervention tailored and targeted for Pacific people will help reduce health disparities. In the clinical context, the ‘line of sight’ beneficiaries will be Pacific patients with gout, and the general practitioners, practice nurses and community pharmacists collaborating with them in their gout management. Well-managed gout leads to reduced time off work and fewer hospitalisations, hence considerable socio-economic benefits.

Potential longer-term impact is improved management for Pacific gout patients translating this knowledge to a pathway to be used by primary care practices throughout Aotearoa. Although the study focuses on Pacific people, Māori have similar issues, and innovative interventions are likely to translate to Māori health care, and possibly to the management of gout patients of all ethnicities. It may also have international implications. The indigenous Taiwanese population, who are genetically related to Polynesians (Māori and Pacific people), have similar issues with gout,20 and gout is also on the increase in sub-Saharan African countries.21

The project will contribute to Pacific capacity and capability research gains in NZ, with supervision and mentoring of two Pacific masters students, a Pacific service delivery manager and a research assistant to help them develop further research skills, as well as general upskilling of the community, practice and PHO members involved in the co-design process.

Gout management is the first of many studies envisaged by the PPHAG and PPBRN of the AH+ to be tackled using a co-design approach, in collaboration with university-based researchers, to answer their questions aimed at improving health outcomes for Pacific people. Prof Goodyear-Smith currently leads an HRC Activation Grant (#20/1119) aimed at supporting AH+ clinical lead Dr Hinamata Lutui to work with the PPHAG/PPBRN Collective to develop a further specific health delivery project for grant application in 2021. Successful completion of this gout project will provide support for this study platform and assist with future research agenda-setting.

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