

# **Health literacy and the prevention and early detection of gout**

**May 2014**

This report was prepared for the Ministry of Health by Susan Reid, Carla White and Leon Hoffman from Workbase Education Trust.

Disclaimer: The information in this report is presented in good faith using the information available to the authors at the time of preparation. The authors are not liable to any person or organisation for any damage or loss that may occur in relation to taking or not taking action in respect of information or advice in this report

## **Acknowledgements**

The authors would like to thank the people and organisations that participated in the health literacy and gout project including the members of the Reference Group, Christine Lynch and the Maaori Gout Action Group. We would also like to thank the many people and organisations that contributed to the project including people with gout (and their whānau), rheumatologists, general practitioners (GPs), practice nurses, employers, the Maaori Gout Action Group, Arthritis New Zealand, the Greater Auckland Integrated Health Network (GAIHN) and the Ministry of Health.

# Contents

<b>Glossary</b> .....	<b>5</b>
<b>Executive Summary</b> .....	<b>7</b>
<b>Part 1. Introduction</b> .....	<b>10</b>
1.1 Health literacy .....	10
1.1.1 Prevention of gout .....	11
1.1.2 Management of gout.....	12
1.1.3 Summary .....	12
1.2 The Present Project .....	12
1.2.1 Project team .....	13
1.2.2 Reference group.....	13
1.2.3 Report structure.....	13
<b>Part 2. Method</b> .....	<b>14</b>
2.1 Phase 1. Literature and Resources .....	14
2.1.1 Health literacy literature review.....	14
2.1.2 Gout literature review .....	15
2.1.3 Environmental scan .....	15
2.1.4 A list of the health literacy demands placed on a person with, or at risk of, gout.....	15
2.2 Phase 2. Consultation.....	15
2.2.1 Whānau interviews .....	15
2.2.2 Health practitioner interviews.....	16
2.3 Phase 3. Resource Development .....	16
2.4 Phase 4. Resource Trialling.....	16
2.4.1 Patients and whānau .....	16
2.4.2 Health practitioners.....	17
<b>Part 3. Health literacy barriers and facilitators</b> .....	<b>19</b>
3.1 Phase 1. Literature Review.....	19
3.1.1 Health Literacy.....	19
3.1.2 Gout.....	20
3.1.3 Environmental Scan .....	21
3.2 Phase 2. Stakeholder Consultation.....	22
3.2.1 Whānau .....	22
3.2.2 Health practitioner interviews.....	22
3.2.3 Health practitioner surveys .....	23
3.3 Summary .....	24
<b>Part 4. Interventions to strengthen health literacy</b> .....	<b>25</b>
4.1 Phase 1. Literature and Resources .....	25
4.1.1 Literature review .....	25
4.1.2 Environmental Scan .....	26
4.1.3 Health literacy demands .....	27
4.1.4 Stages of gout .....	27
4.2 Phase 2. Stakeholder Consultation.....	27
4.2.1 Patients and whānau .....	27
4.2.2 Health practitioner interviews.....	28
4.2.3 Health practitioner surveys .....	28
4.3 Phase 3. Resource Development .....	29

4.3.1	To Stop Gout booklet.....	29
4.3.2	Short gout prevention leaflet.....	30
4.3.3	Talking Points for health professionals .....	30
4.4	Summary .....	30
<b>Part 5.</b>	<b>Increasing health literacy.....</b>	<b>32</b>
5.1	To Stop Gout Booklet .....	32
5.1.1	Patients and whānau .....	32
5.2	Short gout prevention leaflet .....	33
5.3	Talking Points .....	33
5.4	Summary .....	33
<b>Part 6.</b>	<b>Discussion.....</b>	<b>34</b>
6.1	The Challenges.....	34
6.1.1	Build new knowledge and change longstanding beliefs about gout.....	34
6.1.2	Identify skills and knowledge needed to prevent onset of gout.....	34
6.2	The Process.....	35
6.3	The Outcome.....	35
<b>Part 7.</b>	<b>Recommendations.....</b>	<b>37</b>
	<b>References .....</b>	<b>39</b>
<b>Part 8.</b>	<b>Appendices .....</b>	<b>42</b>
Appendix 1.	Gout Literature Review.....	42
Appendix 2.	Health Literacy Literature Review.....	65
Appendix 3.	Health Literacy Demands .....	76
Appendix 4.	Interviews With People With Gout, Whānau and Community Members.....	79
Appendix 5.	Resource Trialling With People With Gout, Whānau and Community Members .....	81
Appendix 6.	Trialling of Resources with Health Practitioners .....	86
Appendix 7.	List of Those Involved in Resource Development .....	89
Appendix 8.	1-12 Stages of Gout .....	90
Appendix 9.	Uric Acid Card .....	92
Appendix 10.	Booklet - To Stop Gout.....	93
Appendix 11.	Draft Prevention Leaflet.....	105
Appendix 12.	Talking Points.....	107
Appendix 13.	Summary of Current and Earlier New Zealand Gout Research Projects.....	110

#### List of Tables

<i>Table 1.</i>	<i>Alignment of research objectives with research phases.....</i>	<i>14</i>
<i>Table 2.</i>	<i>Iron Māori Group, Maataatua Marae, Mangare, Auckland (N=20).....</i>	<i>79</i>
<i>Table 3.</i>	<i>Douglas Manufacturing Ltd, Henderson, Auckland (N=6).....</i>	<i>81</i>
<i>Table 4.</i>	<i>Kinleith, Tokoroa (N=13).....</i>	<i>82</i>
<i>Table 5.</i>	<i>Korowai Aroha Health Centre, Rotorua (N=5).....</i>	<i>83</i>
<i>Table 6.</i>	<i>Rheem, Avondale, Auckland (N=14).....</i>	<i>84</i>

## Glossary

Adherence	Where a patient takes their medication and follows advice from their health practitioner.
Asymptomatic	Having no symptoms.
Chasm	Gap.
Chronic disease	A disease that develops over a long period of time.
CME	Continuing medical education session provided to health practitioners.
Convergence	Coming together, joining.
Dialogue	A conversation between two people.
Entrenched	Fixed.
GAIHN	Greater Auckland Integrated Health Network.
Genetic predisposition	An inherited risk of developing a disease or condition.
Gout	A painful form of arthritis (joint inflammation) that mostly affects the big toe, ankles, heels, knees, wrists, fingers and elbows.
Gout attack	Sudden severe joint pain, sometimes with redness, swelling and tenderness of the joint.
Gout Clinical Pathway	A pathway designed mostly for primary care practitioners which contains a series of steps and questions to assist the health practitioner to correctly diagnose and treat gout: Acute gout: <a href="http://www.healthpointpathways.co.nz/acute-gout/">http://www.healthpointpathways.co.nz/acute-gout/</a> Gout prevention: <a href="http://www.healthpointpathways.co.nz/gout-prevention">www.healthpointpathways.co.nz/gout-prevention</a>
Gout flares	Another term for gout attack.
Health literacy	The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions which is influenced by health professionals, healthcare organisations and the health system.
Hyperuricaemia	High uric acid levels.
Inflammatory arthritis	A group of auto-immune diseases, including gout and rheumatoid arthritis, where the immune system attacks healthy cells in the body by mistake.
Infographics	Resources that communicate key messages through visuals and pictures.
Intermittent	Occurring at intervals.
Modifiable	Can be changed.
Monologue	A single person speaking to other people.
Non-modifiable	Cannot be changed.

NSAIDs	Non-steroidal anti-inflammatory drugs commonly used to treat the pain and inflammation of gout attacks.
Prevalence	The chance of something being common and widespread.
Prevalent	Common.
Preventive	Helping to stop.
Reflotron machine	Diagnostic machine supplied by Roche Diagnostics which accurately measures uric acid levels using pin prick technology.
Schema	The beliefs and knowledge a person has.
Schema theory	A theory about how people represent and organise knowledge in their long-term memory.
Serum urate	Uric acid.
Teach-back	A health literacy technique where the health practitioner takes responsibility for, and checks the clarity of their communication by, asking their patient to 'teach-back' by explaining or demonstrating what the health practitioner has asked the patient to do.
Titration	Gradually increasing the dose of urate lowering medication until it reaches a level where uric acid levels reach target and/or tophi dissolve.
Tophi	A build up of uric acid crystal deposits in the joints (often seen as a hard lump) that destroy cartilage and, in advanced cases, cause bone erosion.
Urate lowering therapy (ULT)	Medications used in New Zealand that reduce the uric acid levels in the blood. The most commonly prescribed ULT is Allopurinol.
Uric acid	A chemical in the body. If your body produces too much uric acid or doesn't get rid of enough, the build up of uric acid can cause a gout attack.

## Executive Summary

Gout is the most prevalent form of chronic arthritis in the world. Gout is a chronic disease, a long-term illness. Untreated, a person with gout has high levels of uric acid in their blood. A person with gout does not excrete enough uric acid and, as a result, suffers from intermittent gout attacks, caused by uric acid forming painful crystals in their joints. The onset and progression of the condition are well documented, there are effective preventive measures and treatment can remove all symptoms.

The national prevalence for gout in New Zealand is between 2.7 percent and 3.8 percent of people over the age of 20 years. The prevalence for Māori and Pacific populations is much higher at 6.1 percent and 7.6 percent respectively (Winnard et al 2012). Prevalence of gout for men is 5.9 percent (Winnard et al 2012) and up to 14.0 percent for Māori men (Gow 2005; Jackson et al 2012). At present there appear to be largely inaccurate beliefs about the causes and 'cures' for gout held by Māori (and the general population). These beliefs are reinforced in many primary care settings by the long-term prescribing or recommending of non-steroidal anti-inflammatory drugs (NSAIDs) as appropriate medication for gout and an emphasis on management through lifestyle factors, such as diet and exercise.

Health literacy is about health organisations, health practitioners, and patients and their families. It is described as 'the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions' (Institute of Medicine 2004, p 2; Ministry of Health 2010). For health practitioners, health literacy is about their ability to communicate health information and for health organisations it is about the appropriateness of the health information and services they provide for patients and their families. There is a strong relationship between a person's health literacy and their health status (Ministry of Health 2012b).

Workbase was contracted by the Ministry of Health to undertake research in health literacy, with a focus on the prevention and early detection of gout. A Reference Group (Dr Karen Lindsay, Dr Natalia Valentino and Leanne Te Karu) was established to provide clinical guidance to the project team. The aim of the project was to identify the influence health literacy has on improving prevention and early detection of gout, particularly for Māori men. The objectives of the research were to:

1. identify how health literacy is a barrier and/or a facilitator in the prevention and early detection of gout
2. highlight any interventions or approaches that may be effective in strengthening health literacy for Māori at risk of developing gout or who are living with the condition
3. demonstrate ways to increase health literacy in order to improve outcomes associated with gout.

## Method

The research was undertaken in four phases:

1. Literature reviews for health literacy and gout, as well as an environmental scan, were completed. The gout literature review focused on initial prevention, early detection and management of gout. Lists of the health literacy demands (required knowledge and skills) placed on people (and their whānau) at risk of, and diagnosed with, gout were also developed.
2. Consultation was undertaken with patients, whānau members and health practitioners. Interviews were held with 27 people to identify the messages they had received about gout. Interviews were held with nine health practitioners and 193 health practitioners provided survey responses.
3. Resources were developed for people with gout. These included a booklet containing infographics (i.e. resources that communicate key messages through visuals and pictures); a short gout prevention leaflet; a list of the health literacy demands made on a person with, or at risk of, gout (and their whānau); and a document describing the different stages of gout for patients and whānau and action points required at each stage. The action points were then reshaped to become *Talking Points* (scripts) for health practitioners to follow when they used the booklet and leaflet to talk about gout with patients and whānau.

4. Resource trialling. The resources developed during phase 3 were trialled in workplaces, with patients and whānau with and without gout and at health practitioner continuing medical education (CME) meetings. Feedback was sought on the usefulness of the resources, whether the messages were appropriate and whether health practitioners would use the resources with patients and whānau at risk of, or with, gout.

## Findings

### a. Health literacy barriers and facilitators

These barriers and facilitators are different from but linked to the barriers and facilitators identified as part of the literature review (see 3.1.1.a and b). The barriers and facilitators listed below were specifically identified during the phases of this research project.

Health literacy barriers for patients and whānau:

- Many people with gout (and their whānau) have strong and inaccurate beliefs about gout. Information provided about gout therefore conflicts with people's health schema (pre-existing beliefs and knowledge).
- People confuse the chronic condition of gout with the acute condition of a gout attack.
- People confuse medication for chronic gout, such as urate lowering therapy (ULT), with medication such as NSAIDs for the relief of pain from gout attacks.

Health literacy barriers among primary care providers:

- There is a lack of current knowledge among health practitioners about gout.
- There is a lack of understanding that the health literacy (knowledge and skills) of a person with gout (and their whānau) needs to be built and reinforced over a number of occasions using methods which best work for that person (and their whānau).
- Only a small number of primary care health practitioners understand and use health literacy strategies.

Health literacy facilitators for patients, whānau and health practitioners:

- People with gout (and their whānau) want to learn more about gout.
- The Gout Clinical Pathway (Healthpoint 2012) developed by the Greater Auckland Integrated Health Network (GAIHN) presents an opportunity to promote accurate information and practice.
- Secondary specialists are able to work with primary providers in some circumstances.
- Arthritis New Zealand's networks can be used to disseminate information.

### b. Interventions to strengthen health literacy

- Messages about the initial prevention of gout (for people with a whānau history and/or high uric acid levels but no diagnosis of gout) need to be focused on lifestyle factors, alongside genetic risk.
- Messages about gout management need to be clearly differentiated from prevention messages to avoid confusion and overcome pre-existing, inaccurate knowledge about management (i.e. the belief that diet and lifestyle are the main management factors).
- Messages about gout management should include information about physiology, cause and effect, the serious long-term impacts of gout and the role played by ULT.

### c. Increasing health literacy - resources

The resources (booklet, leaflet, lists of health literacy demands, Stages of Gout and *Talking Points*) were developed so they could be used flexibly by patients and whānau, and health practitioners. For example, the action points in the Stages of Gout developed for patients (and their whānau) were redeveloped to become *Talking Points* (scripts) for use during a health practitioner consultation when the booklet and/or leaflet were being discussed with patients and whānau. The Stages of Gout document that describes the different stages a person with gout might experience (for example, being

on NSAIDs only or taking ULT) included suggested questions patients and whānau could ask health practitioners. In the *Talking Points* these questions were refocused as questions that health practitioners could use with patients and whānau to identify their level of health literacy (knowledge and skills) about gout. The *Talking Points* also included references to different pages in the booklet and leaflet that health practitioners could refer to in order to reinforce their messages about gout prevention and management.

The list of health literacy demands was also designed so it could be used by patients and whānau as well as health practitioners. For health practitioners the demands form a checklist that can be used over a period of time to identify what health literacy (skills and knowledge) patients and whānau already have about gout and which two or three new pieces of knowledge or skills needed to be built and/or reinforced at each consultation.

In a similar way the list of health literacy demands has been designed to be used by patients and whānau; namely, to identify the knowledge and skills they already have about gout and what new knowledge and skills they need to develop so that they can seek this knowledge from health practitioners or other sources.

### **Conclusion**

This project has demonstrated that preventing and managing gout requires action, not just on the part of patients and whānau, but mostly by health professionals and health organisations. There are a number of opportunities to build the health literacy of people at risk of, or with, gout (and their whānau), as well as the health literacy of primary care health professionals.

There are a number of health literacy strategies that could be used by primary care health professionals to build the health literacy of people at risk of, or with, gout (and their whānau). Because gout (once diagnosed) is entirely preventable with ULT, gout provides an opportunity to trial health literacy approaches and strategies that could then be transferred to other long-term conditions.

### **Summary of recommendations**

The truncated recommendations below are points for the Ministry of Health to consider. Recommendations are explained fully on page 36.

- Publish online the key resources developed during this project.

*For people with, or at risk of, gout (and their whānau):*

- Develop a public awareness campaign that includes:
  - a series of key messages about gout using a well-known personality
  - an online knowledge and skill building module relating to gout.

*For primary care practitioners:*

- Develop an online module about health literacy and strategies to build it.
- Encourage practitioner use of four key health literacy strategies during consultations.
- Develop an online module initially assessing and building on practitioner knowledge and understanding about gout.

## Part 1. Introduction

As the sphere of health continues to grow and become more complex, the relationship between the health system and the health consumer also continues to change and evolve. One of the drivers for this change is the growth of chronic diseases (Zarcadoolas et al 2006). As part of doing more with fewer resources, patients now find themselves having to do more self-management of their conditions and being increasingly responsible for adherence to long-term health goals and self care in a complex health system (Pignone et al, 2005; Koh et al, 2012). Evidence from around the world shows that patients' knowledge and skills are usually below those demanded of them by their health system (Rudd et al 1999; Rudd et al 2007). As Koh et al (2012, p 435) state, 'a wide chasm often separates what providers intend to convey in written and oral communication and what patients understand'. Health literacy interventions are designed to close this chasm.

Health literacy is described as 'the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions' (Institute of Medicine 2004, p 2; Ministry of Health 2010). The present research in response to findings from phases 1 and 2 focused mainly on the development of resources to facilitate the health literacy of Māori patients with, or at risk of, gout.

This introduction provides a brief overview of health literacy and gout. This will be expanded upon in Parts 3-5 of the present report when the literature on health literacy and gout is examined for insight into the barriers to and facilitators of health literacy and interventions to strengthen health literacy to improve outcomes associated with gout.

### 1.1 Health literacy

Health literacy is more than improving access to information, quality of information and information flow between individuals, communities, health practitioners and the health system. More importantly health literacy is 'about the skills and knowledge of individuals, whānau and communities, so that they synthesise the information they receive from both the health system and other sources, decide whether they have enough information and if not gather more, and then act on the information' (Workbase 2011, p 3). This concept of empowered self-care runs alongside the process and outcome of becoming more health literate.

There are a number of behaviours that may indicate a person has low literacy, although these alone do not constitute evidence of low health literacy. These indicators include: regularly missing medical appointments, ignoring or misunderstanding health instructions or advice, asking a number of questions or asking no questions, arriving with incomplete forms, avoiding filling in forms or taking additional spare copies, and making excuses about forgetting their glasses and needing to read the information at home (Weiss 2007). In addition 'patients rarely identify themselves as struggling with literacy issues' and they also seldom ask for assistance in reading health related materials (Rudd et al 1999, p183).

More than half (56.2 percent) of adult New Zealanders have poor health literacy skills (Ministry of Health 2010). Groups with poor health literacy include older people, Māori, people in Pacific and other ethnic minority groups and people on low incomes. Māori have poorer health literacy than non-Māori regardless of age, gender, income, employment status, education level or location. There is a strong relationship between a person's health literacy and their health status (Ministry of Health 2012b). There is no specific research that investigates the link between health literacy and patients with gout. However there is evidence that the health literacy skills of Māori and Pacific people who have the highest prevalence of gout also have poorer health literacy skills than the rest of the population (Ministry of Health 2010; Ministry of Health 2012b).

Health literacy is also about the communication skills of the health practitioners a patient is interacting with and the ability of other stakeholders, such as health organisations and media, to provide health information and services in a way that is appropriate for that individual (Institute of Medicine 2004). Health dialogue has now replaced monologue (Zarcadoolas et al 2006). It is now widely accepted that health literacy reaches beyond the ability of the individual patient and is a product of the convergence of numerous factors and stakeholders (Rudd et al 2007; Koh et al 2012). The solution to low health literacy therefore lies in a concerted effort from all sectors including schools, government agencies and the health care system (Ministry of Health 2010).

The role of culture in health literacy is widely accepted. Zarcadoolas et al (2006) state that as a component of health literacy, cultural literacy (i.e. the ability to understand and use culture and social identity to interpret and act on information) is clearly needed by all stakeholders in order to improve health care and health outcomes. Kickbusch et al (2005) mirror this sentiment and state that culture (including the culture of the health system) affects attitudes, perceptions and behaviours at both the patient and provider end, or for both those receiving and delivering health services, with this including health information, messages, treatment, decisions and actions.

Gout is the most prevalent form of chronic arthritis in the world. Gout is a chronic disease, a long-term illness. Untreated, a person with gout has high levels of uric acid in their blood (hyperuricaemia), because their kidneys are not excreting enough uric acid. As a result they will suffer from intermittent gout attacks caused by uric acid forming painful crystals in their joints. Some people, including many Māori and Pacific people, have a genetic tendency to store uric acid (Merriman and Dalbeth, 2010). The onset and progression of the condition are well documented, there are effective preventive measures and treatment can remove all symptoms.

The national prevalence for gout in New Zealand is between 2.7 percent and 3.8 percent of people over the age of 20 years. The prevalence for Māori and Pacific populations is much higher at 6.1 percent and 7.6 percent respectively (Winnard et al 2012). Prevalence of gout for men is 5.9 percent (Winnard et al, 2012) and up to 14.0 percent for Māori men (Gow 2005; Jackson et al 2012). Two studies have found that many Māori diagnosed with gout were not prescribed ULT for a number of years (Lindsay et al 2011; Te Karu 2011). 'For Māori men the average length of time from onset of acute symptoms of gout to successful allopurinol commencement was more than 22 years' (Te Karu 2011). As a result many Māori with gout are currently using pain relief, such as NSAIDs, to manage the pain of gout attacks whereas a prescription for ULT would address the underlying cause of continually high levels of uric acid.

Although gout attacks may sometimes be triggered by lifestyle factors, in the community there are very strong and longstanding beliefs that gout is caused solely by lifestyle factors, including having too much meat, seafood and beer. These beliefs are shared by people diagnosed with gout (and their whānau) and are generally reinforced by primary care providers who often focus on lifestyle factors rather than prescribing ULT.

### **1.1.1 Prevention of gout**

There are a number of non-modifiable factors and modifiable factors that may influence the onset of gout. Non-modifiable factors are defined as elements that one has no control over and cannot change in order to prevent the onset of gout. These include age, gender, genetics and the after-effects of organ transplants. Modifiable factors are those that can be attributed to choices made by the individual and can therefore be changed in a preventive manner, such as dietary intake, body weight/Body Mass Index (BMI) and physical activity. Advice about the prevention of gout for the Māori population at risk relies on managing modifiable lifestyle factors and reinforces beliefs about the causes of gout (see above). However there is very little literature on the prevention of gout that might inform alternate advice (Singh et al 2011).

### **1.1.2 Management of gout**

Acute gout impacts a person well beyond pain to include issues such as dependency and familial impact, isolation and work disability (Lindsay et al 2011). However gout can effectively be 'cured' by reducing the probability of acute gout (and therefore pain) and tophi (a build up of uric acid crystal deposits in the joints which destroy cartilage and, in advanced cases, cause bone erosion) to near zero. Once a person has an initial diagnosis of gout, the focus for secondary prevention (of gout attacks or other symptoms) needs to shift primarily (but not entirely) from modifiable factors to a focus on getting a person established on ULT to reduce their uric acid levels. This will prevent the ongoing formation of disabling tophi and acute gout attacks.

Effective treatment is dependent on both the patient and prescribing health practitioner; both need significant levels of knowledge about gout (Dalbeth and Lindsay 2012; Harrold et al 2010; Ogdie et al 2010; Becker and Chohan 2008; Gow et al 2011; Arroll et al 2009). This knowledge is built over a period of time and requires intensive input (Rees et al 2012). Once patients and health practitioners have gained this knowledge patients are more likely to adhere to taking ULT long term and health practitioners are more likely to appropriately treat and manage patients to prevent further gout attacks.

### **1.1.3 Summary**

Health literacy approaches can be used to build new knowledge and skills around gout in individuals and health practitioners. Health literacy approaches will need to be used by primary care health practitioners to build new knowledge and skills about gout and provide information to people at risk of, or with, gout. This will prevent the prevailing beliefs about gout from being intentionally or unintentionally reinforced by health practitioners. The current project sought to locate international approaches that will strengthen the health literacy (knowledge and skills) of Māori with, or at risk of, developing gout.

## **1.2 The Present Project**

This project builds on an earlier 2011 review of publicly available gout medication resources project for the Ministry of Health (earlier review project). The findings of the earlier review project (Ministry of Health 2012b) highlighted that the majority of the patient education resources for those diagnosed with gout emphasised the importance of, and gave priority to, information about lifestyle factors (by putting it at the front of the resource) and unintentionally downplayed the importance of ULT by placing this information at the back of the resource. The earlier review project also found that most gout resources were difficult to access and that health practitioners did not engage with patients around the resources but instead handed them to patients to 'read later', which often did not occur.

The aim of the present project was to identify the influence health literacy has on improving prevention and early detection of gout, particularly for Māori men. The objectives of the research were to:

1. identify how health literacy is a barrier and/or a facilitator in the prevention and early detection of gout
2. highlight any interventions or approaches that may be effective in strengthening health literacy for Māori at risk of developing gout or who are living with the condition
3. demonstrate ways to increase health literacy in order to improve outcomes associated with gout.

The prevention research in the present project focused on two areas:

- Prevention of the onset of gout (initial prevention), in younger Māori men (in their late teens, 20s and 30s) who have a whānau history of gout and/or asymptomatic hyperuricaemia (high uric acid levels). It is this younger group who are less likely to suspect they have gout, as this group is often more active and believe they may have incurred an injury rather than be suffering from an acute gout attack.
- Prevention of gout attacks and other symptoms, once gout is diagnosed (secondary prevention), for men over 55 years as, at this age, it was likely these men had already experienced gout. This requires the appropriate treatment of gout as a chronic condition.

### **1.2.1 Project team**

A project team of health literacy researchers and resource developers from Workbase was established. A primary health care nurse specialist was recruited to assist the project team by providing clinical expertise during interviews with patients and whānau, and to facilitate contact with health practitioners.

### **1.2.2 Reference group**

A Reference Group (Dr Karen Lindsay, Dr Natalia Valentino and Leanne Te Karu) guided this project. Additional assistance was provided by members of the Maaori Gout Action Group<sup>1</sup> (in particular Dr Peter Gow, Dr Nicola Dalbeth, Dr Doone Winnard, Donna Snell, Dr Tony Merriman and Caran Barratt-Boyes); Dr Peter Jones, a rheumatologist at the Waikato District Health Board; Leonie Matoes from Te Hotu Manawa Māori and the Arthritis New Zealand educators based in the greater Auckland area.

### **1.2.3 Report structure**

Part 2 of this report follows this Introduction and describes the research method used in the project.

Part 3 describes the findings related to Objective 1; that is, the barriers to and facilitators of health literacy in the prevention and management of gout.

Part 4 describes the findings related to Objective 2; that is, interventions that may be effective in strengthening health literacy to allow the better prevention and management of gout.

Part 5 describes the development and assessment of health literacy resources in fulfilment of Objective 3; that is, demonstrating ways to increase health literacy in order to improve outcomes associated with gout.

Part 6 provides an overall discussion of the research.

Part 7 contains the recommendations of the research.

---

<sup>1</sup> Note: The name Maaori Gout Action Group reflects the double letter spelling for long vowels used by local Tainui iwi in the Counties Manukau area where the group originated

## Part 2. Method

The research was conducted in four phases. Phase 1 involved the search of relevant literature and health literacy resources along with an environmental scan. In Phase 2 patients, whānau and health practitioners were interviewed and health practitioners were also surveyed. In Phase 3 health literacy resources were developed based on the findings from Phases 1 and 2. In Phase 4 the resources were trialled with health practitioners and in workplaces with people who had, or were at risk of having, gout. The alignment of each phase with the three research objectives is outlined in Table 1 below.

**Table 1. Alignment of research objectives with research phases**

Research Objectives	Phase 1	Phase 2	Phase 3	Phase 4
1 Identify how health literacy is a barrier and/or a facilitator in the prevention and early detection of gout	✓	✓		
2 Highlight any interventions or approaches that may be effective in strengthening health literacy for Māori at risk of developing gout or who are living with the condition	✓	✓	✓	
3 Demonstrate ways to increase health literacy in order to improve outcomes associated with gout			✓	✓

### 2.1 Phase 1. Literature and Resources

The project began with an information-gathering phase that built on the earlier review of gout medication resources. The earlier review project identified issues and gaps in information resources about gout. A review of national and international literature about gout was carried out. Later in the project a further review was undertaken of the literature around the initial prevention of gout. (See Appendix 1 for the overall literature review.) A separate literature review on health literacy was also undertaken looking for literature specific to health literacy and gout (Appendix 2). As well, an environmental scan was carried out.

#### 2.1.1 Health literacy literature review

##### a. Search terms

One, or a combination of two or more of these words, was used when searching for relevant articles and research: (non)-adherence, (non)-compliance, ability, access, advice, barriers, behaviour, change, clarity, clinical, clinician, communication, community, comprehension, confirm, consultation, conversation, definition, dialogue, disparities, education, empowerment, examples, facilitators, feedback, framework, health, individual, instructions, knowledge, literacy, Māori, model, New Zealand, NZ, outcomes, patient, practitioner, provider, questioning, responsibility, self-care, skills, statistics, strategies, system, teach-back, understanding.

##### b. Databases

The main databases used for this literature review were Google Scholar, PubMed and BMJ. We also systematically scoured the reference lists of articles to find further research. Also used were publications in Workbase's specialist library and information from the New Zealand Literacy Portal [www.nzliteracyportal.org.nz](http://www.nzliteracyportal.org.nz) and Workbase's health literacy website [www.healthliteracy.org.nz](http://www.healthliteracy.org.nz).

### **2.1.2 Gout literature review**

#### **a. Search terms**

One or a combination of two or more of these key words were used when searching for relevant articles and research: adherence, allopurinol, beliefs, caffeine, care, coffee, communication, community, comorbidities, comorbidity, diuretics, education, exercise, experience, gene(s), genetic(s), gout, guide, health, health care, hyperuricaemia, impact, knowledge, learn(ing), lifestyle, management, male, Māori, men, mortality, myths, New Zealand, NZ, Pacific, pain, patient(s), perception(s), physical exercise, purine, quality, quality of life, risk(s), serum urate, serum uric acid, teach(ing), test, testing, treatment, urate, urate level(s), urate lowering therapy, uric acid, work, youth.

The following search terms were added for the prevention aspect of the literature review: prevent(ion) of gout, preventing gout, transplants, modifiable, medication, diet, activity.

#### **b. Databases**

A large proportion of searches were conducted using Google Scholar. Other databases used included: PubMed, BMJ, Wiley, ScienceDirect, JSTOR, Scopus and IngentaConnect. The reference lists of articles were also systematically scoured to find further articles. In addition, members of the Reference Group and the Maaori Gout Action Group sent additional research and commented on the Literature Review at different stages. After feedback from the Ministry of Health, an additional section about preventing gout was added to the Literature Review.

### **2.1.3 Environmental scan**

An environmental scan was carried out to identify any current initiatives and activities associated with strengthening health literacy in relation to gout and/or prevention, early detection and management of the condition.

### **2.1.4 A list of the health literacy demands placed on a person with, or at risk of, gout**

A list of the health literacy demands (the literacy and numeracy skills and knowledge) required of patients and whānau to initially prevent and then manage gout as a chronic condition, was prepared (Appendix 3). The list of demands was developed initially from information gathered during the earlier review project, the literature review and interviews with rheumatologists. The demands were later verified by the members of the Maaori Gout Action Group.

## **2.2 Phase 2. Consultation**

### **2.2.1 Whānau interviews**

Twenty-seven people (including those with gout (and their whānau)) were interviewed to identify the messages they had received about the prevention, early diagnosis and management of gout. Interviews took place on a marae where 27 people meet regularly as part of training for Iron Māori. The group includes members who have a range of long-term health conditions. The members of the group are involved in a range of physical activities to improve their health and management of their long-term conditions. At these regular meetings the members of the group share progress in relation to exercise goals and have their weight and blood pressure measured. In order to accommodate the regular activities of the group, interviews were mostly undertaken individually using two Māori researchers and facilitated using a written handout to identify the knowledge people already had about gout. Four people were interviewed in pairs. Interviews typically took about 10 minutes although interviews with people who had a whānau history or a diagnosis of gout took longer, sometimes up to 20 minutes. People who had a diagnosis of gout were specifically asked about the medications they had taken and were currently taking if relevant. Written notes were kept of all interviews. After the interviews people had their uric acid levels checked using the Reflotron machine.

## 2.2.2 Health practitioner interviews

Information was collected from health practitioners and health organisations about what they were doing to improve the prevention, early diagnosis and management of gout.

Information was gathered through:

- online surveys (Survey Monkey), with responses from 18 rheumatologists, 109 health practitioners, 52 pharmacists and 14 representatives from PHOs and District Health Boards (DHBs)
- individual face-to-face or phone interviews with nine health practitioners: two rheumatologists, two GPs, a primary practice nurse, a health and safety nurse, a clinical nurse leader (Rheumatology) and two Arthritis New Zealand educators who were interviewed together. Interviews generally took one hour, were all audiotaped and took place in the interviewee's workplace or the Workbase offices. Both the online surveys and interviews with health practitioners were based on these questions:
  - What information and advice about gout do you provide and how is this done?
  - How do you check understanding (or health literacy) with your audience?
  - Are you aware of clients who are primarily using NSAIDs to manage the symptoms of gout?
  - How and when do you work with Māori individuals, whānau or communities?
  - Why do you think gout is undiagnosed or untreated for so long?
  - What is involved in identifying and managing gout e.g. how difficult is the testing process, what is required to get ongoing medication?
  - What other health conditions are being managed effectively, how and why and what might be relevant for gout?

## 2.3 Phase 3. Resource Development

Information gathered during Phases 1 and 2 informed the development of gout resources. Two resources (the first draft of the *To Stop Gout* booklet containing infographics, and a leaflet aimed at people and whānau at risk of gout) were developed as well as a Stages of Gout document for people and whānau at risk of, or with a diagnosis of, gout. The Stages of Gout included actions points for people at different stages of gout as well as questions to ask their health practitioners. The primary audience for the resources is people at risk of, or living with, gout (and their whānau).

The Stages of Gout were redeveloped into '*Talking Points*' (scripts) for primary care health practitioners to use with people and whānau to build an understanding of uric acid and the need to take ULT to effectively manage gout and to guide discussion around the resources.

The resources were designed for use during discussion (guided by *Talking Points*), rather than as standalone resources.

## 2.4 Phase 4. Resource Trialling

The resources developed in Phase 3 were used in interviews with health practitioners, people at risk of, or with, gout (and their whānau). More information about the trials is in Appendix 6.

### 2.4.1 Patients and whānau

#### a. First draft of *To Stop Gout* booklet

Four education sessions were held for people at risk of, or with, gout (and their whānau). These sessions were held in three workplaces: Douglas Manufacturing and Rheem Industries in Auckland; CHH Kinleith Mill in Tokoroa; and Korowai Aroha, a Māori health provider, in Rotorua. The three workplaces were selected because they had identified they had numbers of employees with, or at risk of, gout who mostly were not managing their gout or risk of getting gout. The health care organisation

approached Workbase and requested that an education session be held for a number of patients with a diagnosis of, or at risk of, gout. A total of 38 people participated in the sessions. Participants were predominantly male (79 percent) and either had gout or had a whānau member with gout.

In these sessions the first draft of the *To Stop Gout* booklet developed in the Investigation phase was trialled (see pages 4-7 of the final version of *To Stop Gout* booklet, attached in Appendix 10), participants' uric acid levels were tested and there were extended opportunities to discuss gout. An indication of participants' knowledge about gout was gained using a written handout before the introduction of the first draft of the booklet.

The first draft of the booklet covered the causes of gout and how the body gets rid of uric acid and the role of ULT. Copies of the PHARMAC *Out with Gout* booklet were also handed out although participants were advised that the PHARMAC booklet was now four years old. Participants were referred to various pages in the PHARMAC booklet in response to their questions (e.g. pictures of uric acid crystals in joints) (Appendix 10). The sessions then focused on uric acid, how it causes gout, the genetic link and how people get rid of uric acid from their bodies.

#### **b. Prevention leaflet**

The draft leaflet about the prevention of gout (see Appendix 11) was trialled by Arthritis New Zealand educators as part of community testing activities with 13 people at risk of gout either because of high uric acid levels or whānau history.

### **2.4.2 Health practitioners**

Phase 4 activities for the health workforce included CME sessions in Tokoroa and Auckland, presentations and seminars that enabled the trialling of approaches to providing current clinical messages and resources for health practitioners about gout. The activities sought ways to constructively engage with health practitioners, provide them with information they may not have and talk about the resources and the Gout Clinical Pathway developed by the Greater Auckland Integrated Health Network (GAIHN). These were opportunities to invite feedback as well as encourage health practitioners to review their knowledge around gout and current practice in relation to gout prevention and management.

#### **a. CME Session Tokoroa**

This session took place in a GP practice in Tokoroa on 21 August 2012. Health practitioners (including GPs, practice nurses, practice managers, pharmacists and a physiotherapist) were given a copy of the first draft of the booklet and a copy of the GAIHN Gout Clinical Pathway. Dr Peter Jones, a rheumatologist, presented the clinical pathway and answered health practitioners' questions about the pathway. Leanne Te Karu, pharmacist and member of the Reference Group, presented about gout medications and in particular the lengthy delays before Māori are prescribed ULT.

#### **b. CME Seminar with Rheumatology Clinical Nurse Leaders**

This seminar was held in Auckland on 23 September 2012 as part of their annual conference. At this session the nurses were given a copy of the final draft of the booklet, the leaflet, the Stages of Gout for patients and whānau and a copy of the *Talking Points*. Participants were asked to give feedback on the resources and how they could be improved.

#### **c. Outing Gout Hui**

The Outing Gout Hui took place on 1 and 2 November 2012 at Reweti Marae in Auckland. Workbase was asked to present at this Hui about the use of Teach-back by health practitioners as well as

provide a workshop for patients and whānau using the final draft of the *To Stop Gout* Booklet (Appendix 10) and prevention leaflet (Appendix 11). The opportunity was taken to gather further feedback and suggestions for improvement on these two resources.

## **Part 3. Health literacy barriers and facilitators**

The barriers to and facilitators of health literacy related to the prevention and early detection of gout were elicited through the literature reviews and parts of the environmental scan (Phase 1), and the stakeholder consultation (Phase 2).

### **3.1 Phase 1. Literature Review**

The literature review identified barriers to, and facilitators of, health literacy as well as the prevention and early detection of gout.

#### **3.1.1 Health Literacy**

##### **a. Barriers to health literacy**

Difficulty in reading materials and difficulty in communicating with health care providers are two major health literacy barriers that individuals face when they access and use the health care system (Rudd et al 1999). Kickbusch et al (2005, p 9) assert that 'access to good reliable information is the cornerstone of health literacy' yet most health related material is written at a level beyond what most patients can understand (Kickbusch et al 2005; Levandowski et al 2006; Zarcadoolas et al 2006; Rudd et al 1999; Rudd et al 2007). Patients who have trouble reading may better understand a spoken message. Spoken interactions are also context-rich and rely on more than words to communicate information and meaning, with tone, body language and gestures all playing an important part (Zarcadoolas et al 2006). On the other hand, speech is ephemeral and once the interaction is over there is nothing left except the memory (which may be incomplete) of what was said (Vandergrift 2006). Kelly and Haidet (2007) also claim that many health care providers overestimate the health literacy levels of their patients. This leads to a lack of tailored communication that in turn leads to information that is beyond the understanding of the patient, with the potential outcome of non-adherence to a treatment plan.

Another major barrier to health literacy is an overload of information. There is a vast amount of health information available to patients, from an equally vast number of information sources, which can make finding and understanding the right information difficult (Kickbusch et al 2005; Zarcadoolas et al 2006; Institute of Medicine 2004). An additional outcome of an increase in information is a decrease in the consistency of the information. These days it is not uncommon for patients to get conflicting information from their information sources including their health care practitioners, the health system, the media, and their family and friends. Eagle et al (2006) found that consistency of advice between doctors and pharmacists was rated as very important by a sample of patients.

##### **b. Facilitators of health literacy**

Facilitators of health literacy that health practitioners can use include:

- Using face-to-face opportunities as much as possible to give medical advice.
- Using the Teach-back method to check the clarity of the health practitioner's message and thus patient understanding. This involves the health practitioner checking on the clarity of their communication by asking the patient to explain or demonstrate what they have been told.
- Reading written materials with patients or supporting the materials with verbal explanations.
- Supporting oral explanations with pictorial material or visual aids.
- Using plain language in spoken and written texts and making materials easier to use through a greater consideration of design, font, layout and pictures (Rudd et al 2007; Weiss 2007).

Although good knowledge of a health condition is essential for good health literacy, improved patient knowledge will not always lead to the desired change in behaviour. Kickbusch et al (2005, p 9) state that 'health information alone will not be useful to people who do not feel they have the power to act.'

Confidence and self-efficacy to act on the information and to help others is what counts and this requires additional inputs such as community development and education (Nutbeam 2008; Kickbusch et al 2005; Zarcadoolas et al 2006). The ultimate goal is greater independence and empowerment in individuals and communities to effectively manage their health. For this to happen a greater understanding is needed around the potential of health education to help focus health dialogue on the social determinants of health (Nutbeam 2008).

Rudd et al (2007, p183) cite recent medical and public health reports that recommend that future studies in the area of health literacy 'continue to include – but move beyond the doctor-patient encounter ... and include investigations into health-related activities at home, in the workplace, in the community, and in a range of health systems and care settings.' In addition, Rudd et al highlight the importance of attention to the broad range of skills involved in health literacy, including a closer examination of patient information-seeking skills. Other areas that Rudd et al consider could facilitate better health literacy, and which require closer attention, include:

- considering the importance of patient background, knowledge and experience in health related activities and paying attention to assumptions information-givers have about these
- considering the value that new technologies can add to the field of health literacy (Rudd et al 2007).

### **3.1.2 Gout**

Many people with gout are not managing their condition at an optimal level (Arroll et al 2009). Barriers to optimising gout management relate to knowledge and understanding at differing levels: the person with gout, their whānau, health care practitioners and health providers.

Barriers to gout management are often found within the patient's understanding (or otherwise) of gout as a chronic condition, in particular a lack of knowledge and understanding of the causes and management of gout. Numerous studies point to the fact that a large number of those who suffer from gout only have a basic awareness of the underlying causes of gout, and many people appear to have mixed and differing interpretations and understandings about what gout is, how dangerous it can be if left untreated, what causes it and what it means to live with and treat gout.

For people to understand gout they need to have an understanding of how their bodies work and particularly around how food is digested and used to fuel their body. A 2012 New Zealand study entitled *Living With Gout in New Zealand* found large gaps in gout knowledge concerning issues such as causes, dietary needs and complications, age, treatment and management. The study found that only 33 percent of participants knew which medications they should use acutely and which prophylactically (Martini et al 2012).

Patients often lack understanding about the difference between acute and chronic gout, the role of ULT in managing gout, that ULT is available and how ULT must be taken (Spencer et al 2012; Lindsay et al 2011; Arroll et al 2009; Reach 2011). Other studies have found that a common misunderstanding of gout is that it is an acute, rather than a chronic condition, leading to poor adherence to ULT (Lindsay et al 2011; Spencer et al 2012; Martini et al 2012).

Often, prescribing health practitioners have assumed patient adherence to taking ULT when the reality was otherwise (Harrold et al 2008). Lack of patient knowledge or understanding may arise from improper or poor patient educational input from health practitioners and providers (Doherty 2012; Harrold et al 2010; Spencer et al 2012; Dalbeth and Lindsay 2012). The educational approaches that are being used to teach patients about their condition may not be conveying information in ways that lead to building appropriate knowledge.

Barriers to gout treatment are just as likely to be caused by health practitioners and providers who in turn may lack important understanding and knowledge of gout, leading them to misdiagnose, ill-prescribe, or make assumptions about the underlying causes of a patient's condition (Dalbeth and Lindsay 2012; Harrold et al 2010; Ogdie et al 2010; Becker and Chohan 2008). A major barrier to gout management and treatment is the 'low adherence of primary care physicians to published evidence-based treatment guidelines for the diagnosis and management of gout' (Doherty et al 2012, p 4). The lack of incentives for health practitioners to adhere to practitioner guidelines is a barrier to effective treatment (Spencer et al 2012; Becker and Chohan 2008).

A number of studies have concluded that health practitioner education is needed to enable more effective gout treatment and management. Training is needed to educate providers and health practitioners about the physiology and management of gout and also about how they themselves should undertake the education of their patients (Spencer et al 2012; Becker and Chohan 2008; Singh 2012; Gow et al 2011).

The positive result of patient education has been noted in a recent United Kingdom study where participants were enrolled in a nurse-led intervention that offered education, lifestyle advice and information on urate levels and urate lowering therapy and, as a result, 90 percent of participants were able to reduce their serum uric acid to target levels. The authors state that a 'full explanation and discussion about the nature of gout and its treatment options and individualisation of management probably account for [the] success' (Rees et al 2012, p 1) of the intervention.

The studies in the review have almost universally concluded that patient education is highly important in removing barriers to gout management. However, the majority of research fails to address the systemic and process barriers to gout management, tending to focus more on what information patients do not appear to know and should be taught. This approach fails to address lack of knowledge as a health literacy issue not just for patients but also for health practitioners and providers (Smith et al 2011). It is clear from the review of the literature that health literacy and effective communication has become a substantial barrier to the management of both chronic and acute gout (Becker and Chohan 2008; Harrold et al 2010; Ogdie et al 2010; Shulten et al 2009).

### **3.1.3 Environmental Scan**

This environmental scan identified a number of current activities and initiatives that are directly focused on improving the prevention, early detection and management of gout in New Zealand. Many are related to facilitating access to health care for gout rather than specifically on health literacy. Projects related to health literacy interventions for gout are described below (section 4.1.2).

#### **a. Summary of New Zealand gout research**

A search for research projects on gout identified only one project that was partly focused on the initial prevention of gout (Te Karu 2011). We identified that there was no collection of New Zealand research on gout. As a result we have developed a summary of New Zealand gout research projects identified to date (see Appendix 13). We circulated the list to the Maaori Gout Action Group and researchers attending the Outing Gout Hui for feedback and verification.

#### **b. Gout Clinical Pathway**

In 2012 GAIHN (Greater Auckland Integrated Health Network) facilitated a group (including rheumatologists, GPs, secondary clinical nurse leaders, primary care nurses, pharmacists and consumers) to develop a Gout Clinical Pathway for primary care. Workbase was a consumer representative on the group and helped develop patient resources for different parts of the Pathway. The Pathway, which does not include people who have hyperuricaemia but are asymptomatic, was released on Healthpoint in June 2012 and disseminated by GAIHN and Healthpoint in one of its

regular email updates. During the project we identified that there was no knowledge of the Pathway outside Auckland and, in fact, little knowledge of it within Auckland.

During the development of this Pathway we were advised that diet (including sugary drinks) accounts for only 10 percent of the reasons for high uric acid in the body. Genes, kidney problems and being overweight account for 90 percent of the reasons people are unable to excrete uric acid from the body (Choi 2010). This new information, which was not identified in the literature review for this project, became the basis for ongoing discussions with the Reference Group and Maaori Gout Action Group about its evidentiary basis. This information (adjusted to a 20/80 percent split) was incorporated into the final version of the *To Stop Gout* booklet (see Appendix 10) that was trialled (UpToDate, accessed 1 September 2012).

### **c. Maaori Gout Action Group**

The Maaori Gout Action Group continues to support a range of activities for gout such as research, new medicines, clinical pathways, public awareness campaigns and collaboration. Workbase attends bi-monthly Maaori Gout Action Group meetings and provides regular updates to the Maaori Gout Action Group in relation to this research project.

## **3.2 Phase 2. Stakeholder Consultation**

### **3.2.1 Whānau**

A group of 27 people who were training for Iron Māori had a good knowledge of many factors that are detrimental to and beneficial for gout (e.g. types of food, drinks, need to exercise, maintenance of a healthy weight). However, 17 (63 percent) of the group thought that all fizzy drinks, including diet fizzy drinks, were bad for gout. None of the group was aware of the genetic link to gout for some Māori and Pacific people. (See Appendix 4 for more information on the health of a sub-group of these participants.)

### **3.2.2 Health practitioner interviews**

The health practitioners described barriers to patients accessing health care, as well as barriers to health literacy about gout. The health practitioners also talked about what they discussed with their patients and when their practices involved the use of resources to improve patients' health literacy. These are described below (section 4.2.2).

**Cost issues for patients:** The GPs, primary care nurse, occupational health nurse and Arthritis New Zealand educators, identified significant barriers for patients in terms of transport, the cost of GPs' visits, cost of prescriptions, the need for follow up visits before starting on ULT and the need for regular blood tests to monitor uric acid levels. Patients also have to take time off work for blood tests and medical appointments.

**Poor practice in relation to prescribing of ULT:** The Arthritis New Zealand educators, rheumatologists, clinical nurse leader and primary care nurse all identified poor practice in primary care prescribing of ULT as being one of the main reasons patients often need a number of attempts before ULT is successfully established. Poor practice included failing to prescribe a pain medicine at the same time as starting ULT resulting in a gout attack, and not regularly testing uric acid levels and using this information to titrate the dose of ULT so that target uric acid of .36mmol/L is achieved. In addition, primary care health professionals often start patients on too high a dose of ULT precipitating a major gout attack which puts the patient off taking ULT again. Alternatively, the patient is started on too low a dose and then left on that dose so that the patient continues to get gout attacks as their uric acid levels do not reduce sufficiently.

**Systemic issues:** Some interviewees identified a number of changes that they believed could make a difference to the management and treatment of gout:

- Make uric acid testing a requirement for all blood tests.
- Make point of contact testing available in primary care settings.
- Create a health target around gout similar to targets for diabetes and cardiovascular disease.
- Provide a public awareness campaign about gout.
- Provide specific funding for gout.

These interventions are outside the scope of this research project.

### 3.2.3 Health practitioner surveys

Survey responses related to the barriers to and facilitators of health care access and health literacy are presented below. Additional information from the health surveys related to gout resources and interventions is included in section 4.2.3.

#### a. Rheumatologists

In their responses to the online survey, rheumatologists gave three reasons why patients with gout might not be using ULT:

- Bad patient experiences when first starting ULT.
- Patient preference not to be on long-term medication.
- Health practitioners unsure how to prescribe and titrate ULT.

Most respondents said they do not discuss with patients the prevention of gout in the next generation. If they were to, they would stress lifestyle factors (diet, weight, exercise and alcohol), although they appreciated that lifestyle factors are not going to prevent gout where there is a genetic predisposition.

Rheumatologists also identified three key barriers to monitoring uric acid levels and titrating ULT:

- A lack of regular contact and monitoring of patients by health practitioners.
- Inadequate understanding of titration by health practitioners.
- A lack of regular contact by patients.

Many of the rheumatologists (N=15) responded that there is inadequate understanding of gout and gout management by health practitioners. A respondent stated:

*'Many practitioners need support to help overcome cynicism and treatment nihilism (i.e. patients don't help themselves by coming to the clinic and adhering to their medication so what's the point?)'.*

#### b. Health workforce survey responses

One hundred and nine health practitioners responded to the survey, 54 percent of them from general practice. Others came from emergency care, specialist secondary care, Arthritis New Zealand, community health services and allied health practitioners. All DHBs were represented. Key findings from the survey responses were (see section 4.2.3 for findings related to resources used):

- 79 percent of respondents did not have access to point of contact testing for uric acid and the same percentage of overall respondents also identified that this would assist them in managing their patients' gout.
- 77 percent of respondents identified that they have patients who are primarily using NSAIDs to manage gout. When asked what percentage of their patients currently had ULT, just over one fifth of respondents were in each of the following categories: under 20 percent, 21-40 percent, 41-60 percent and 61-80 percent. A further 5 percent reported 81-99 percent of their patients were on ULT and 4 percent reported all of their gout patients are on ULT. The main barriers to monitoring

and titrating ULT were identified as an inadequate understanding of gout management by patients and a lack of regular contact by patients.

- When asked the reasons for gout being undiagnosed or untreated, 90 percent of health practitioners put this down to patients' lack of understanding about gout and patients using over the counter medicines rather than seeking prescription medicine. Furthermore, the reasons for patients not using ULT were put down to patient knowledge and behaviour issues such as patients only seeking treatment during an acute attack (75 percent) and patients preferring not to be on long-term medication (72 percent).
- The respondents to this survey identified two key barriers to monitoring uric acid levels and titrating ULT:
  - Inadequate understanding of gout and gout management by patients.
  - A lack of regular contact by patients.

### **c. PHOs' and DHBs' survey responses**

DHBs' Communication Managers and PHOs were sent an online survey. Fourteen responses were received (from nine PHOs and three DHBs). The response rate was so low that no analysis of the results is included.

### **3.3 Summary**

The purpose of the stakeholder consultation was to build an in-depth understanding of how individuals, whānau, communities, the health workforce and health system are working to improve the prevention, early diagnosis and management of gout. The information gathered confirmed the widespread belief (among people with gout (and their whānau), and a significant number of the health workforce) that the primary causes of gout relate to diet and lifestyle factors.

The information also showed the differing viewpoints within the health system about what needs to be done to address the high incidence of gout in New Zealand. Rheumatologists were clear that the majority of gout cases could be managed in primary care using ULT. Health practitioners working in primary care believed that patients' lack of knowledge about gout impacted on their management of gout with an over reliance on long-term use of NSAIDs.

Interviews with people at risk of, or with, gout (and their whānau) confirmed that most were not aware of the genetic influences on gout, the difference between gout and gout attacks, the key role of uric acid, how ULT works and why modifying their diet alone would not get rid of gout.

## **Part 4. Interventions to strengthen health literacy**

The research into effective interventions or approaches to strengthen health literacy for Māori at risk of developing gout or who are living with gout spanned the literature reviews and the environmental scan (Phase 1), stakeholder consultation (Phase 2) and resource development (Phase 3). The development of resources was in response to the findings from Phases 1 and 2.

### **4.1 Phase 1. Literature and Resources**

The literature was examined for interventions that successfully strengthened health literacy.

#### **4.1.1 Literature review**

Communications between health practitioners and patients can be improved so they facilitate health literacy. To minimise the risk of patients not understanding what they read, it is now recommended that all written health care material in the United States be graded to the reading age of a 10 year old (Wilson 2009; Zarcadoolas et al 2006). While using plain language in written material is widely recommended, the validity of this readability approach has been questioned as, apart from the fact that adult patients are not 10 year old children, this approach fails to take account of the important role that sense, logic, familiarity, tone and cohesion play in the comprehension of a text (Ministry of Health 2012c; Rudd et al 2007). Many experts in the health literacy field now claim that the most effective way to improve patient understanding is to support one form of information with another; that is, reinforcing spoken explanations with written materials or supporting written materials with visuals (Weiss 2007). As a result it is essential that written, spoken and visual messages are consistent and repeated.

Rethinking how information is given to patients, with the most important information being given first and the rest at a later point, can lessen the cognitive load for all patients and act as a facilitator to improve uptake (Rudd et al 1999). Zarcadoolas et al (2006, p 90) acknowledge the fleeting nature of spoken interactions and for this reason recommend that spoken messages 'contain facilitators such as brevity, narrative structure and repetition.' Even though there is not much that can be done about information that is received from sources outside the health system, consistency in health and medication messages is important.

Kickbusch et al (2005 p18) note the importance of cultural relevance and claim that 'health messages and solutions must be placed within settings relevant to their target audiences and encompass both a social and health dimension.' This reinforces the need for health practitioners to sensitively and appropriately explore what patients know and believe about their health and use this as the basis for building new knowledge and understanding with a patient. This approach to building knowledge is based on schema theory, a theory about how people represent and organise knowledge in their long-term memory. Schema theory says that people relate new information to what they already know or have experienced. Schema theory emphasises the critical role of knowledge in understanding our world (Anderson 2004). Health practitioners have the opportunity to access the schema of patients and whānau and build on this.

Sudore and Schillinger (2009) developed a framework and description for best practice interventions to improve care for patients with low health literacy. The framework and description are the result of a comprehensive literature review to identify feasible health literacy interventions at the practitioner-patient level, at the system-patient level and at the community patient level. Although designed to address health literacy levels in the United States, the framework provides a useful starting point for analysing and developing effective health literacy interventions in New Zealand (Workbase 2011).

Key messages from interventions at the health practitioner-patient level include:

- patient-centred communication, where existing patient knowledge and experiences are built on clear health communication, including use of plain language
- confirmation of understanding, including use of the teach-back method
- reinforcement of information, including using multiple modalities and using the patient's support network
- clear numeracy and risk information, including providing absolute risks instead of relative risks
- medication reconciliation, including simplifying regimens as much as possible and confirming regimen dosage.

Key messages from interventions at the system-patient level include:

- health education materials, including incorporating the target audience in the design of the tools
- medication drug labels, including using concrete examples
- disease self-management support systems that need to be proactive and disease-specific
- creating an empowering environment, including making signs and forms easy to read and encouraging the patients to use the ask-me-3 strategy
- clinician training, including health literacy education while clinicians are in training.

Key messages from interventions at the community-patient level include:

- referrals to adult literacy classes
- use of lay health educators/navigators
- use of mass media to disseminate health information (Sudore and Schillinger 2009).

Most people with low health literacy do not know they have an issue and, if they do, they are unlikely to tell health practitioners that they have a health literacy problem. To work within this context, health practitioners in the United States are implementing a universal precautions approach to health literacy. Universal precautions in relation to blood-borne diseases is a concept that is familiar to health practitioners. In health literacy, universal precautions means health practitioners approach every interaction with health consumers as if the consumers might have health literacy needs. Universal precautions also means providing clear communication (both written and spoken) to all consumers and actively building their health literacy knowledge and skills (DeWalt et al 2010).

#### **4.1.2 Environmental Scan**

This environmental scan describes a number of current activities and initiatives that are focused on improving health literacy related to gout. Other projects identified in the scan that are related to the prevention, early detection, or management of gout are described above (Section 3.1.3).

##### **a. Arthritis New Zealand**

Arthritis New Zealand is considering a public awareness campaign about gout (dependant on funding) and key messages for the campaign, in collaboration with the Maaori Gout Action Group, have been developed.

Information was collected from Arthritis New Zealand staff about key messages (developed as part of the earlier review project) used when talking to people with gout (and their whānau). Arthritis New Zealand staff were asked to identify which messages would be used with people with gout (and their whānau) at each stage of the condition and whether each message was a key concept and/or a difficult concept. Not all staff responded to all parts of the survey but the results showed a strong preference for giving patients experiencing an acute attack a lot of information about gout and its causes. A patient in considerable pain is not likely to take in a lot of information. Instead a tailored approach, where the information the patient can cope with and needs at that time, is recommended.

In 2012, Arthritis New Zealand, with support from local rheumatologists, held a number of public education seminars for staff and students at all Te Wānanga o Aotearoa campuses.

## **b. Patient education resources**

Surveys and interviews confirmed findings from the earlier review project that health practitioners use a relatively limited range of information resources with patients (PHARMAC *Out with Gout* booklet, Pharmaceutical Society Self care booklet, Medtech and Everbody information sheets, and the *Starting on Allopurinol* card).

Workbase has been in touch with a couple of the resource producers about possible updates of the resources so that they prioritise key information and also focus more on the role of genes in managing uric acid (and the importance of ULT in this process), rather than on diet. Some of the resources are also inconsistent with GAIHN's Gout Clinical Pathway and none of them focus on the initial prevention of gout.

### **4.1.3 Health literacy demands**

In the earlier review of gout medication resources we developed an initial list of the health literacy skills and knowledge required by a person with gout. In this project this initial list of skills has been expanded to reflect the demands placed on patients and whānau in relation to knowledge about gout that a person with gout (and their whānau) need to know as well as the skills they need to manage the condition. A list of the demands placed on people at risk of gout (initial prevention) has also been developed. The Maaori Gout Action Group assisted by reviewing the list of demands and noting that the knowledge and skills may not be built in a linear (one step logically following after the other) fashion. These lists of demands are useful for health practitioners as they seek to develop the health literacy of people at risk of, or with, gout (and their whānau). The lists of demands ensure that health practitioners do not make assumptions about the level of knowledge and skills held by people at risk of, or with, gout (and their whānau). The lists are also useful for patients and whānau so they can identify what they currently know and are able to do and what other knowledge and skills they still need to develop. (See Appendix 3 for lists of demands.)

### **4.1.4 Stages of gout**

Various stages of gout were also identified requiring different levels of knowledge and skills. As part of this the actions people at risk of, or with, gout (and their whānau) could take at each of these stages to build their own knowledge and skills were identified. These actions relate to self-management activities as well as suggested discussions to have with health practitioners and whānau in relation to the prevention and management of gout. The first two stages relate to initial prevention and the other ten stages relate to secondary prevention (see Appendix 8). These stages of gout mirror messages in the *Talking Points* (see Appendix 12) that was developed for health practitioners to use with patients and whānau when discussing the booklet and leaflet.

## **4.2 Phase 2. Stakeholder Consultation**

Stakeholder feedback about current health literacy practices, as well as any ideas for other health literacy interventions, is presented below.

### **4.2.1 Patients and whānau**

During this consultation stage it became clear that incorrect beliefs about lifestyle factors being the cause of gout are very well entrenched for patients, whānau and communities.

#### 4.2.2 Health practitioner interviews

The health practitioners interviewed described barriers to health literacy related to gout (Section 3.2.2) and ideas from their own practice about interventions to support health literacy about gout as well as facilitate patients' access to health care for their gout.

**Information about gout:** The GPs gave more general information about all aspects of gout than the other interviewees. Other health practitioners tended to provide targeted information depending on the degree to which a patient's gout had advanced.

**Target uric acid 0.36mmol/L:** The Arthritis New Zealand educators and health practitioners operating in secondary care contexts were likely to mention the need for patients to achieve the uric acid target. They either used the graph page in the PHARMAC *Out with Gout* book to demonstrate this concept or showed patients their uric acid data on computers.

**Diet and weight:** The GPs focused on diet and weight factors more than health practitioners operating in other contexts. One GP in particular identified that this was the approach he used with younger asymptomatic patients who wanted to prevent gout.

**The role of genes:** Four of the nine health practitioners (Arthritis New Zealand educators, a primary care nurse and a clinical nurse leader all based in Auckland) specifically mentioned that they discuss the role of genetics in gout.

**Health literacy:** Only the primary care nurse articulated strategies she used to actively check patients' understanding about gout and their situation. This nurse had more time to spend with patients than the other health practitioners. The other health practitioners used standard phrases such as 'Do you understand?' or 'Do you have any questions?' to check understanding.

**Patient education materials:** Most of the interviewees used the PHARMAC *Out with Gout* booklet. Some also used the *Starting on Allopurinol* card from the Counties Manukau District Health Board. The rheumatologists and the clinical nurse leader also used pictures of gouty joints and tophi. The health and safety nurse was using a pamphlet developed by a final year nursing student as part of a clinical project and signed off by the student's School of Nursing as well as other health organisations. The pamphlet contained a number of incorrect statements about gout, did not promote ULT as the primary method of managing gout and instead contained a lot of information about alternative therapies. With input from members of the Reference Group we gave feedback to the health and safety nurse that she should stop using this pamphlet.

#### 4.2.3 Health practitioner surveys

##### a. Rheumatologists

In their responses to the online survey all the 18 rheumatologist respondents said they provided face-to-face information on gout to patients, with most also providing printed information. All provided information on how gout affects the body, how to deal with an acute gout attack, instructions about ULT and adherence, and target uric acid levels. Most also provided dietary and lifestyle advice. Fifteen respondents provided information about the dangers of untreated hyperuricaemia/gout. Printed information might be used in the consultation and/or left with patients to read later.

##### b. Health workforce survey responses

Key findings from the survey responses were (see section 3.2.3 for findings related to barriers to health care access):

- Over 80 percent of respondents said they provide information on how and why gout occurs, what gout is, lifestyle and dietary advice. Seventy six percent provide information on managing gout attacks (with pain relievers), 62 percent provide information on ULT and less than 40 percent provide information on genetic links and uric acid levels. Only 38 percent of respondents give patients information on the dangers of untreated hyperuricaemia.
- Nearly all respondents provided information to patients in face-to-face settings, while a further 82 percent also provided printed information, most often in the form of leaflets and printouts. Just over half of the respondents reported working through this information with patients.
- Nine key messages were identified for health practitioners to rank in order of importance. Over half of the respondents identified the most important or second most important message is telling patients gout is a painful form of arthritis. This was followed by the need to treat chronic gout with ULT and the long-term consequences of not treating gout. Interestingly, these last two responses were not ranked as highly in the earlier responses to the question about what information health practitioners provide about gout.
- This group was specifically asked about what advice they gave to patients who had hyperuricaemia but who were asymptomatic. Just over 60 percent of people responded to this question. Those who did talk to asymptomatic patients gave a range of responses mostly focusing on diet, lifestyle and weight. Smaller numbers mentioned genetics, the need for ongoing screening, medication (without being specific about what type of medication) and that if the patient did develop gout it was treatable.
- Those who responded to a question about what they say to patients about preventing gout in the next generation gave similar responses to the previous question about asymptomatic patients – a focus on diet, lifestyle and weight. However, a couple of respondents made more specific suggestions including whānau talking openly about the risk factors and destigmatising gout to make sure people realise it is not their fault.

### **c. Pharmacists' survey responses**

Fifty-two pharmacists (46 of whom were community pharmacists) responded to the survey. They came from all DHB areas except Lakes, South Canterbury and West Coast.

There were a number of comments from individual pharmacists that many issues began with the GP and pharmacists can play a useful part in education about gout as long as the pharmacists have the resources (funding, space and time).

Consistent with their role, all pharmacists reported providing information to customers about medication instructions for gout and over 80 percent explain how and why gout occurs, and what it is, along with dietary and lifestyle advice.

All of the pharmacists reported providing face-to-face information with most also using the Pharmacy Self Care gout pamphlet and the PHARMAC *Out with Gout* resource. Over half of the respondents go through information resources with customers, while 30 percent put the information in the bag with the medication being dispensed or suggest a customer read it later.

When asked why gout goes undiagnosed or untreated, all of the respondents considered this was because customers lack knowledge of gout and most pharmacists thought this was also because people choose to use over the counter medicines.

## **4.3 Phase 3. Resource Development**

### **4.3.1 To Stop Gout booklet**

Based on the findings from the literature reviews, interviews and surveys as well as discussions with the Reference Group, the final draft of the *To Stop Gout* booklet was developed (including

infographics that communicate key messages through visuals and pictures). The infographics included:

- two pie graphs showing the causes of gout and the most important things to work on to reduce uric acid levels
- visuals showing how your body gets rid of or stores uric acid
- the impact of ULT on stored uric acid (see *To Stop Gout* booklet, p 4-7, Appendix 10).

#### **4.3.2 Short gout prevention leaflet**

The audience for initial prevention messages about gout is male (teenagers and those in their 20s and 30s) and mainly Māori and Pacific peoples. This audience has only been engaged with indirectly in Phases 1 and 2. With input from GPs and practice nurses, Arthritis New Zealand educators the Reference Group and the Māori Gout Action Group, a draft gout prevention leaflet was developed, *Things you can do to reduce your chances of getting gout* that focuses on the three modifiable lifestyle factors in relation to gout (see Appendix 11).

#### **4.3.3 Talking Points for health professionals**

The earlier review project identified that health professionals do not talk about gout education resources when engaging with patients (and their whānau). Most health professionals give out resources for patients (and their whānau) to read later. In the earlier review project it was also identified that primary health care professionals could build the health literacy of patients (and their whānau) by the active and repeated use of clinically accurate gout resources. Feedback from this project has confirmed that health professionals may not have the health literacy strategies to build requisite knowledge with people at risk of, or with, gout (and their whānau).

As a result and based on the Stages of Gout Resource, a series of suggested scripts (*Talking Points*) was developed that health professionals could use with people with gout (and their whānau) in relation to both the prevention leaflet and the *To Stop Gout* booklet. These *Talking Points* have been developed to model good health literacy practices and to ensure that key messages about gout are introduced and then reinforced, in order to replace, over time, entrenched beliefs about lifestyle factors and food and drink. The *Talking Points* for the prevention leaflet and the *To Stop Gout* booklet are in Appendix 12. The messages in the *Talking Points* mirror key messages in the Stages of Gout resource for patients and whānau at risk of, or with a diagnosis of, gout.

#### **4.4 Summary**

There is a range of interventions that could be used to build health literacy about gout. These involve clear, patient-centred communications from health practitioners, often combined with the use of resource material that patients are able to take with them and refer back to. Some health practitioners have developed patients' and whānau knowledge of gout by providing oral information during consultations or by handing over the PHARMAC *Out with Gout* booklet or the Pharmaceutical Society's Self Care pamphlet on gout. Some health practitioners go through the resources with patients (and their whānau).

From Phases 1 and 2 it was apparent that there is a need for gout resources that:

- update and prioritise the key messages for people at risk of, or with, gout (and their whānau)
- help engage people at risk of, or with, gout (and their whānau) in preventing and managing gout
- provide easy to understand, succinct information
- provide information for people at risk of, or with, gout (and their whānau) relevant to the stage of their condition
- can be used flexibly by both patients, whānau, communities and health practitioners
- build primary care providers' understanding of gout causes, treatment and management

- support health practitioners to use multiple strategies to build understanding of gout for people at risk of, or with, gout (and their whānau)
- build accurate and consistent understandings of gout amongst health practitioners and people at risk of, or with, gout (and their whānau)
- influence deeply held beliefs regarding the main causes of gout (diet and lifestyle).

## Part 5. Increasing health literacy

This section reports on the feedback received to the resources developed to increase health literacy in relation to gout.

### 5.1 To Stop Gout Booklet

#### 5.1.1 Patients and whānau

Of the 38 people who participated in the workplace education session, 47 percent (18) were men over 50 years old. Only two were significantly overweight (a risk factor for gout). One of these men had a diagnosis of gout and was on ULT. The majority of participants 65 percent (25) had been diagnosed with gout but only 23 percent (9) were on ULT. Of the 25 people who had had a diagnosis of gout, 72 percent (18) had uric acid levels above 0.36mmol/L, including two people who were on ULT. If participants had hyperuricaemia and gave their permission, the clinical nurse supporting the project rang the participant's practice nurse to explain their patient's involvement in the research project. (See Appendix 5 for additional information about participants and sessions.)

#### a. Pre-existing knowledge

At Douglas Manufacturing participants made strong links between food, alcohol and gout. One participant (a non-Māori male on ULT) had an in-depth understanding of gout medication. None of the participants had knowledge of any genetic links to gout particularly for some Māori and Pacific peoples.

None of the men at the Kinleith Mill session could remember when they last had their uric acid levels checked by their GP. Ten of the men had uric acid levels above 0.36mmol/L (the recommended target level) including one man taking ULT. All of the men thought that food and alcohol were the primary causes of gout even though some of them were on ULT and had a vague understanding the medicine was treating a chemical in their bodies. None of the men who were taking ULT or had taken ULT had an understanding of how the ULT was acting on the uric acid levels in their bodies. In the same way, they did not understand how the different types of medicines to manage gout including ULT worked.

At the Korowai Aroha Health Centre the three people taking ULT understood it was to treat their gout but were not able to describe how ULT worked. The other two women in the group who did not have gout but had other whānau members with gout believed that food and alcohol triggered gout. The three people who did have gout agreed with this even though they were all on ULT therapy.

Two men in the Rheem Industries sessions currently prescribed ULT were not aware of what it was for and, because of this, one of the men had not been taking it.

#### b. Feedback

While participants were appreciative of the information that was new to them, it was not at all aligned to their prevailing belief that food and alcohol are the primary causes of gout. The participants had a lot of questions (particularly about uric acid: what it was and why it mattered). From the participants' questions and the information they told us about their level of understanding of ULT and NSAIDs, it became clear that the first draft of the *To Stop Gout* booklet was inadequate to address the range of issues raised by the participants. In particular these sessions identified the need for the booklet to also cover gout medicines, starting ULT, more information about uric acid, why monitoring uric acid levels matters and what it means if uric acid levels remain high. A final draft of the booklet was then developed.

### **c. Additional session outcomes**

At the end of the Kinleith session one of the men (whose GP had taken him off Allopurinol because of a rash) identified himself as a manager at the Mill. He said that the men in the group were all recognised leaders at the Mill and would take the information back to others in the areas where they worked. The Health and Safety nurse who attended the session was going to follow up with all the men who had attended the session. A local GP attends the Mill on a regular basis and, if the participants were unable to get better treatment from their own GPs, then if necessary the nurse was going to book participants in to see the visiting GP. The nurse was given copies of both the booklet and prevention leaflet once they were re-developed.

The sessions at Rheem Industries resulted in the HR Supervisor being more informed about the circumstances of one employee who had gout. He was going to speak to the man's immediate supervisor and explain the situation to him as well offer the man a place on a literacy programme. The HR Advisor also planned to talk with company management about contracting a local general practice to provide a company doctor who could then provide consistent information about gout and gout medications to employees.

### **5.2 Short gout prevention leaflet**

Feedback about the leaflet that was trialled by Arthritis New Zealand with 13 people at risk of developing gout included:

- 'really useful to know what I need to do'
- 'helps me remember what you told me in 2011'
- 'know what I need to do so I don't get gout like the rest of my family'
- 'I can talk to my GP about checking my uric acid levels'.

The educators also identified that it was really useful to have the leaflet to discuss with and then leave with people at risk of gout. Previously, the educators had relied on oral information. Similar feedback was received from 10 other practice and research nurses at the Outing Gout 4 Hui. Marama Parore from PHARMAC has also endorsed this leaflet as being 'clear and straightforward.'

### **5.3 Talking Points**

One primary practice nurse confirmed that these matched her practice when discussing gout with patients. This nurse ran a gout research project in South Auckland for two years. All of the Rheumatology Clinical Nurse leaders and the Maaori Gout Action Group also gave feedback on the *Talking Points* which are aimed primarily (but not exclusively) at primary care health practitioners.

### **5.4 Summary**

This feedback on the first draft of the *To Stop Gout* booklet (primarily from patients and whānau) led to the development of the final draft of the booklet incorporating the other topics wanted by people at risk of, or with, gout (and their whānau) (Appendix 10). The Reference Group, the Maaori Gout Action Group, a rheumatologist and Arthritis New Zealand educators were involved in this final draft (see Appendix 7).

The feedback on the leaflet and the *Talking Points* was positive, albeit from a small sample of people.

## Part 6. Discussion

This project has demonstrated that preventing and managing gout requires action, not just on the part of patients and whānau, but mostly by health professionals and health organisations. There are a number of opportunities to build the health literacy of people at risk of, or with, gout (and their whānau), as well as the health literacy of primary care health professionals.

There are a number of health literacy strategies that could be used by primary care health professionals to build the health literacy of people at risk of, or with, gout (and their whānau). Because gout (once diagnosed) is entirely preventable with ULT, gout provides an opportunity to trial health literacy approaches and strategies that could then be transferred to other long-term conditions. The recommendations made in this report (see page 36) require action by the Ministry of Health and health professionals. Before these recommendations are canvassed the challenges, processes and outcomes of the present research project are explored.

### 6.1 The Challenges

There were two main challenges for this project.

#### 6.1.1 Build new knowledge and change longstanding beliefs about gout

The first challenge was to build new knowledge about gout and change longstanding beliefs about gout held by people with gout, their whānau and the wider community which are passed on from generation to generation. These beliefs, primarily that gout is caused by eating too much meat and seafood and drinking too much beer, are founded on the view that gout is not a long-term condition but rather a series of painful episodes of inflammation (gout attacks or gout flares). As a result, whānau and the wider community treat gout as an acute condition without any knowledge of the chronic condition that arises because of permanently elevated uric acid levels. Secondary prevention messages need to focus almost entirely on reducing the production (or improving the excretion) of uric acid by taking a long-term medication and losing weight, with food and alcohol being a much less important factor. A focus on lowering uric acid levels requires a new and different approach to patient and whānau education. Patients with gout (and their whānau) need to build their health literacy in relation to gout. This relies on multiple engagements to build new knowledge and skills.

Multiple engagements rely on a range of primary care health practitioners to build and reinforce key messages about gout. The key messages are: gout is a long-term condition not just acute gout attacks; to treat gout you need to lower your uric acid levels; this requires long-term medication; gout should never be ignored; and ULT treatment usually needs to start after the second gout attack (if that attack occurs within 12 months of the first attack).

A health literacy approach will require primary health care practitioners to discuss resources and messages with patients (and their whānau) on a number of occasions, check patient and whānau understanding at every occasion and make explicit links between what patients (and their whānau) currently know and new knowledge that needs to be built.

#### 6.1.2 Identify skills and knowledge needed to prevent onset of gout

The second challenge was to identify what knowledge and skills were needed for people with a whānau history, or at risk, of gout to enable them to prevent (or significantly delay) a diagnosis of gout. Initial prevention activities focus on a very different population, namely younger Māori and Pacific men who are likely to have high uric acid levels. Initial prevention relies on trying to reduce intake of purine rich food and drinks as well as improve the excretion of uric acid (stay active and maintain a healthy weight). Key messages for this group need to take into account this audience's

realities, for instance, they are likely to be drinking alcohol and eating takeaways, which means that messages need to be focused less on avoidance approaches and more on moderation.

Very few initial prevention activities are taking place. Rheumatologists are not having prevention conversations with patients whose whānau members are at risk of gout and primary care health practitioners are not having these conversations either. One Auckland based GP who works with mostly Pacific families says a few young men who want to avoid getting gout are approaching him to ask for advice about what they can do.

As part of the project consultations took place with a range of health practitioners (rheumatologists, primary health care practitioners, public health specialists and Arthritis New Zealand educators) to develop a resource that could be used with people at risk of getting gout either because of whānau history or high uric acid levels. The focus for these people is to keep active, not eat a diet that is high in purines and have healthy drinks (rather than beer and sugary drinks). The irony of the key messages for initial prevention is that they reinforce the beliefs so prevalent in whānau and the community that gout is caused by eating too much and drinking beer. Any attempt to educate whānau and communities about preventing an initial diagnosis of gout and then properly managing gout and preventing gout attacks (secondary prevention) once it is diagnosed will have to make a careful distinction about the different messages that support these two strategies and when one strategy changes.

## **6.2 The Process**

Information gaps and health literacy needs were confirmed in the present research. In particular, the first draft of the *To Stop Gout* booklet showed the impact of uric acid (in comparison to food and drink) on gout, how uric acid is excreted from the body and how the production of uric acid is reduced using medication. In the Investigation phase, feedback from people with gout (and their whānau) identified that they wanted more information about gout than was provided by the first draft of the booklet. As a result, additional information was incorporated into the final version of the booklet trialled later in the Demonstration phase with health practitioners and clinical nurse leaders.

In the Demonstration phase, the booklet and leaflet, Stages of Gout document and *Talking Points* were developed primarily for primary care health practitioners to use with people and whānau to build an understanding of uric acid and the need to take ULT to effectively manage gout. The primary audience for the resources are people at risk of, or living with, gout (and their whānau). However, the resources are designed to be used as part of a discussion between patients, whānau and health practitioners (guided by *Talking Points*) rather than as standalone resources.

The draft resources were trialled with people at risk of, or living with, gout and health practitioners. Feedback from the trial was incorporated in the resources that are included in this report.

## **6.3 The Outcome**

It was clear that any information provided on a single occasion, on its own, was unlikely to change deeply rooted perceptions of food and alcohol as the main causal factors of gout, or to be sufficient to fully address the participants' skill and knowledge needs. The trial demonstrated that a lot of knowledge and skill is needed to understand and engage with the prevention and management of gout and gout attacks. The trial also demonstrated that the required knowledge is complex, unfamiliar and overwhelming. This finding reinforces our understanding that it will be necessary for people at risk of, or with, gout (and their whānau) to have more than a single engagement with new information. This may be different to the expectation of health professionals, that having provided an explanation once, this will be sufficient and retained for subsequent discussions.

The sessions in workplaces, including the positive responses of the employers to holding health education sessions and the findings on the negative consequences for some employees who needed to take a lot of sick leave as a result of their gout, shows there are opportunities to disseminate information about gout to workplaces. The New Zealand Occupational Health Nurses' Association and the Employers' and Manufacturers' Association are potential distribution points for information.

The complexity and unfamiliarity of the knowledge needed to understand gout and the willingness of the participants to ask questions also suggests the value of developing resources to support guided discussions, in workplaces and elsewhere. Similar workplace initiatives have been trialled in the area of financial literacy. For example, The Commission for Financial Literacy and Retirement Income has developed seminars on a range of money topics linked to its Sorted resources. The seminars can be run by employers or external facilitators. Employers don't have to be topic experts to deliver seminars because each Sorted seminar comes with a comprehensive facilitator's guide as well as a presentation linked to the relevant Sorted booklet for employees.

Analysing the findings of the project and recommendations, as provided in this report, was the final phase of the project.

## Part 7. Recommendations

Gout is the most common form of inflammatory arthritis in men. In New Zealand there is evidence of inequity in relation to:

- long delays before ULT is commenced and poor titration of ULT for Māori
- prolonged use of NSAIDs by Māori for treatment of acute gout attacks resulting in long-term damage
- disability caused by pain, frequent gout attacks and tophi resulting in time off work, reduction in income, unemployment and ongoing impacts on individuals, whānau and the Māori community.

Eliminating inequities in the effective prevention and management of gout means recognising the inequities are complex, multi-layered and long standing. Remedying the inequity in relation to gout requires good information, good resources, changing practices and beliefs, commitment and goodwill from all stakeholders to resolve the issues, as well as time to achieve the necessary changes. While the focus of the project was on the initial prevention and early diagnosis of gout, it is equally important that Māori receive appropriate advice and treatment following diagnosis.

In this section of the report we outline interventions and approaches to strengthen health literacy. These are not just for people with gout (and their whānau), but also for health practitioners and other stakeholders who need to be able to identify the health literacy demands they are placing on people with gout (and their whānau), and modify those demands accordingly. Building health literacy is necessary for better understanding, prevention and management of gout. Better practice by health practitioners treating Māori at risk of, or with, gout is needed for better outcomes and to eliminate the inequities of gout.

### Overall recommendations for the Ministry of Health

Changing entrenched beliefs will take time, require multiple points of contact and need appropriate resourcing.

We recommend that the Ministry of Health consider the following action point as well as the points relating to the two stakeholder groups indicated below.

- **Resource publication:** Consider separate publishing online of the booklet, pamphlet and talking points developed during this project - for use by people at risk of, or with, gout (and their whānau), as well as by health practitioners.
- a. For people at risk of, or with, gout (and their whānau):**
  - **Public campaign:** We recommend that the Ministry of Health collaborate with other stakeholders to develop a public awareness campaign relating to the prevention and management of gout. This would be aimed at people at risk of, or with, gout (and their whānau). Possible components are suggested below.
    - *Key messages:* Develop a series of key messages about gout using a recognisable New Zealand identity. The messages can be used in an ongoing manner (e.g. posters in primary health care practices, marae, workplaces, churches, other community buildings and sports clubs). This would enable people (and their whānau) to engage with the health system as informed consumers.
    - *Online information:* Develop a module, preferably online as well as using other media, about gout to build the associated knowledge and skills of people at risk of, or with, gout (and their whānau). The module would cover prevention, causes, treatment (including medicines), initial management and the need for ongoing management. (The Gout Channel from the United Kingdom is an example although the content would need to be rewritten.)

**b. For health practitioners**

The findings of this research project are that health practitioners, particularly in primary care, lack knowledge and understanding about gout as well as health literacy. Accordingly, some recommendations are set out below.

- **Health literacy online module:** We recommend the development of an online module about health literacy with a particular focus on health literacy strategies (see below) that health practitioners can use to build the health literacy of patients and whānau. (This would be building on the existing online Foundation Course in Cultural Competence that contains a substantive module on health literacy and is available free to all health workers.)
- **Health literacy strategies:** We recommend encouraging primary care health practitioners to consistently use four health literacy strategies, outlined below, with people who have gout (and their whānau).
  - Find out what people know at the beginning of each consultation.
  - Use 'teach-back' (taking responsibility for communicating clearly with a patient (and their whānau) by asking a patient at the end of the consultation to repeat back or demonstrate what they have been asked to do).
  - Encourage questions.
  - Explicitly acknowledge the health literacy (knowledge and skills) of people with gout (and their whānau) in relation to gout.
- **Gout online module for practitioners:** To increase knowledge and understanding about gout for primary care health practitioners, we recommend the development of an online module about gout that initially assesses and then builds on their knowledge and understanding. The module would cover the prevention, diagnosis, treatment, management and monitoring of gout.

## References

- Anderson RC. 2004. Role of Reader's Schema in Comprehension, Learning and Memory. In Ruddell RB and Unrau NJ (eds), *Theoretical Models and Processes of Reading*, 5<sup>th</sup> ed. Newark, Del: International Reading Association.
- Arroll B, Bennett M, Dalbeth N, et al. 2009. More allopurinol is needed to get gout patients <0.36 mmol/l: a gout audit in the form of a before–after trial. *Journal of Primary Health care* 1(4): 315-318.
- Baker DW, Parker RM, Williams MV, et al. 1998. Health literacy and the risk of hospital admission. *Journal of General Internal Medicine* 13(12): 791-798.
- Becker MA, Chohan S. 2008. We can make gout management more successful now. *Current Opinion in Rheumatology* 20: 167-172.
- Choi HK. 2010. A prescription for lifestyle change in patients with hyperuricemia and gout. *Current Opinion in Rheumatology* 22: 165-172.
- Dalbeth N, Lindsay K. 2012. The Patient's Experience of Gout: New Insights to Optimize Management. *Current Rheumatology Reports* 14: 173-178.
- DeWalt DA, Callahan LF, Hawk VH, et al. 2010. *Health Literacy Universal Precautions Toolkit*. Rockville, MD: Agency for Healthcare Research and Quality.
- Doherty M, Jansen TJ, Nuki G, et al. 2012. Gout: why is this curable disease so seldom cured? *Annals of the Rheumatic Diseases* 0: 1-6.
- Eagle L, Hawkins J, Styles E, et al. 2006. Breaking through the invisible barrier of low functional literacy: Implications for health communication. *Studies in Communication Sciences: Special Issue on Health Literacy* 5(2): 29-55.
- Gow P. 2005. Gout and its management – the devil is in the detail. *New Zealand Family Physician* 32(4): 261-264.
- Gow PJ, Gow VF, Waldon J. 2011. Societal and Cultural Attitudes to Gout: An Important Consideration in the Successful Management of Gout among Māori in Aotearoa New Zealand. *Current Rheumatology Reviews* 7: 170-180.
- Harrold BL, Briesacher B, Raebel M, et al. 2008, October. *Adherence with Urate-Lowering Therapy for the Treatment of Gout*. Paper presented at the American College of Rheumatology Annual Scientific Meeting, San Francisco, CA.
- Harrold LR, Mazor KM, Velten S, et al. 2010. Patients and providers view gout differently: a qualitative study. *Chronic Illness* 6: 263-271.
- Healthpoint. 2012. *Acute Gout – Auckland Region Clinical Pathways*. URL: [www.healthpointpathways.co.nz/acute-gout/](http://www.healthpointpathways.co.nz/acute-gout/) (accessed 28 August 2012).
- Healthpoint. 2012. *Gout Prevention – Auckland Region Clinical Pathways*. URL: [www.healthpointpathways.co.nz/gout-prevention/](http://www.healthpointpathways.co.nz/gout-prevention/) (accessed 28 August, 2012).
- Institute of Medicine. 2004. *Health Literacy: A prescription to end confusion*. Washington, DC: The National Academies press.
- Jackson G, Wright C, Thornley S, et al. 2012. Potential unmet need for gout diagnosis and treatment: capture-recapture analysis of a national administrative dataset. *Rheumatology* 51:1820-1824.
- Kelly PA, Haidet P. 2007. Physician overestimation of patient literacy: A potential source of health care disparities. *Patient Education and Counseling* 66(1): 119-122.

- Kickbusch I, Wait S, Maag D. 2005. *Navigating Health: The Role of Health Literacy*. Alliance for Health and the Future, International Longevity Centre: UK. URL: [www.ilonakickbusch.com/health-literacy/NavigatingHealth.pdf](http://www.ilonakickbusch.com/health-literacy/NavigatingHealth.pdf).
- Koh HK, Berwick DM, Clancy CM, et al. 2012. New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. *Health Affairs* 31(2): 434-443.
- Levandowski BA, Sharma P, Lane SD, et al. 2006. Parental Literacy and Infant Health: An Evidence-Based Healthy Start Intervention. *Health Promotion Practice* 7: 95-102.
- Lindsay K, Gow P, Vanderpyl J, et al. 2011. The Experience and Impact of Living With Gout: A Study of Men With Chronic Gout Using a Qualitative Grounded Theory Approach. *Journal of Clinical Rheumatology* 17: 1- 6.
- Martini N, Bryant L, Te Karu L, et al. 2012. Living with Gout in New Zealand: An Exploratory Study Into People's Knowledge About the Disease and Its Treatment. *Journal of Clinical Rheumatology* 18(3): 125–129.
- Merriman TR, Dalbeth N. 2011. The genetic basis of hyperuricaemia and gout. *Joint Bone Spine* 78: 35-40.
- Ministry of Health. 2010. *Kōrero Mārama: Health Literacy and Māori*. Wellington: Ministry of Health.
- Ministry of Health. 2012a. *Tupu Ola Moui Pacific Health Chart Book 2012*. Wellington: Ministry of Health.
- Ministry of Health. 2012b. *Review of Health Education Resources on Gout Medication: Summary of report to the Ministry of Health*. Wellington: Ministry of Health.
- Ministry of Health. 2012c. *Rauemi Atawhai: A guide to developing health education resources in Aotearoa*. Wellington: Ministry of Health.
- Nutbeam D. 2008. The evolving concept of health literacy. *Social Science & Medicine* 67: 2072-2078.
- Ogdie AR, Hoch S, Dunham J, et al. 2010. A roadmap for education to improve the quality of care in gout. *Current Opinion in Rheumatology* 22: 173-180.
- Pignone M, Dewalt D, Sheridan S, et al. 2005. Interventions to improve health outcomes for patients with low literacy. *Journal of General Internal Medicine* 20(2): 185-192.
- Reach G. 2011. Treatment adherence in patients with gout. *Joint Bone Spine* 78(5): 456-459.
- Rees F, Jenkins W, Doherty M. 2012. Patients with gout adhere to curative treatment if informed appropriately: proof-of-concept observational study. *Annals of the Rheumatic Diseases*. DOI: 10.1136/annrheumdis-2012-201676.
- Rudd RE, Moeykens BA, Colton T. 1999. Health and Literacy: A review of the medical and public health literature. In Comings JP, Smith C, Garner B (eds). *Annual Review of Adult Learning and Literacy*. San Francisco CA: Josey-Bass.
- Rudd RE, Anderson JE, Oppenheimer S, et al. 2007. Health Literacy: An Update of Public Health and Medical Literature. In Comings JP, Garner B, Smith C (eds). *Review of Adult Learning and Literacy, volume 7*. Mahway NJ: Lawrence Erlbaum Associates.
- Shulten P, Thomas J, Miller M, et al. 2009. The role of diet in the management of gout: a comparison of knowledge and attitudes to current evidence. *Journal of Human Nutrition and Dietetics* 22: 3-11.
- Singh J, Reddy S, Kundukulam J. 2011. Risk factors for gout and prevention: a systematic review of the literature. *Current Opinion in Rheumatology* 23(2): 192–202.
- Singh JA. 2012. Can racial disparities in optimal gout treatment be reduced? Evidence from a randomized trial. *BMC Medicine* 10: 15.

Smith HS, Bracken D, Smith, JM. 2011. Gout: Current Insights and Future Perspectives. *The Journal of Pain* 12(11): 1113-1129.

Spencer K, Carr A, Doherty M. 2012. Patient and provider barriers to effective management of gout in general practice: a qualitative study. *Annals of the Rheumatic Diseases*. DOI: 10.1136/annrhumdis-2011-200801.

Sudore RL, Schillinger D. 2009. Interventions to Improve Care for patients with Limited Health Literacy. *Journal of Clinical Outcomes Management* 16(1): 20-29.

Te Karu L. 2011. *Hyperuricaemia in Māori - To treat or not to treat? Exploring the reality of gout in Māori and whether there is rationale to treat hyperuricaemia before the onset of gout*. Unpublished master's thesis. Auckland: University of Auckland.

UpToDate. 2012. *Gout*. URL: [www.uptodate.com/contents/gout-beyond-the-basics](http://www.uptodate.com/contents/gout-beyond-the-basics) (accessed 1 September 2012).

Vandergrift L. 2006. Second language Listening: Listening ability or language proficiency? *Modern Language Journal* 90 (1): 6-18.

Weiss BD. 2007. *Removing barriers to better safer care. Health literacy and patient safety: Help patients understand. Manual for clinicians. 2nd edition*. Chicago. American Medical Association.

Wilson M. 2009. Readability and patient education materials used for low-income populations. *Clinical Nurse Specialist* 23(1): 33-44.

Winnard, D, Craig W, Taylor WJ, et al 2012. National prevalence of gout derived from administrative health data in Aotearoa New Zealand. *Rheumatology*. URL: <http://rheumatology.oxfordjournals.org>.

Workbase 2011. Proposal for Māori Health Research focused on gestational diabetes mellitus. Unpublished tender document. Auckland, New Zealand.

Zarcadoolas C, Pleasant AF, Greer DF. 2006. *Advancing Health Literacy: A Framework for Understanding and Action*. San Francisco, CA: Jossey-Bass.

## Part 8. Appendices

### Appendix 1. Gout Literature Review

#### Glossary

Abdominal obesity	Excess stomach fat.
Adiposity	Fatness.
Atherosclerotic cardiovascular disorder	A build up of fatty deposits in the arteries, causing a thickening of the artery wall, leading to a heart attack or stroke.
Comorbidity	A medical condition that exists simultaneously with, and usually independently of, another medical condition.
Diuretic	A substance that causes an increased output of urine.
Dyslipidemia	An abnormal amount of cholesterol or fat in the blood.
Eicosapentanoic or docosahexanoic acid	Omega-3 fatty acid found especially in fish oils.
Genetic predisposition.	An inherited risk of developing a disease or condition.
Gout	A painful form of arthritis (joint inflammation) that mostly affects the big toe, ankles, heels, knees, wrists, fingers and elbows.
Gout attack	Sudden severe joint pain, sometimes with redness, swelling and tenderness of the joint.
HDL-cholesterol	High density lipoprotein ('good' cholesterol). It removes harmful 'bad' cholesterol from the bloodstream.
Health literacy	The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions which is influenced by health professionals, healthcare organisation and the health system.
Hyperglycemia	An excess (too much) of glucose (sugar) in the bloodstream.
Hypertension	High blood pressure.
Hyperuricaemia	High uric acid levels.
Inflammatory arthritis	A group of autoimmune diseases, including gout and rheumatoid arthritis, where the immune system attacks healthy cells in the body by mistake.
Intraarticular steroid	A medicine injected directly into the joint space of a painful, inflamed arthritic joint.
Metabolic abnormalities	Occurs when the process your body uses to get or make energy from the food you eat, is disrupted. When this happens you might have too much of some substances or too little of other ones that you need to stay healthy.

Metabolic syndrome	A name for a group of risk factors that occur together and increase the risk for coronary artery disease, stroke and diabetes.
Monosodium urate	Uric acid crystals, caused by high levels of uric acid in the blood. These crystals can deposit in the joints and cause tophi (small lumps which appear under the skin).
NSAIDs	Non-steroidal anti-inflammatory drugs commonly used to treat the pain and inflammation of gout attacks.
Purines	Occur naturally in the body (human tissue) and found in many foods. Uric acid results from the breakdown of purines.
Serum acid	Uric acid.
Serum urate	Uric acid.
Therapeutic	Level where the medication has the correct effect in the case of gout it means reducing uric acid levels to the target 0.36mmol/L.
Titration	Gradually increasing the dose of urate lowering medication until it reaches a therapeutic level where uric acid levels reach target and/or tophi dissolve.
Urate lowering therapy (ULT)	The medication used in New Zealand that reduces the uric acid levels in the blood. The most commonly prescribed ULT is Allopurinol.
Uric acid	A chemical in the body. If your body produces too much uric acid or doesn't remove enough, it can cause a gout attack.
Uricosurics	A substance that increase the excretion of uric acid in the urine.
Xanthine oxidase inhibitors	Reduces uric acid levels in the blood by reducing the production of uric acid.

## Section 1 - Introduction

The aim of this review is to provide insight into the relationship between the initial and secondary prevention and management of gout and health literacy. This review has a particular focus on the New Zealand Māori population and the barriers they face in accessing, assessing and understanding information about good health practices, as well as the preventive measures they may be able to take to reduce the risk of developing gout, and once diagnosed prevent gout attacks. Many barriers are created by the way knowledge and information is conveyed. As a result, this review will investigate how gout information is distributed and obtained and how it is disseminated and understood by people at the risk of, or with gout, as well as those who provide treatment for gout. The review will identify the barriers to treating and managing gout from the perspectives of people at risk of, or with gout, and health care providers, identifying what measures are currently being taken, which of these work and do not work and what might be undertaken to provide positive change in gout prevention and management.

Gout is a chronic disease although the general public does not generally understand this. Most people associate gout with acute gout flares rather than the chronic form. Gout is the most prevalent form of chronic arthritis in the world today. The disease is well documented, there are effective preventive measures and treatment can remove all of the symptoms. However, despite all this, gout still affects approximately one percent of the adult population in the Western World (Hardy 2011). The numbers of people diagnosed with gout is steadily increasing (Becker and Chohan 2008). Research from the United States identifies between 3 and 5 million (1-2 percent) of American adults as gout sufferers (Zychowicz et al 2010), while in the United Kingdom close to 700,000 (1.4 percent) people are thought to be affected by this often-debilitating condition (Spencer et al 2012). In New Zealand, a recent study undertaken by Winnard et al (2012) found national prevalence for gout to be 2.69 percent and 3.75 percent in people aged over 20 years old. The prevalence for gout in men was found to be 5.98 percent, while women's prevalence was drastically lower than this at 1.76 percent. Winnard et al (2012) also reiterated past studies in finding that Māori and Pacific populations had a much higher prevalence for gout than other ethnic groups, at 6.06 percent and 7.63 percent respectively. Jackson et al (2012) also reported this prevalence for gout within Māori and Pacific populations in a study with duplicate results.

People with acute gout experience inflammation around joints, commonly in the big toe but also in the 'ankles, knees, elbows, wrists and fingers' (Smith et al 2011). Acute gout is often associated with incapacitating pain that settles only after 7-10 days (Smith et al 2011). The pain from acute gout can render the sufferer immobile for the duration of the attack (Lindsay et al 2011).

Gout occurs due to hyperuricaemia, or a concentration of serum uric acid in the blood due to overproduction or underexcretion (Vázquez-Mellado et al 2004) at levels greater than 0.36 mmol/L (Dalbeth 2007). Choi et al (2005) state that 10 percent of hyperuricemia results from urate over production and 90 percent from urate underexcretion, or often a combination of the two. At a concentration greater than 0.36 mmol/L, crystallisation of uric acid into monosodium urate occurs within joint fluid, leading to an inflammatory reaction. If untreated long-term, the monosodium urate crystals may begin to form hard, painless deposits around joints, also known as tophi (Smith et al 2011), as well as potential damage to bones and joints. Hyperuricaemia is frequently caused by a genetic predisposition. This is especially true for Māori and Pacific populations. Other factors can cause or worsen the condition, including diet, comorbid medical conditions, medication and diet. Hyperuricaemia may be induced through excessive consumption of high-purine food sources such as seafood, red meat, alcohol and drinks that have been sweetened with fructose (Choi et al 2004). However, current estimations state that only a small amount of variations in uric acid levels are the result of dietary purines, with the remaining amassing from factors which influence the body's ability to process purines through synthesis and cell turnover (Choi et al 2005). The risk of hyperuricaemia has similarly been found to increase in people with particular comorbidities such as metabolic syndrome,

obesity, insulin resistance and hypertension (Zhang et al 2006). Several studies have reported correlations between these health issues and the presence of hyperuricaemia and gout (Annemans et al 2008; Singh and Strand 2008; Harrold et al 2006).

Medication such as aspirin and diuretics may induce hyperuricaemia in some people (McAdams De Marco et al 2012). Several studies have shown that particular diuretics are also associated with an increase in serum acid levels (Staessen 1991; Savage et al 1998), which, as mentioned in section 2.2.1 below, can pose a serious risk for the development of gout.

If left untreated, gout may lead to the development of comorbidities such as 'increased adiposity, hypertension, dyslipidemia, insulin resistance, hyperglycemia, certain renal conditions, and atherosclerotic cardiovascular disorders' (Choi 2010, pp. 166), which increases the risk of mortality (McLachlan et al 2011). A study from the United States on metabolic syndrome and metabolic abnormalities conducted by Choi et al (2007) found a large discrepancy between adults with and without gout in the prevalence of the aforementioned comorbidities. 47 percent of gout sufferers were found to have low HDL-cholesterol and hyperglycaemia (Choi et al 2007). Over 60 percent were found to have metabolic syndrome and abdominal obesity and fewer than 70 percent were diagnosed with hypertension (Choi et al 2007). Similarly, two Japanese studies, conducted by Tomita et al (2000) and Iseki et al (2004), found high correlations between high serum urate levels and both renal failure and end stage renal disease. Correlated complications also include coronary artery disease that was found in gout sufferers in the United Kingdom at a rate of 25 percent (Annemans et al 2008) and in the United States at 18 percent (Choi and Curhan 2007). Finally, studies have made less overt correlations between gout and health complications such as kidney stones (Kramer et al 2003) and diabetes (Mikuls et al 2005; Choi and Curhan 2007).

## **Section 2 - Preventing the onset of gout**

There is a dearth of research and review articles concerning the prevention of the onset of gout. This has been iterated by recent research, including that conducted by the Ministry of Health (S. Lungley, personal communication, 15 August 2012) and Workbase, as well Singh et al (2011) who were unable to find any articles that provided information on the primary prevention of gout in their systematic literature review of 53 studies.

However, there are a number of factors that may influence the onset of gout. These factors can be separated into two specific groups: non-modifiable factors and modifiable factors. Non-modifiable factors are defined as elements that one has no control over and cannot change in order to prevent the onset of gout. The most common non-modifiable factors found within the literature are age, sex and genetics. Also thought to be non-modifiable due to necessity or inevitability are the after-effects of organ transplants. Modifiable factors are those which can be attributed to choices made by the individual and can therefore be changed in a preventive manner, such as dietary intake, medications taken, bodyweight/BMI and physical activity.

### **Non-modifiable factors**

#### **Age**

The presence of gout is found to be in direct association with age (Saag and Choi 2006). Uric acid levels increase with age as the body loses its ability to actively excrete it, leading to hyperuricaemia. While this does not occur in all people, this degradation of excretion ability is most commonly found in older males and post-menopausal women (with the exception of those receiving post-menopausal hormone therapy) (Vázquez-Mellado et al 2004; Hak et al 2010). Furthermore, because 'the prevalence of ... gout increases with the duration of hyperuricemia' (Saag and Choi 2006), populations in nations with longer average life spans may contribute to increased frequency of gout.

## Sex

As mentioned earlier in this review, men are found to have a higher prevalence for gout than women (Winnard et al 2012). However, because of the effects of menopause, elderly populations are more likely to have a close spread of gout patients between sexes. Saag and Choi (2006) state that in adults over 65, the ratio of males to females with hyperuricaemia narrows from 4:1 to 3:1.

## Genetics

Genetic factors may play a large part in determining if a person will suffer from hyperuricaemia. Vázquez-Mellado et al (2004) write that it is estimated that hereditary influence may contribute to approximately 40 percent of cases of inflated concentration of uric acid. They further note that this can be the factor that contributes to the prevalence of hyperuricaemia in specific ethnic groups, such as Māori and Pacific mentioned in section 1.1 and expanded upon in section 3.3 of this review.

## Transplants

While some literature purports the results of organ transplants to be modifiable factors, for this review they are included as non-modifiable factors as the necessity for an organ transplant is not often the result of hyperuricaemia-inducing behaviours. Saag and Choi (2006) state that 'hyperuricemia and gout are common complications of renal and other major solid-organ transplants'. Several research projects reveal that there is a high rate of new hyperuricaemia and new-onset gout in patients who have received organ transplants. Abdelrahman et al (2002) note that in patients receiving transplants, up to 50 percent may become hyperuricaemic, while new-onset gout will be experienced by 13 percent. Furthermore, an article by Burack et al (1992) notes that the potential for new hyperuricaemia in heart transplant patients can be as high as 81 percent with new-onset gout being experienced by 8-12 percent.

In kidney transplant patients, new-onset gout and new hyperuricaemia is thought to result from a complication with post-operative medications. In a study by Lin et al (1989), the incidence of new hyperuricaemia and new gout was measured in kidney transplant patients who had been prescribed either azathioprine or cyclosporine. Their research found that while patients receiving azathioprine had a relatively high chance of becoming hyperuricaemic (30 percent), new hyperuricaemia was found in 84 percent of patients prescribed cyclosporine (Lin et al 1989).

## Modifiable factors

While a majority of people may not be susceptible to the non-modifiable factors for high uric acid mentioned in section 2.1, people are often still at risk from modifiable lifestyle factors. Similarly, many people who are susceptible to non-modifiable factors may be able to delay or inhibit the onset of gout by making changes to the modifiable factors in their life.

## Medication

While the intake of medications which can lead to the development of new hyperuricaemia or new-onset gout may be a modifiable behaviour, it must be noted that in many circumstances the individual taking the medication is not responsible for titrating their intake. It is often the role of a surgeon (pre or post surgery) or general practitioner to prescribe these drugs to their patients and therefore they are responsible for predicting and managing any side effects that might be attributed to drug intake.

Numerous studies have found that the use of particular medications may lead to the development of new hyperuricaemia or new-onset gout (as well as gout attacks). The most common medications found in these correlations are diuretics and aspirin (see section 1.1) and, as mentioned in section 2.1, medications associated with organ transplant surgeries (Saag and Choi 2006).

Aspirin has been found to have a dual effect on uric acid levels. At consistent (daily) low dosages (under 2g per day), aspirin works to reduce the ability for uric acid excretion, whereas at higher dosages (above 3g per day), aspirin acts to increase uric acid excretion, however these higher dosages are unlikely to be prescribed in current times (Vázquez-Mellado et al 2004). The low dose uric acid retention effect has been described in a study by Caspi et al (2000) who noted that elderly patients on a daily dose of 75mg aspirin were found to display a 15 percent decrease in uric acid excretion alongside a small yet significant gain in uric acid concentration.

As mentioned in section 1.1, diuretics have the potential to induce hyperuricaemia (McAdams De Marco et al 2012). Studies by Saag and Choi (2006), as well as Roubenoff et al (1991), have shown links between the use of diuretics in the treatment of hypertension and increased hyperuricaemia. While hypertension is often associated with gout and hyperuricaemia, these studies state that those patients who are prescribed consistent dosages of thiazide diuretics are likely to develop gout. In the study by Roubenoff et al (1991) they found that '13 of the 15 men with hypertension who later developed gout were treated with diuretics' (p 3005).

### Diet

As mentioned in section 1.1, diet can be a contributing factor in the development of new hyperuricaemia and gout. While Merriman (2009) estimates that diet only contributes 10 percent towards uric acid variation, numerous aspects of diet have been rigorously studied and the restriction or addition of particular foods is often suggested for the prevention of hyperuricaemia or new-onset gout. Research by Choi et al (2004) examined the diets of 47,120 men with no history of gout. They focused their study on purine (e.g. meat, seafood, lentils) and protein rich foods, as well as dairy intake, finding that men with increased meat and seafood intake were at 1.41 and 1.51 (respectively) times higher risk of developing gout. No risk increase was found in high-protein foods or high-purine vegetables (such as peas, leeks, lentils). Furthermore, while high-purine foods are found to increase serum urate concentrations, long-term fasting has also been discovered to be strongly associated with the advent of new hyperuricaemia (Maclachlan and Rodnan 1967).

Alcoholic beverages, especially beer, are also found to have links with an increase in uric acid concentration (Vázquez-Mellado et al 2004). This has been confirmed in a literature review by Singh et al (2011) who found 15 articles that identified alcohol as a risk factor for the development of hyperuricaemia or gout. One of the studies, completed by Bhole et al (2010), found that in participants with an alcohol intake of over one ounce/week, men were two times and women were three times more at risk of developing gout. Similar results have been found in a number of other studies (e.g. Chang et al 1997; Choi et al 2004; Zhang et al 2006).

Soft drink beverages are also found to have a connection with heightened uric acid concentration. Choi and Curhan (2008) found that men who consume 2 or more non-diet soft drinks per day were at a 1.85 times higher risk of gout development than men who do not consume these beverages. Their study also investigated the role of fruit juices, which are high in fructose, in a diet, showing that men with a high fruit juice and therefore high fructose intake are also at a high risk of developing hyperuricaemia or gout (Choi and Curhan 2008). On the other hand, other studies, such as Williams (2008) have recommended an intake of two pieces of fruit per day (reduced level of fructose) as a way to reduce the chances of hyperuricaemia.

### Bodyweight

People with higher body mass index (BMI) figures, as well as those who are considered overweight or obese, are at a higher risk of developing hyperuricaemia and gout than those at a regular BMI (Singh et al 2011). A study by Choi et al (2005) found a significant relationship between BMI and risk of gout, with the higher the BMI, the more elevated the risk of developing gout. They also note that excessive weight gain over time may pose a risk for the development of gout, reiterating a finding noted in earlier gout studies (e.g. Roubenoff et al 1991). Other studies purport that the state of obesity has a

direct correlation with the increased production and reduced excretion of uric acid from the blood (Dessein et al 2000). At least 12 studies examined in Singh et al's (2011) literature review provided similar conclusions, regardless of comorbidities that may exist.

Work by Williams (2008) also found a correlation between BMI and the risk of gout development. His analysis reported a 16-fold greater risk of developing gout in men with a BMI higher than 27.5 and a four-fold greater risk in men over 25 (BMI) when compared with those with a body mass index of less than 20. His work also found that risk of gout development increased with greater chest and waist measurements (Williams 2008).

### Physical activity

While physical activity is often overlooked, Williams (2008) also investigated the link between physical activity and gout prevention. He investigated 28,990 male runners, finding that as well as the maintenance of an ideal body weight and appropriate dietary lifestyle; men who are more active are less likely to develop hyperuricaemia or gout. He states that men who ran four kilometres per day, or faster than four metres per second, 'had significantly lower risk of developing gout than slower, less active men' (Williams 2008, p 1485). However, he does note that the more active men are also likely to be leaner, more easily achieving an ideal BMI – which as stated earlier is a component often cited as a risk factor for gout development.

That physical activity contributes to lower uric acid concentrations was also noted in a study by Lippi et al (2004), which investigated 80 male professional cyclists and 37 male professional cross-country skiers during their peak season. The study found that while the athletes were seen to display a wide distribution of uric acid concentration values, as a group they showed significantly reduced concentrations in comparison to the control group of 60 regular healthy males at rest. These results reflect those of various other studies, each which have found a correlation between an increase in physical activity and a decrease in serum uric acid concentration (e.g. Wannamethee et al 2000; Lee et al 1995).

### Prevention

This section has provided evidence of both modifiable and non-modifiable factors that put people at risk of developing new hyperuricaemia or new-onset gout. While people do not have control over non-modifiable factors, making changes to modifiable factors may help to prevent the onset of gout or even the initial development of issues with uric acid excretion and production.

The review by Singh et al (2011) revealed that there is a dearth of research and literature pertaining to the initial prevention of hyperuricaemia and gout. While much of the information found within the literature is aimed at reducing the serum uric acid concentration in those who are already hyperuricaemic, the advice may also be applicable in both preventing non-hyperuricaemic people becoming hyperuricaemic and those who have asymptomatic hyperuricaemia developing gout.

In light of this, Saag and Choi (2006) note that many of the recommendations for preventing gout attacks are based on general lifestyle changes that are often applicable for a number of other morbidities, as well as their prevention. They write that 'weight control, reduced consumption of red meat, and daily exercise are important lifestyle modifications for patients with gout or hyperuricaemia [as well as] ... heart disease, diabetes, and certain types of cancer' (Saag and Choi 2006). Their article further recommends a dietary restriction of purine-rich foods in the 'prevention and management of hyperuricaemia and gout' (Saag and Choi 2006). They also recommend substituting eicosapentanoic or docosahexanoic acid supplements for fish and that following general recommendations for dairy intake will not increase the risk of hyperuricaemia (Saag and Choi 2006).

Other studies have looked at dietary additives that have the potential to help prevent the incidence of hyperuricaemia and gout, such as vitamin C (ascorbic acid), folate and coffee. In a study by Stein et al (1976) the ingestion of 4.0g of vitamin C produced a two-fold increase in uric acid excretion for the following six hours and an 8.0g was able to provide reduced serum urate levels for up to 3-7 days following ingestion. Similar results have been reproduced by researchers such as Huang et al (2005) and Gao et al (2008) who, in respective studies, found that a daily intake of 4-500mg of vitamin C per day was correlated with a reduction in serum uric acid concentration.

In two studies (Choi and Curhan 2007; Choi et al 2007) the effects of coffee on uric acid concentration were investigated; results showing that for men, increased coffee intake was significantly attributed to reduced rates of gout. It is suggested that coffee consumption reduces insulin resistance and insulin levels, which in turn lead to heightened uric acid excretion (Choi and Curhan 2007). In an analysis of 14,314 participants in the Third National Health and Nutrition Examination Survey, Choi and Curhan (2007) found that 'serum uric acid level tended to decrease with increasing coffee intake' (p 817) but was not correlated with caffeine intake from other sources such as tea, or total caffeine intake. Furthermore, Choi and Curhan (2007) found that decaffeinated coffee was also associated with decreased uric acid levels, however, not to the extent seen in caffeinated coffee. A further study by Choi et al (2007) noted that risk of gout was inversely correlated to coffee intake. They state that in their 12 year study of 45,869 men, 'the risk of gout was 40 percent lower with coffee intake of 4-5 cups per day and 59 percent lower with  $\geq 6$  cups per day, compared to no use' (Choi et al 2007, p 2052).

### **Section 3 - General findings from the literature review**

#### **a. Treatment**

Gout can effectively be 'cured' in that someone with gout can reduce the probability of acute gout (and therefore pain) and tophi to close to zero incidents. Effective treatment is dependent on both the patient and prescribing health practitioner and will involve one or more of the following interventions: urate lowering therapy (ULT) and lifestyle management.

As mentioned above, 'there is evidence to support that dietary factors, including consumption of alcohol and purine-rich foods such as seafood and meat, increase the risk of gout' (Shulten et al 2009). Alongside this, several foods have been noted to reduce the risk of gout attacks, including low-fat dairy products, coffee and the supplementation of 500mg per day of vitamin C (Choi et al 2005). However, research by Shulten et al (2009, p 3) provides evidence that people with gout are often unlikely to make dietary changes at the request of their rheumatologist or physician and often make unnecessary food-avoidances (such as tomatoes, nuts and legumes) in attempting to manage their gout.

Many people with gout manage the pain of their acute gout through the use of nonsteroidal anti-inflammatory drugs (NSAIDs) such as aspirin and ibuprofen. While the use of NSAIDs often alleviates the pain of acute gout, these medications will not prevent further attacks or the effects of long-term gout damage such as tophi or joint damage. In addition, long-term use of NSAIDs can cause renal disease and other complications such as gastrointestinal and cardiovascular effects (Primatesta et al 2011; Schneider et al 2006). For patients who are unable to take NSAIDs, Colchicine is often prescribed for acute gout attacks. Historically prescribed as a preventive medication, Colchicine is currently only distributed for immediate pain relief. However, due to numerous restrictions on intake and severe side effects (such as diarrhoea, vomiting, renal impairment and gene mutation), colchicine is rarely presently prescribed for acute gout attacks (Medsafe 2011). Colchicine is however routinely prescribed as 'cover' for people starting on ULTs (Healthpoint 2012a; Healthpoint 2012b).

Prescription medications are available for managing gout. These are known as urate lowering therapy (ULT). These medicines include 'xanthine oxidase inhibitors (allopurinol and febuxostat) [febuxostat is not currently available in New Zealand] and uricosurics (probenecid and benzbromarone)' (New Zealand Guidelines Group 2012, p 8-9), with allopurinol being the most commonly administered. As gout is a chronic disease, ULT is prescribed as a life-long prevention medication that must be taken continuously and regularly in order for results (reduction in serum urate levels) to occur. ULT is prescribed to patients with the intention of lowering their serum urate levels to under 0.36 mmol/L (Dalbeth 2007) and stabilising these levels through prolonged intake. While ULT is thought to be the 'cure' for gout, numerous studies have found that fewer than half of the people with gout 'receive urate lowering therapy and of those that do, many are on an insufficient dose to effect a cure' (Spencer et al 2012). Furthermore, Perez-Ruiz writes that 'there is no consensus on when to start therapy with urate-lowering drugs' (2009, p ii12), but notes that 'all experts would agree that patients with severe gout should be encouraged to start a urate-lowering drug' (pp ii12). While specific statistics on the prevalence of ULT is not known in New Zealand, Martini et al (2012), in their study of 60 people with gout, found that 56 (93 percent) of the participants had been prescribed urate-lowering drugs and that 44 (79 percent) were compliant with their prescription; only 3 (12 percent) of the prescribed patients admitted to be non-compliant. These figures are countered by Te Karu (2011) who found that of 382 people who were diagnosed by a health practitioner as having gout, 279 (73 percent) were not receiving allopurinol.

Initial treatment with ULT is a difficult process that must start when there is no acute gout. Starting ULT is likely to cause an acute gout attack due to a rapid drop in serum urate levels (Perez-Ruiz 2009) and as a result the mantra for starting ULT is 'low and slow' (p ii12). The dose of the ULT needs to be gradually increased until the target serum urate level of under 0.36mmol/L is achieved. Other NSAID medications must be prescribed for any acute attack following the onset of ULT. As this attack is often severe, people stop taking their ULT and are reluctant to start taking ULT again.

## **b. The impact of gout**

Research by Lindsay et al (2011) has revealed that acute gout impacts a person well beyond the pain that is often mentioned in the literature. The research concluded that while pain is normally found to be a similar experience shared between gout sufferers, acute gout also raises issues in terms of dependency and familial impact, isolation and work disability.

In this piece of research, pain was described with ascending adjectives, ranging from a 'twinge' to 'bursting' and 'burning'. The authors note that one participant felt their pain was intense enough to warrant an amputation while the inability to bear weight on the affected joint without serious pain was mentioned by the majority of participants. While pain is the most common physiological outcome of acute gout, it is also a precursor to other issues that may arise. Patients in Lindsay et al's (2011) research iterated that gout attacks often led them to dependency upon those around them for 'basic care including toileting, washing, and providing food and drink ... [while they were] bedridden and unable to walk' (p 3). Participants also alluded to the isolation which acute gout may bring about for them. Feelings of pain and shame reduced their ability and desire to interact with others, leading to both physical and social isolation. For some, the very thought that they might be caught away from home and experience acute gout can lead to a reduced tendency to participate in desired activities. Finally, Lindsay et al's (2011) research revealed that 'gout had a direct impact on the ability to work' (p 3) and the type of work people with gout were able to undertake. In early stages of the condition many of the participants were still able to manage their employment by taking sick leave. As the condition progressed, a change to more sedentary occupations was necessary in order for employment and acute gout to coexist. Research by Kleinman et al (2007) identifies a different issue, noting that while gout sufferers feel they are able to successfully manage their gout-work balance, employers believe that employees with gout are the cause of reduced productivity and, in the United States, cost an average of 4.6 working days per year.

Other research teams have investigated the correlation of gout and specific biological outcomes. Addressing the speculation that gout can lead to bone erosion, Dalbeth et al (2008) constructed computed tomographic (CT) images of the hands and wrists of 20 individuals with gout. They discovered that there is a strong relationship between the presence of tophi and evidence of bone erosion. Further researchers have looked into the relationship between gout and the biomechanics of the hands and feet. Rome et al (2012) studied the effects of chronic gout upon the function of the feet, while Dalbeth et al (2007) investigated how gout affects the function of the hands. Both research teams were able to conclude that the presence of chronic gout led to patients experiencing disability and impairment in the areas in which they commonly experience gouty flares.

### **c. Māori and gout**

It has long been understood that there is a high prevalence of gout in New Zealand, especially among Māori populations (Lennane et al 1960). Various studies have estimated the rate of gout incidence in Māori to be on the increase with figures approximating 10 percent among adult males (Gibbons and Merriman 2010). Winnard et al (2012), however, suggest that this figure is most probably a gross underestimation of the real extent of the issue as Māori often share medications for the treatment of acute gout, use alternative remedies and are often unwilling to speak up about their health problems due to fears of stigmatisation.

High prevalence of gout within Māori is mainly due to a hereditary predisposition combined with a modern diet. Gibson et al (1984) note that this is similar to other indigenous populations that have been colonised by Europeans (e.g. Australian Aborigines and Torres Strait Islanders, Filipinos), 'gout was rare among the indigenous population of New Zealand before the adoption of European diets and habits' (pp 280). Gibson et al (1984) also state that 'evidence suggests that Māori men may be endowed with a relative impairment of uric acid excretion' (pp 280). This idea, assumed in early research about Māori and gout, has been mostly confirmed through a University of Otago study on the 'Genetics of gout in Aotearoa' (Hollis-Moffatt et al 2009). The study focused upon a variant of the GLUT9 gene – one that is responsible for increased vulnerability for hyperuricaemia and gout – and found a higher prevalence of this variant within Māori than within other populations (Hollis-Moffatt et al 2009).

There is a considerable lack of awareness and understanding concerning gout within the Māori community. While rates are high, the common understanding is that gout is an old man's disease (Gibbons and Merriman 2008) and the result of over-eating and over-indulgence. This sentiment is, more often than not, met with inaccurate health messages in the form of jokes and ribbing (Gow et al 2011), leading to attitudes of acceptance and tolerance as opposed to those who promote treatment and symptom avoidance. In this way, gout within Māori communities becomes normalised but also a source of shame due to its perceived links with excessive alcohol and food consumption. It is for these reasons that treatment for Māori gout sufferers reaches a reducing proportion of the total affected population (Winnard et al 2008).

Of those who do seek medical attention, understanding the disease, its short and long-term impacts, prescribing practice and medication adherence become significant barriers to positive treatment outcomes. As mentioned above, the need to eat a modified diet is often prioritised and misunderstood and actual dietary changes may not be consistent with health messages. Similarly, medications used to treat gout are often not taken as prescribed or adherence levels are low due to lack of understanding about the ways in which their medications need to be taken. In many circumstances, these barriers are the result of poor health literacy and health literacy practices in both those who suffer from gout and health care practitioners and providers. These barriers to gout management are further discussed in the following section.

#### **d. Barriers to management**

Many people with gout are not managing their condition at an optimal level (Arroll et al 2009). As mentioned above, barriers to gout management lie with both the person with gout, health care practitioners and the health provider. This section will expand upon barriers to the management of gout from the perspective of both the patient and the health provider. Several case studies and investigations will be referenced and, where possible, information pertaining to Māori will be included.

##### **Patient**

Barriers to gout management are often found within the patient's understanding of gout as a chronic condition. This subsection addresses a number of issues which are considered to be barriers to gout treatment from the patient's perspective: lack of knowledge or understanding of gout, masculine acceptance of pain and stigma surrounding the condition and adherence to taking ULT.

##### **Lack of knowledge/understanding**

The key barrier to effective treatment discussed in the literature is an overt lack of knowledge and understanding surrounding both the causes and management of gout. Numerous studies point to the fact that a large number of those who suffer from gout only have a basic awareness of the underlying causes of gout and many people appear to have mixed and differing interpretations and understandings about what gout is, how dangerous it can be if left untreated, what causes it and what it means to live with and treat gout. For people to understand gout they need to have an understanding of how their bodies work and particularly around how food is digested and used to fuel their body. A survey performed by the Gout and Uric Acid Education Society in the United States found that more than 70 percent of adults did not know that gout is a form of arthritis (Ogdie et al 2010). Further, in a survey of Chinese and American patients by Zhang et al (2011), while many reported an understanding of gout as a state of having too much uric acid, only one third correctly reported that crystals within the joint caused attacks of gout. These findings are reinforced by a 2012 study by Martini et al entitled *Living With Gout in New Zealand* which found large gaps in gout knowledge concerning issues such as causes, dietary needs and complications, age, treatment and management. In this study, while over 85 percent of participants knew about food and beverage avoidance, only 33 percent made an effort to avoid alcohol and only 51 percent avoided trigger foods (Martini et al 2012). Further, only 33 percent of participants were found to know which medications they should use acutely and which prophylactically (Martini et al 2012).

Another study, completed by Spencer et al (2012) in England, found a widespread lack of knowledge surrounding gout among patients. They were seen to be unaware of the need to make lifestyle changes and of the way in which treatments and medications must be administered. Long-term health effects were similarly found to be universally misunderstood (Spencer et al 2012). These studies reinforce that there is a growing health literacy gap between patient and health practitioner and provider knowledge surrounding gout and how it is meant to be prevented, managed and treated. These results are mirrored by Lindsay (2011, unpublished) who, in a study of health practitioners, found that many believed that patients' lack of understanding and knowledge about gout are the most important barriers to correct treatment and management.

##### **Poor education from health practitioner and providers**

It has been suggested that this lack of knowledge or understanding may arise from improper or poor patient educational input from health practitioners and providers (Doherty et al 2012). In the study by Harrold et al (2010), a number of the patients interviewed stipulated that their prescribing physician did not give them enough information. They felt ill-informed and uneducated about the causes of gout and why they must take particular medications and for what period (Harrold et al 2010), a view similarly reported in work by Spencer et al (2012). This is reflected in the actions of participants in Dalbeth and Lindsay's (2012) study that described participants who did not feel that their immediate

personal actions were responsible for their gout attacks, even though they were able to state diet, comorbidities or diuretic use as a contributing factor towards their condition. These results identify that while patients may understand why they get acute gout, the educational approaches that are being used to teach them about their condition may not be conveying information in a way that leads to building appropriate knowledge for each individual patient.

The positive result of patient education has been noted in a recent UK study by Rees et al (2012). In an observational study, 106 participants who report ongoing gout attacks were enrolled in a nurse-led intervention that offered education, lifestyle advice and information on urate levels and urate lowering therapy. The results found that 90 percent of those who participated in the intervention were able to reduce their serum uric acid to target levels. The authors state that a 'full explanation and discussion about the nature of gout and its treatment options and individualisation of management probably account for [the] success' (Rees et al 2012, p 1) of the intervention. It should be noted that this intervention took place in a secondary rather than primary setting, where patients regularly attended gout clinics.

### Stigma and masculinity

For many people with gout, attitudes towards masculinity, acceptance of pain and stigmatisation mean that they are often reluctant to seek treatment (Spencer et al 2012). Participants in a study by Spencer et al (2012) revealed that during extremely painful acute attacks they would 'put up with the pain and muddle through ... [or] grin and bear it' (p 3). This understanding is mirrored in research by Lindsay et al (2011) whose study showed 'the perception among individuals, families, and communities was that the pain and disability of gout were something that must be endured and accepted with stoicism' (p 4-5). Men also felt uneasy and embarrassed about seeking medical attention for an issue when a small and normally unnoticeable part of their body was so painful (Spencer et al 2012). Further, many people with gout are reluctant to advertise their acknowledgement of symptoms due to the association of gout with old age and 'overindulgence in certain foods or alcoholic drinks and [link] their condition to an unhealthy lifestyle' (Spencer et al 2012, p 3). For this reason, gout is often transmogrified into a topic which is met with humour, jokes and ridicule, a situation which, again, serves to remove the desire for gout sufferers to speak up about and seek treatment for their condition (Dalbeth and Lindsay 2011). This theme is similarly present in interviews conducted with Māori gout sufferers (Lindsay et al 2011). As mentioned earlier, stigma surrounding gout within Māori communities concerning intemperate eating and drinking habits often leads those affected to remain silent during an acute gout attack. This, in turn, has led to a tolerance of pain and disability, low expectations of treatment and significant impact on quality of life (Gow et al 2011).

### Issues with adherence

A major barrier to gout management is the non-adherence to taking ULT. Reach (2011) has described gout as having one of the lowest adherence rates of all chronic illnesses, with rates of adherence being 'poorer among younger patients' (pp 459). One study has described that fewer than 40 percent of their participants prescribed allopurinol were completely adherent to the medicine (Becker and Chohan 2008). Another study by Harrold et al (2008) discovered that prescribing physicians often assumed patient adherence when the reality was otherwise. Many studies have articulated that non-adherence is a large problem among people who suffer from gout, with several reasons being suggested as to why non-adherence to ULT might occur.

The first of these reasons is that patients often have a lack of understanding about the role of ULT in managing gout. Many gout sufferers are unaware that ULT is available for their condition (The New Zealand Guidelines Group 2012), while others lack an understanding of how ULT must be taken. Harrold et al (2010), in a study of 26 people prescribed ULT, found that a number of participants would self-medicate their gout, raising and lowering, or only taking their dose of ULT during an attack

when starting ULT is contraindicated, because if taken during an acute gout attack, ULT may in fact exacerbate the symptoms and pain associated with the attack (The New Zealand Guidelines Group 2012). Other studies have found that a common misunderstanding of gout is that it is an acute, rather than a chronic condition, leading to poor-adherence of ULT (e.g. Lindsay et al 2011; Spencer et al 2012). People equate gout with acute gout only and think they only have gout sporadically. In reality, they have gout continuously (chronically) and occasionally experience acute gout (attacks). Spencer et al (2012), after interviewing 20 gout sufferers in England, found that the majority felt that treatment for gout was only necessary during an attack and need not be taken long-term. This aligns with the findings of a study by Zhang et al (2011) who found that only 36 percent of the participants of their study were aware that ULT must be taken as a long-term medication. In New Zealand, Martini et al (2012) found in a study of 60 gout sufferers, only 52 percent knew that ULT was to be taken daily. In terms of Māori, research with gout sufferers from South Auckland (an area of high Māori population) found that a majority of patients (11/13) believed that allopurinol was a short-term medication (Arroll et al 2009).

While a lack of knowledge or understanding is the most common reason for non-adherence to ULT, other research has found that non-adherence to medication such as allopurinol (the most commonly prescribed ULT) may be an intentional decision made by an informed patient. In a study by Harrold et al (2010), the majority of gout sufferers found to be non-adherent to allopurinol had made a conscious decision to not take the allopurinol, but that decision was influenced by external factors such as 'clinical factors and financial concerns' (Harrold et al 2010, p 269). Other studies such as that of Spencer et al (2012) found that participants actively stopped taking ULT because they felt they had experienced detrimental side effects such as increased frequency of acute gout or were concerned about the effectiveness of the medication in treating gout. Intentional non-adherence was also seen in Reach's (2011) study that found that beliefs such as an incompatibility between medication and alcohol consumption meant patients would not medicate on days when they would be drinking alcohol.

#### Health practitioners and providers

As mentioned earlier in this section, barriers to gout treatment are just as likely to be caused by health practitioners and providers as much as patient knowledge, understandings, perceptions or drug adherence. A number of studies have found many of the issues pertaining to poor gout treatment figures can also be attributed to the provider or health practitioners. This section provides insight into studies completed by researchers Dalbeth and Lindsay (2012), Harrold et al (2010), Ogdie et al (2010), Becker and Chohan (2008) and Lindsay (2011, unpublished).

As studies such as Spencer et al (2012) have found, many providers lack important understandings and knowledge of gout, leading them to misdiagnose, ill-prescribe or make assumptions about the underlying causes of a patient's condition. In Becker and Chohan's (2008) article on successful gout management, they state that the first issue to contend with is 'diagnostic inaccuracy' (p 168).

#### Differing perceptions of gout

One issue is that perceptions concerning the severity of gout are often found to differ between health practitioners as well as between patients and health practitioners. Patients commonly rate their gout symptoms as more severe than their health practitioners (Lee et al 2009). This reveals an underlying provider and health practitioner misinterpretation or lack of understanding of the symptoms of gout and how these affect the patient. Similarly, Dalbeth and Lindsay (2012) note that 'gout-specific health-related quality-of-life measures such as overall gout concern, well-being during a gout attack, and gout concern during a gout attack' (p 176) are of high importance to patients in determining the severity of their condition. On the other hand, providers and physicians are found to rate the severity of gout in more objective measures such as 'the amount of health care utilisation and presence of tophi' (Dalbeth and Lindsay 2012, pp 176). Further, well informed health practitioners note that gout is

easy and rewarding to treat and that management of symptoms in both acute and chronic gout is highly effective (Dalbeth and Lindsay 2012).

In a similar investigation by Harrold et al (2010) patients and providers were found to perceive gout differently. Providers felt that they were adequately educated in gout and gout management and that patients also had a well-rounded and similar understanding. By contrast, patients were found to have a wide range of beliefs and understandings regarding gout – especially concerning treatment. Many thought ULT to be ineffective or were unsure on their prescription duration. Furthermore, while providers felt that their patients were informed enough to make positive self-management decisions, patients stated that they would like to have more and better education on gout.

A third study on the perceptions of gout severity, conducted by Sarkin et al (2010), found that different measures of severity were often used between patients and practitioners. The results of their study revealed that patients were inclined to rate their gout as severe if it had a noticeable and debilitating impact on their quality of life. On the other hand, physicians were found to rate gout severity on clinical observation. Whereas physicians found objective signifiers of gout, such as the presence of tophi, to be indicators of illness severity, patients may find tophi to be less restricting or debilitating than other symptoms of the disease.

#### Lack of and inconsistency of knowledge

Just as patients often display a lack of knowledge or understanding about gout and its causes and treatments, providers and health practitioners have also been found to have limited familiarity with the condition for which they are providing education and treatment. One example of this comes from a health practitioner survey in Beijing which found that knowledge surrounding gout management was often inconsistent with current understandings of diagnosis and management (Fang et al 2006). These findings were reiterated further in an international study on gout management by Zhang et al (2011), again finding that provider knowledge was often inconsistent with current understandings. Limited education and training has been suggested as one reason for a lack of knowledge and understanding of gout in providers and health practitioners, leading to assumptions about symptoms and treatment, and management errors and deficiencies. Ogdie et al (2010) note that health care workers in different positions often receive inconsistent information about gout and methods of treatment, leading to disparate diagnoses and treatment methods. In their study, they note that patients who have had consultation with a rheumatologist were more likely to 'receive intraarticular steroid injections and less likely to be treated with colchicines [while] patients treated by primary care physicians were found to be underdosed [and] have less frequent monitoring of uric acid levels' (Ogdie et al 2010, p 174). This notion is continued by Doherty et al (2012) who state that the problem lies in the lack of priority for gout education during training. They state that gout is commonly sidestepped during formal education and what little information is included in textbooks is often outdated and incorrect concerning contemporary medicine (Doherty et al 2012). This often leads to health practitioners having a poor understanding of the long-term complications of gout, often providing advice to patients which will help to stem acute attacks, but having little effect on the long-term complications associated with gout. This notion is also found within specialists such as rheumatologists who often regard gout as a basic, less academic challenge and tend to stick with other conditions such as arthritis. (Doherty et al 2012).

The New Zealand Guidelines Group (2012) has found that lack of clinical knowledge may be an issue. While this may be attributed to issues of physician education, such as a lack of interest in *common* health issues in medical students and hospital residents (Ogdie et al 2010), it has also been found to be a potential result of inconsistent information provided by institutions such as community laboratories. They note that in the local context, some Auckland 'community labs [were] reporting different normal ranges for uric acid' (The New Zealand Guidelines Group 2012, p 13), leading to the prescription of incorrect quantities of ULT. In another study by Spencer et al (2012), this lack of knowledge was found within some practice nurses who had only 'encountered gout as a comorbidity

in patients who accessed nurse-led chronic disease management clinics' (p 4). This led to nurses making assumptions about gout which reflected incomplete knowledge shared by the general population such as 'it is predominantly self-inflicted and due to unhealthy lifestyles' (Spencer et al 2012, p 4).

An unpublished study completed by Lindsay (2012) in primary practices South Auckland also reported a number of barriers to gout treatment and management that can be attributed to health practitioners. A summary of the findings reveals that health practitioners: find that there is not enough time to adequately manage or treat gout and often focus on treating acute attacks rather than providing long-term management; lack sufficient technical knowledge concerning gout (uric acid targets, what information to provide to patients, proper use and titration of specific medications); often feel that their efforts to prescribe preventive medications are futile as the patients do not take them; and, feel that gout should be treated at specialist clinics, rather than all health practitioners being required to have an in depth knowledge regarding gout.

#### Adherence to quality indicators

Doherty et al (2012) note that a major barrier to gout management and treatment is the 'low adherence of primary care physicians to published evidence-based treatment guidelines for the diagnosis and management of gout' (2012, p 4).

In a study by Singh et al (2007) assessing the 'quality of care provided to veterans with gout diagnoses' (p 827) in the United States, numerous deficiencies were found which could be attributed to a lack in adherence to prescribed quality indicators. After testing for three quality indicators concerning the dosage and monitoring of ULT in patients and finding similar results to a study undertaken in the United Kingdom by Mikuls et al (2005), they conclude that there is a need for improvement of physicians' management of gout if morbidity and disability resulting from chronic gout are to be relieved. Doherty et al (2012) state that reasons for diminished adherence could include the lack of both financial incentives to improve care and general practitioner contribution to the development of guidelines.

As noted earlier, non-adherence to medication is a problem among patients prescribed ULT. However, while the act of taking the drug is ultimately decided by the patient, the education about why it needs to be taken, how it needs to be taken, the prescribing of a NSAID in the case of an acute attack, the need to increase ULT dosage, the need for ongoing blood tests and the need to aim for a target of 0.36 mmol/L or lower is the responsibility of health practitioners and providers.

### **Section 4 - Addressing the barriers**

As has been shown above, people with gout, health practitioners and providers can attribute barriers to gout management to understanding and knowledge of gout, as well as perceptions of the condition. The reasons for these barriers are complex and in order to make positive advances in the management of gout, numerous studies and reports suggest that people with gout, health practitioners and providers need to become involved with better educational processes and techniques. This section will provide details of the educational initiatives that have been suggested in current literature for patients, health practitioners and providers.

#### **a. Health practitioners and providers**

A number of studies have concluded that health practitioner education is needed to enable more effective gout treatment and management. Training is needed not only to educate providers and health practitioners about the physiology and management of gout, but also about how they themselves should undertake the education of their patients. As studies such as Spencer et al (2012) have found, many providers lack important understandings and knowledge of gout, leading them to misdiagnose, ill-prescribe or make assumptions about the underlying causes of a patient's condition.

In Becker and Chohan's (2008) article on successful gout management, they state that the first issue to contend with is 'diagnostic inaccuracy' (p 168). They propose that education is the key to overcoming this and that this should focus on 'diagnosis and course, circumstances likely to promote or mark progression, the significance of comorbid associations, and means to monitor therapy and maximize adherence to therapeutic recommendations' (Becker and Chohan 2008, p 168). Furthermore, Becker and Chohan (2008) note that the rheumatology community has the ability to use its 'clinical and educational specialist roles in [gout] to promote our primary care provider colleagues the knowledge to address such issues' (p 168).

Singh (2012) identifies that increasing patient awareness of gout and its effective treatments is pertinent to reducing racial disparities in gout management. For Māori, Gow et al (2011) note that management of gout must reflect the culture of the people who are being treated. In the article on gout management among Māori in New Zealand, the authors (Gow et al 2011) state that further research, using multidisciplinary inputs for the collection of qualitative data, is needed in order to create educational programmes for providers which draw upon and encourage diverse cultural and health beliefs.

The lack of practitioner guidelines has also been mentioned as a barrier to effective treatment. Spencer et al (2012) suggest that while guidelines for treatment and patient education often exist, practitioners need incentives to adhere to these. These incentives will be key to encouraging health practitioners to effectively educate their patients, write Becker and Chohan (2008), which in turn will become major determinants of any successful effort to improve gout management. One example of an incentive proposed by Spencer et al (2012) is to push the idea of curative treatment rather than acute management, a change which will hopefully ensure health practitioners treat gout because the ability to essentially 'cure' the condition can be thought of as a positive incentive and motivation to follow best practice guidelines in order to create real and beneficial changes.

## **b. Patient education**

The studies in this review have almost universally concluded that patient education is highly important in removing barriers to gout management. However, the majority of articles fail to address the systemic and process barriers to gout management, tending to focus more on what information patients do not appear to know and should be taught. These suggestions fail to address this lack of knowledge as a health literacy issue not just for patients but also for health practitioners and providers. For example, Smith et al (2011) write that in order to manage patients' use of ULT, education is highly important, but they attempt only to inform the reader that 'patient education should emphasize the need for strict compliance with medication regimens' (p 1124), rather than addressing why it might be that previous messages about gout management have not been assimilated into patients' knowledge of the condition. This is similarly found in Hardy (2011) where her section on patient education focuses entirely on the topics of concern which should be taught to gout sufferers such as joint destruction, treatment compliance and dietary changes (p 18).

From the studies mentioned in this review, it is clear that health literacy and effective communication has become a substantial barrier to the management of both chronic and acute gout. Becker and Chohan (2008) write that in order to develop patients who are knowledgeable about treating and managing their condition, effective communication is the key. They state that 'communication skill is particularly critical ... to transmit the respective rationales to the patient in understandable terms' (Becker and Chohan 2008, p 170). In their study on gout management, Harrold et al (2010) note that health practitioners felt that 'they had adequate training and skills necessary to teach disease self-management behaviours' (p 269) but in contrast to this, patients were found to have a wide range of varying 'knowledge, beliefs and experiences regarding gout' (p 269). This mismatch in patient and health practitioner and provider knowledge about gout and its treatment suggests a high potential for 'patient and provider miscommunication' (Harrold et al 2010, p 269) and is explained by Harrold et al

as 'inadequate health literacy, which is increasingly being recognized as a large problem that impedes patient education, following instructions from a physician and taking medicine properly' (2010, p 269). Similarly, Ogdie et al (2010) have noted that one barrier to patient understanding and knowledge surrounding gout is physician education practices. Their advice is that:

'Effective education needs to be written in a clear, easily understood language. This has been an obstacle to effective patient information pamphlets in the past. Taking into account the health literacy of the general population is a critical first step in reaching out to the public in a patient education program' (Ogdie et al 2010, p 177).

This understanding is also iterated in Shulten et al (2009) who, in their study of nutrition and gout, conclude that poor adherence to dietary advice and inappropriate food avoidances need to be targeted by 'appropriate current promotional materials ... [which] may help to raise awareness and access to information regarding diet and gout' (p 9). While health literacy is mentioned by Ogdie et al (2010), these recommendations are reflective of the educational conclusions across the literature. However, health education needs to be concerned with more than creating educational pamphlets at the right language level.

A number of studies have recommended the use of analogies when working with people with gout (Wortmann 2006; Skeff 1998). Analogies include damp matches (Wortmann 2006), a factory (Lindsay, personal communication 2012), taps and blocked sink (Aringer and Graessler, 2008). These various analogies provide a useful basis for patient education but require inference that may not work for some populations particularly those who have different cultural frameworks.

## **Conclusion**

Gout is a form of chronic arthritis, which is highly prevalent and poorly managed in the Western world. This review has attempted to discover the barriers to gout management, as well as what might be done to identify and remove these barriers and create more effective management and treatment opportunities. Barriers to gout were found to exist within the realm of both the patient and the provider. In terms of people at risk of or with gout, this review has found that barriers to management and treatment include poor understanding and knowledge of the condition, poor educational programmes and systems, community perceptions surrounding masculinity and stigmatisation of gout, and poor adherence to medication and treatment procedures. Barriers to gout prevention, management and treatment exist for health practitioners and providers as well. Like patients, they were often found not to possess a knowledge and understanding about gout and its treatment. They were also found to have differing perceptions of gout both between themselves and between providers and patients. Finally, providers were seen to not comply with quality management indicators.

From the literature, it appears that education and communication are the keys to removing barriers to gout prevention and management and that these changes must be aimed at the health practitioners, providers and patients. Patients need education that is accessible, using correct information that is easy to understand, tailored for their phase of gout prevention or treatment, as well as being culturally sensitive. Health practitioners and providers need education that is motivating and encourages them to want to learn about gout. They also must learn new health literacy knowledge and techniques for educating patients so that communication is clear, concise and easy to understand and links to what the patient already knows and believes about gout.

## Gout Reference List

Abdelrahman M, Rafi A, Ghacha R, et al. 2002. Hyperuricemia and gout in renal transplant recipients. *Renal Failure* 24(3): 361-367.

Annemans L, Spaepen E, Gaskin M, et al. 2008. Gout in the UK and Germany: prevalence, comorbidities and management in general practice 2000–2005. *Annals of the Rheumatic Diseases* 67(7): 960–966.

Aringer M, Graessler J. 2008. Understanding deficient elimination of uric acid. *The Lancet* 372: 1929-1930.

Arroll B, Bennett M, Dalbeth N, et al. 2009. More allopurinol is needed to get gout patients <0.36 mmol/l: a gout audit in the form of a before–after trial. *Journal of Primary Health care* 1(4): 315-318.

Becker MA, Chohan S. 2008. We can make gout management more successful now. *Current Opinion in Rheumatology* 20: 167-172.

Bhole V, de Vera M, Rahman MM, et al. 2010. Epidemiology of Gout in Women: Fifty-two–Year Followup of a Prospective Cohort. *Arthritis & Rheumatism* 62(4): 1069–1076.

Burack DA, Griffith BP, Thompson ME, et al. 1992. Hyperuricemia and gout among heart transplant recipients receiving cyclosporine. *The American Journal of Medicine* 92(2): 141-146.

Caspi D, Lubart E, Graff E, et al. 2000. The effect of mini-dose aspirin on renal function and uric acid handling in elderly patients. *Arthritis & Rheumatism* 43(1): 103-108.

Chang SJ, Ko YC, Wang TN, et al. 1997. High prevalence of gout and related risk factors in Taiwan's Aborigines. *The Journal of Rheumatology* 24(7): 1364-1369.

Choi HK. 2010. A prescription for lifestyle change in patients with hyperuricemia and gout. *Current Opinion in Rheumatology* 22: 165-172.

Choi HK, Atkinson K, Karlson EW, et al. 2004. Purine-Rich Foods, Dairy and Protein Intake, and the Risk of Gout in Men. *New England Journal of Medicine* 350: 1093-1103.

Choi HK, Curhan G. 2007. Independent Impact of Gout on Mortality and Risk for Coronary Heart Disease. *Circulation* 116: 894-900.

Choi HK, Curhan G. 2008. Soft drinks, fructose consumption, and the risk of gout in men: prospective cohort study. *BMJ* 336. DOI: 10.1136/bmj.39449.819271.BE.

Choi HK, Ford ES, Li C, et al. 2007. Prevalence of the metabolic syndrome in patients with gout: The Third National Health and Nutrition Examination Survey. *Arthritis Care & Research* 57(1): 109-115.

Choi HK, Mount DB, Reginato AM. 2005. Pathogenesis of Gout. *Annals of Internal Medicine* 143: 499-516.

Dalbeth N. 2007. Gout – Hit the Target. *Best Practice Journal* 8: 9-18.

Dalbeth N, Collis J, Gregory K, et al. 2007. Tophaceous joint disease strongly predicts hand function in patients with gout. *Rheumatology* 46(12): 1804-1807.

Dalbeth N, Lindsay K. 2012. The Patient's Experience of Gout: New Insights to Optimize Management. *Current Rheumatology Reports* 14: 173-178.

Dalbeth N, Smith T, Nicolson B, et al. 2008. Enhanced osteoclastogenesis in patients with tophaceous gout: Urate crystals promote osteoclast development through interactions with stromal cells. *Arthritis & Rheumatism* 58(6): 1854–1865.

Dessein PH, Shipton EA, Stanwix AE, et al. 2000. Beneficial effects of weight loss associated with moderate calorie/carbohydrate restriction, and increased proportional intake of protein and unsaturated fat on serum urate and lipoprotein levels in gout: a pilot study. *Annals of the Rheumatic Diseases* 59: 539-543. DOI:10.1136/ard.59.7.539.

Doherty M, Jansen TJ, Nuki G, et al. 2012. Gout: why is this curable disease so seldom cured? *Annals of the Rheumatic Diseases* 0: 1-6.

Fang W, Zeng X, Li M, et al. 2006. The management of gout at an academic health care center in Beijing: a physician survey. *The Journal of Rheumatology* 33(10): 2041-2049.

Gao X, Curhan G, Forman JP, et al. 2008. Vitamin C Intake and Serum Uric Acid Concentration in Men. *The Journal of Rheumatology* 35(9): 1853-1858.

Gibbons O, Merriman T. 2008. Update: Gout in the Māori community. *Best Practice* 13. URL: <http://www.bpac.org.nz/magazine/2008/may/gout.asp>.

Gibson T, Waterworth R, Hatfield P, et al. 1984. Hyperuricaemia, gout and kidney function in New Zealand Māori men. *British Journal of Rheumatology* 23: 276-282.

Gow PJ, Gow VF, Waldon J. 2011. Societal and Cultural Attitudes to Gout: An Important Consideration in the Successful Management of Gout among Māori in Aotearoa New Zealand. *Current Rheumatology Reviews* 7: 170-180.

Hak AE, Curhan GC, Grodstein F, et al. 2010. Menopause, postmenopausal hormone use and risk of incident gout. *Annals of the Rheumatic Diseases* 69(7): 1305–1309.

Hardy E. 2011. Gout diagnosis and management: What NPs need to know. *The Nurse Practitioner* 36(6): 14-19.

Harrold BL, Briesacher B, Raebel M, et al. 2008, October. *Adherence with Urate-Lowering Therapy for the Treatment of Gout*. Paper presented at the American College of Rheumatology Annual Scientific Meeting. San Francisco, CA.

Harrold LR, Mazor KM, Velten S, et al. 2010. Patients and providers view gout differently: a qualitative study. *Chronic Illness* 6: 263-271.

Harrold LR, Yood RA, Mikuls TR, et al. 2006. Sex differences in gout epidemiology: evaluation and treatment. *Annals of the Rheumatic Diseases* 65(10): 1368–1372.

Healthpoint. 2012a. *Acute Gout – Auckland Region Clinical Pathways*. URL: <http://www.healthpointpathways.co.nz/acute-gout/> (accessed 28 August 2012).

Healthpoint. 2012b. *Gout Prevention – Auckland Region Clinical Pathways*. URL: <http://www.healthpointpathways.co.nz/gout-prevention/> (accessed 28 August 2012).

Hollis-Moffatt JE, Xu X, Dalbeth N, et al. 2009. A role for the urate transporter SLC2A9 gene in susceptibility to gout in New Zealand Māori, Pacific Island and Caucasian case-control sample sets. *Arthritis and Rheumatism* 60: 3485-92.

- Huang HY, Appel LJ, Choi MJ, et al. 2005. The effects of vitamin C supplementation on serum concentrations of uric acid: Results of a randomized controlled trial. *Arthritis & Rheumatism* 52(6): 1843–1847.
- Iseki K, Ikemiya Y, Inoue T, et al. 2004. Significance of hyperuricemia as a risk factor for developing ESRD in a screened cohort. *American Journal of Kidney Diseases* 44(4): 642-650.
- Jackson G, Wright C, Thornley S, et al. 2012. Potential unmet need for gout diagnosis and treatment: Capture-recapture analysis of a national administrative dataset. *Rheumatology* 51(10): 1820-1824.
- Kleinman NL, Brook RA, Patel PA, et al. 2007. The Impact of Gout on Work Absence and Productivity. *Value in Health* 10(4): 231–237.
- Kramer HJ, Choi HK, Atkinson K, et al. 2003. The association between gout and nephrolithiasis in men: The Health Professionals' Follow-Up Study. *Kidney International* 64: 1022–1026.
- Lee J, Sparrow D, Vokonas PS, et al. 1995. Uric Acid and Coronary Heart Disease Risk: Evidence for a Role of Uric Acid in the Obesity-Insulin Resistance Syndrome. *American Journal of Epidemiology* 142(3): 288-294.
- Lee SJ, Hirch JD, Terkeltaub R, et al. 2009. Perceptions of disease and health-related quality of life among patients with gout. *Rheumatology* 48: 582-586.
- Lennane GAQ, Rose BS, Isdale IC. 1960. Gout in the Māori. *Annals of the Rheumatic Diseases* 19: 120-125.
- Lin H-Y, Rocher LL, McQuillan MA, et al. 1989. Cyclosporine-Induced Hyperuricemia and Gout. *The New England Journal of Medicine* 321: 287-292.
- Lindsay K. 2011. *Unpublished research*.
- Lindsay K, Gow P, Vanderpyl J, et al. 2011. The Experience and Impact of Living With Gout: A Study of Men With Chronic Gout Using a Qualitative Grounded Theory Approach. *Journal of Clinical Rheumatology* 17(1).
- Lippi G, Brocco G, Massimo F, et al. 2004. Comparison of serum creatinine, uric acid, albumin and glucose in male professional endurance athletes compared with healthy controls. *Clinical Chemistry and Laboratory Medicine* 42(6): 644–647.
- Maclachlan MJ, Rodnan GP. 1967. Effect of food, fast and alcohol on serum uric acid and acute attacks of gout. *American Journal of Medicine* 42(1): 38-57.
- Martini N, Bryant L, Te Karu L, et al. 2012. Living With Gout in New Zealand: An Exploratory Study Into People's Knowledge About the Disease and Its Treatment. *Journal of Clinical Rheumatology* 18(3): 125–129.
- McAdams De Marco MA, Maynard JW, Baer AN, et al. 2012. Diuretic Use, Increased Serum Urate Levels, and Risk of Incident Gout in a Population-Based Study of Adults With Hypertension. *Arthritis and Rheumatism* 64(1): 121-129.
- McLachlan A, Kerr A, Lee M, et al. 2011. Nurse-led cardiovascular disease risk management intervention for patients with gout. *European Journal of Cardiovascular Nursing* 10: 94-100.
- Medsafe. 2011. *Colgout (Colchicine)*. URL: <http://www.medsafe.govt.nz/profs/Datasheet/c/Colgouttab.pdf>.

- Merriman T. 2009. Fructose and Gout. *Proceedings of a Gout Outing II: Where have we come from and where are we going? 6 November 2009*. Maaori Gout Action Group: Auckland, New Zealand.
- Mikuls TR, Farrar JT, Bilker WB, et al. 2005. Gout epidemiology: results from the UK General Practice Research Database, 1990–1999. *Annals of the Rheumatic Diseases* 64: 267-272.
- New Zealand Guidelines Group. 2012. *Evidence-practice Gap Analysis Report: A report analysing three priority evidence-practice gaps*.
- Ogdie AR, Hoch S, Dunham J, et al. 2010. A roadmap for education to improve the quality of care in gout. *Current Opinion in Rheumatology* 22: 173-180.
- Perez-Ruiz F. 2009. Treating to target: a strategy to cure gout. *Rheumatology* 48(suppl 2): ii9-ii14.
- Primates P, Plana E, Rothenbacher D. 2011. Gout treatment and comorbidities: a retrospective cohort study in a large US managed care population. *BMC Musculoskeletal Disorders* 12: 103.
- Reach G. 2011. Treatment adherence in patients with gout. *Joint Bone Spine* 78(5): 456-459.
- Rees F, Jenkins W, Doherty M. 2012. Patients with gout adhere to curative treatment if informed appropriately: proof-of-concept observational study. *Annals of the Rheumatic Diseases*. DOI: 10.1136/annrheumdis-2012-201676.
- Rome K, Frecklington M, McNair PJ, et al. 2012. Foot pain, impairment and disability in patients with acute gout flares; a prospective observational study. *Arthritis Care Res* 64: 384-388.
- Roubenoff R, Klag MJ, Mead LA, et al. 1991. Incidence and Risk Factors for Gout in White Men. *JAMA* 266(21): 3004-3007.
- Saag KG, Choi H. 2006. Epidemiology, risk factors, and lifestyle modifications for gout. *Arthritis Research & Therapy* 8(Suppl 1). DOI: 10.1186/ar1907.
- Sarkin AJ, Levack AE, Shieh MM, et al. 2010. Predictors of doctor-rated and patient –rated gout severity: gout impact scales improve assessment. *Journal of Evaluation in Clinical Practice* 6: 1244-1247.
- Savage PJ, Pressel SL, Curb JD, et al. 1998. Influence of long-term, low-dose, diuretic-based antihypertensive therapy on glucose, lipid, uric acid, and potassium levels in older men and women with isolated systolic hypertension: the Systolic Hypertension in the Elderly Program. *Archives of Internal Medicine* 158: 741-751.
- Schneider V, Lévesque LE, Zhang B, et al. 2006. Association of selective and conventional nonsteroidal anti-inflammatory drugs with acute renal failure: A population-based, nested case-control analysis. *American Journal of Epidemiology* 164(9): 881-889.
- Shulten P, Thomas J, Miller M, et al. 2009. The role of diet in the management of gout: a comparison of knowledge and attitudes to current evidence. *Journal of Human Nutrition and Dietetics* 22: 3-11.
- Singh JA. 2012. Can racial disparities in optimal gout treatment be reduced? Evidence from a randomized trial. *BMC Medicine* 10: 15.
- Singh J, Reddy S, Kundukulam J. 2011. Risk factors for gout and prevention: a systematic review of the literature. *Current Opinion in Rheumatology* 23(2): 192–202.

Singh JA, Strand V. 2008. Gout is associated with more comorbidities, poorer health-related quality of life and higher health care utilisation in US veterans. *Annals of the Rheumatic Diseases* 67: 1310-1316.

Singh JA, Sarkin A, Shieh M, et al. 2010. Health Care Utilization in Patients with Gout. *Seminars in Arthritis and Rheumatism* 40: 501-511.

Skeff KM. 1998. Living with gout: preventing the fire. *The American Journal of Medicine* 105(6): 549-550.

Smith HS, Bracken D, Smith JM. 2011. Gout: Current Insights and Future Perspectives. *The Journal of Pain* 12(11): 1113-1129.

Spencer K, Carr A, Doherty M. 2012. Patient and provider barriers to effective management of gout in general practice: a qualitative study. *Annals of the Rheumatic Diseases*. DOI: 10.1136/annrhumdis-2011-200801.

Staessen J. 1991. The determinants and prognostic significance of serum uric acid in elderly patients of the European Working Party on High Blood Pressure in the Elderly trial. *The American Journal of Medicine* 90: 50-54.

Stein HB, Hassan A, Fox IH. 1976. Ascorbic acid-induced uricosuria. A consequence of megavitamin therapy. *Annals of Internal Medicine* 84(4): 385-388.

Te Karu L. 2011. *Hyperuricaemia in Māori - To treat or not to treat? Exploring the reality of gout in Māori and whether there is rationale to treat hyperuricaemia before the onset of gout*. Unpublished Master's thesis. Auckland, New Zealand: University of Auckland.

Tomita M, Mizuno S, Yamanaka H, et al. (2000). Does hyperuricemia affect mortality? A prospective cohort study of Japanese male workers. *Journal of Epidemiology* 10(6): 403-409.

Vázquez-Mellado J, Hernández EA, Burgos-Vargas R. 2004. Primary prevention in rheumatology: the importance of hyperuricemia. *Best Practice & Research Clinical Rheumatology* 18(2): 111-124.

Wannamethee, SG, Shaper AG, Alberti GMM. 2000. Physical Activity, Metabolic Factors, and the Incidence of Coronary Heart Disease and Type 2 Diabetes. *Archives of Internal Medicine* 160(14): 2108-2116.

Williams PT. 2008. Effects of diet, physical activity and performance, and body weight on incident gout in ostensibly healthy, vigorously active men. *American Journal of Clinical Nutrition* 87(5): 1480-1487.

Winnard D, Wright C, Taylor WJ. 2008. Debunking the myths to provide 21<sup>st</sup> Century management of gout. *Journal of the New Zealand Medical Association* 121(1274): 79-85.

Winnard D, Wright C, Taylor WJ. 2012. National prevalence of gout derived from administrative health data in Aotearoa New Zealand. *Rheumatology*. URL: <http://rheumatology.oxfordjournals.org>.

Workmann RL. 1998. Effective management of gout: an analogy. *American Journal of Medicine* 105(6): 513-514.

Wortmann RL. 2006. The management of gout: it should be crystal clear. *The Journal of Rheumatology* 33(10): 1921-1922.

Zhang Y, Woods R, Chaisson C, et al. 2006. Alcohol Consumption as a Trigger of Recurrent Gout Attacks. *The American Journal of Medicine* 119: 800e13-800e18.

Zhang LY, Schumacher RH, Su HH, et al. 2011. Development and Evaluation of a Survey of Gout Patients Concerning Their Knowledge About Gout. *Journal of Clinical Rheumatology* 17(5): 242-248.

Zychowicz ME, Pope RS, Graser E. 2010. The current state of care in gout: Addressing the need for better understanding of an ancient disease. *Journal of the American Academy of Nurse Practitioners* 22: 623-636.

## Appendix 2. Health Literacy Literature Review

### Glossary

Adult Literacy and Life Skills Survey (ALLS)	A second literacy survey undertaken by the Organisation for Economic Co-operation and Development (OECD) in a number of countries which measured health literacy. The ALL Survey was undertaken in New Zealand in 2006.
Anticoagulation therapy	Therapy which stops the blood thickening and clotting.
Ask-Me-3	A framework of 3 questions that patients are encouraged to ask their health professional to build the patient's health literacy: <a href="http://www.minuteclinic.com/ask_me_3">www.minuteclinic.com/ask_me_3</a>
Chronic disease	A disease that develops over a long period of time and is the leading cause of deaths in New Zealand.
Conceptual knowledge	Understanding what something is.
Critical thinking	Thinking that involves judgement, analysis and questioning.
Glycemic control	Controlling blood sugar levels.
Health literacy	The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions which is influenced by health professionals, healthcare organisation sand the health system.
International Adult Literacy Survey (IALS)	A first literacy survey undertaken by the Organisation for Economic Co-operation and Development (OECD) in a number of countries. The IAL Survey was undertaken in New Zealand in 1996.
Numeracy	The ability to apply knowledge of numbers to everyday tasks.
Oral literacy	Using speaking and listening skills to communicate.
Print literacy	The ability to read, write and understand printed language.
Proxy	A substitute.
Rapid Estimate of Adult Literacy in Medicine (REALM)	A United States health literacy assessment tool frequently used to assess patients' health literacy.
Test of Functional Health Literacy in Adults (TOFHLA)	A United States health literacy assessment tool frequently used to assess patients' health literacy.

## The Changing Face of Health Care

The sphere of health has extended far beyond its traditional confines and has become a much broader, complex concept. Health is no longer confined to clinical settings but is now a regular feature in print and social media, television and radio (Kickbusch et al 2005). Health now includes what we eat and drink, how much we sleep and exercise and how we manage stress and emotions.

As the sphere of health continues to grow and become more complex, the relationship between the health system and the health consumer also continues to change and evolve. According to Zarcadoolas et al (2006) examples of this new dynamic include health instructions no longer going unchallenged and dialogue replacing monologue as the typical pattern of communication between health provider and patient. One of the drivers for this change is the growth of chronic diseases. Zarcadoolas et al (2006, p 40) state that individual health behaviour is a far greater factor in rates of death and disability in the United States than biomedical advances and that the '21<sup>st</sup> century will likely see a dramatic increase in death and disability from chronic diseases related to lifestyle'. The combination of increasing rates of chronic disease and an ageing population means that the cost of health care is becoming increasingly expensive. Increased rates of chronic disease result in increased and recurring hospital admissions and the necessity of ongoing care, all of which are a huge drain on scarce resources. This rise in rates of chronic disease coupled with the rising cost of health care provision means that doing more with less has become the norm in most health settings. There is an ever increasing amount of health information available to patients and more choice in treatment options. Health care systems are now far more complex than before and encompass a broader range of providers.

As part of doing more with fewer resources, patients now find themselves having to do more self-management of their conditions and being increasingly responsible for adherence to long-term health goals and self care in a complex health system (Pignone et al 2005; Koh et al 2012). As the need to self manage conditions increases, patients are required to develop new skills to find and manage information, understand and manage their rights and responsibilities and make health decisions for themselves and others (Institute of Medicine 2004).

The need to become informed, engaged and active consumers of health means that there are far greater demands being placed on patients (Kickbusch et al 2005). The Institute of Medicine (2004, p 3) states that 'underlying these demands are assumptions about people's knowledge and skills'. A host of national and international research shows these assumptions to be faulty as evidence from around the world shows that patients' knowledge and skills are usually below those **demand**ed of them by their health system (Rudd et al 1999; Rudd et al 2007). As Koh et al (2012, p 435) state 'a wide chasm often separates what providers intend to convey in written and oral communication and what patients understand.'

### a. Defining health literacy

It is now commonly accepted that literacy is a major determinant of health status (Nutbeam 2008; Institute of Medicine 2004; Zarcadoolas et al 2006; Kickbusch et al 2005; Rudd et al 1999; Rudd et al 2007). To be able to understand, interpret and analyse health information a patient needs to draw on their general literacy and numeracy skills. These include basic print literacy (the ability to read, write and understand printed language), oral literacy (using speaking and listening skills) to communicate with health providers and numeracy (the ability to apply numerical knowledge to everyday tasks) (Weiss 2007; Institute of Medicine 2004).

Having the ability to make the right decisions about health in the context of everyday life, or having good health literacy, goes far beyond general literacy skills because it requires advanced skills needed to interpret, evaluate and act on health information (Kerka 2000; Zarcadoolas et al 2006).

Although literacy and numeracy skills play a significant role in health literacy, health literacy is influenced by many factors, making it a more complex construct than literacy (Speros 2005; Zarcadoolas et al 2006).

The US Department of Health and Human Services (2000, p 11) defines health literacy as 'the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions'. The essence of this definition lies with the ability of the individual to obtain information (Rudd et al 2007). However, health literacy goes beyond this and 'emerges when the expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing the information and services' (Institute of Medicine 2004, p 2). In *Kōrero Mārama: Health Literacy and Māori*, the authors of that report acknowledge that the term health literacy is widely used and encompasses a variety of definitions and ideas. The report refers to the earlier definition from the US Department of Health and Human Services (see above) and states that 'Health literacy is essentially the skills people need to find their way to the right place in hospital, fill out medical and insurance forms and communicate with their health providers' (Ministry of Health 2010, p 1).

Health literacy is an outcome of both individual and social factors (Kickbusch et al 2005; Zarcadoolas et al 2006). An individual's health literacy status is mediated by a range of factors, including literacy levels, socio-economic status, and cultural beliefs and attitudes. Of equal significance are the communication skills of the health practitioners the individual is interacting with and the ability of various other stakeholders, including the health system, the media and the market place to provide health information and services in a way that is appropriate for that individual (Institute of Medicine 2004).

Kickbusch et al (2005, p 9) emphasise that health literacy is both an active and dynamic construct and claim that individuals with high levels of health literacy are in 'continuous exchange and dialogue with their environment'. As society changes, so too must individuals learn new information and discard outdated information in order to successfully navigate the health system and make sound health decisions.

Similarly, Edwards et al (2012, p151) emphasise the complex social and changing nature of health literacy by defining it as a 'multi-dimensional construct that develops over time, across different health contexts and through social interactions'. The authors see health literacy as developing along a continuum towards greater knowledge, greater self-management and greater participation in decision making and existing as both a process and an outcome. Zarcadoolas et al (2006) also see health literacy as operating on a continuum with health literacy levels evolving over a lifetime affected by health status and demographic, socio economic and cultural factors.

## **b. Consequences of low health literacy**

Health literacy is likely to be a key factor in health disparity (Kickbusch et al 2005; Baker et al 1998; Nutbeam 2008; Zarcadoolas et al 2006; Institute of Medicine 2004; Ministry of Health 2010). Poor communication between the patient, the health provider and the health system is likely to contribute to disparities in patient understanding of their health status, their health condition, the procedures for prevention and treatment of their condition, and utilisation of health services (Rudd et al 1999).

Highlighting this correlation, the American Medical Association (1999, p 554) found health literacy to be 'a stronger correlate of health status than education level and other socio-demographic correlates'. Similarly, the Institute of Medicine (2004) claims that any reduction in health disparities requires a simultaneous improvement in health literacy levels. Kickbusch et al (2005) refer to health literacy as a building block or pathway to health, with low health literacy levels being a strong factor in health disparities. Just as low literacy is seen to contribute to low health status, so too is low health literacy seen to contribute to socio-economic disadvantage and an inability to engage with and achieve health and wider life goals (Kickbusch et al 2005).

There is a large and growing body of research linking low health literacy levels to low health knowledge and adverse health behaviours and outcomes (Koh et al 2012). In addition to higher health care costs these outcomes include a decreased likelihood of using screening or preventive measures, a decreased likelihood of being compliant with medication, a decreased likelihood of successful self-management of chronic conditions, a decreased likelihood of involvement in consultation and decision making and an increased likelihood of using emergency services (Ministry of Health 2010; Kickbusch et al 2005; Fetter 2009; Zarcadoolas et al 2006; Nutbeam 2008; Edwards et al 2012). Zarcadoolas et al (2006) refer to health policy reports such as Healthy People 2010 which show a strong link between low education, low literacy and poor health, and list the consequences of low health literacy as including financial costs to both individuals and the health system, lack of social empowerment and self efficacy, and an increased risk in emergency situations. More specifically they claim that 'people with low or inadequate health literacy find it difficult, if not impossible, to accurately read instructions for taking medications, understand their health plan restrictions, understand and act on public health warnings, or accurately read evacuation plans and other emergency information' (Zarcadoolas et al 2006, p xv).

Nutbeam (2008) highlights growing evidence of a robust relationship between low literacy levels and a declining use of health information and services. The Institute of Medicine (2004, p 7) highlights studies which show a clear relationship between low health literacy and a number of adverse health behaviours, including 'decreased ability to share in decision making about prostate cancer, lower adherence to anticoagulation therapy, higher likelihood of poorer glycemic control, and lower self-reported health status'. These relationships are reinforced by additional studies which link low literacy to poorer adherence to medication regimes (such as with anticoagulant therapy), decreased ability to identify medications, higher rates of misunderstanding of instructions on prescription drug labels and an increase in medication error rate. In addition, a patient with low health literacy is not likely to access medical care in a timely manner, which in turn can lead to a negative health outcome (Estrada et al 2004; Kripalani et al 2006).

Low health literacy is often referred to as 'a silent killer' or 'a silent epidemic' as it is less diagnosed and treated than more visible medical conditions. Instead of referring to low health literacy, terms such as 'decreased compliance', 'non adherence' or 'DNA - did not attend' have been used to describe a patient's inability to follow a prescribed health process, appointment or regime. These terms may mask an underlying health literacy issue. (Zarcadoolas et al 2006; Institute of Medicine 2004).

Without improvements in the field of health literacy and the growth of a health literate society, advancements in the field of medical science risk being diminished (Institute of Medicine 2004). Similarly, Kickbusch et al (2005) highlight the significance of health literacy in today's society by stating that health literacy is simultaneously an essential life skill, an urgent matter for public health, a critical economic issue and an important part of social capital.

### **c. Who is affected by low health literacy?**

Studies have shown that while low health literacy can occur in a range of populations it is most likely to occur in those comprising the elderly, those with limited education, those with limited income and those with limited language proficiency (Institute of Medicine 2004). Zarcadoolas et al (2006) highlight the fact that education levels are often used as a proxy for literacy levels and refer to the 2003 Canadian report from the International Adult Literacy Survey (IALS) which claims that, while there is a strong correlation between education and literacy levels, this correlation is not exclusive.

New Zealand took part in the 2006 Adult Literacy and Life Skills Survey (ALLS). This survey found that the majority of New Zealand adults do not have the minimum levels of literacy to meet the demands of everyday life and work (Ministry of Health 2010). Data from the health-related items

(linked to health promotion, health protection, disease prevention, health care maintenance and system navigation) in the 2006 ALL survey shows that 'overall the majority of New Zealanders are limited in their ability to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions' (Ministry of Health 2010, p iii). In addition, data from the ALL survey found Māori to have much lower health literacy levels than non Māori, regardless of other demographic factors such as age, gender, income and educational status, and that Māori in the 50-60 and 19-24 years age groups had the lowest levels of health literacy (Ministry of Health 2010).

Although Māori have the worst lowest level of health literacy in New Zealand, it's important not to view this problem as one pertaining solely to the Māori population. In fact Pakeha comprise the largest group with low literacy (Ministry of Education 2008; Ministry of Health 2012). This situation is reflected internationally, including in the United States where a study by Vernon et al (2007) found the majority of adults with low literacy levels to be white, native born Americans, as this group represents the largest section of the overall population.

There are a number of behaviours that may indicate a person has low literacy, but these are just indicators and on their own do not constitute evidence of low health literacy. These indicators are numerous and include: regularly missing medical appointments, ignoring or misunderstanding health instructions or advice, asking a number of or alternatively no questions, arriving with incomplete forms, avoiding filling in forms or taking additional spare copies and making excuses about forgetting their glasses and needing to read the information at home (Weiss 2007).

The challenge of communicating effectively with patients who have low health literacy is highlighted in Rudd et al (1999, p 183), which states that in addition to the fact that 'patients rarely identify themselves as struggling with literacy issues', they also seldom ask for assistance in reading health related materials.

It is also important to distinguish between patients who have ongoing health literacy problems from those who have episodic health literacy problems. Patients who have low health literacy will have ongoing difficulties in making informed health decisions, but most people will at some point in their lives experience an episode of low health literacy. As mentioned earlier, although general literacy skills are the strongest factor in health literacy levels, these skills are not the only factor that affect our 'capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions'. The Institute of Medicine (2004, p 11) illustrates this point well, claiming that 'even highly skilled individuals may find the systems too complicated to understand, especially when these individuals are made more vulnerable by poor health'.

#### **d. Causes of low health literacy**

There is ongoing research into the causes of low health literacy. Fetter (2009) identifies, among other factors, low education levels, poverty, aging, limited English language proficiency, physical, mental and learning disabilities, poor communication, overuse of medical jargon in patient documents and cultural insensitivity.

At the level of each individual patient, factors such as linguistic, cognitive, visual and aural impairment clearly affect health and literacy levels. However the Institute of Medicine (2004) warns against viewing health literacy as a concept that begins and ends with the capacity of an individual and instead argues for it to be viewed as arising from a convergence of socio-cultural factors, health care and education systems and the barriers contained in those systems.

#### **e. Culture and health literacy**

The role of culture in health literacy is widely accepted. Zarcadoolas et al (2006) state that as a component of health literacy, cultural literacy (the ability to understand and use culture and social identity to interpret and act on information) is clearly needed by all stakeholders in order to improve

health care and health outcomes. Kickbusch et al (2005) mirror this sentiment and state that culture (including the culture of the health system), affects attitudes, perceptions and behaviours at both the patient and provider end, or for both those receiving and delivering health services. Apart from their role in shaping individual attitudes, behaviours and interactions, socio-cultural factors are also of great importance when shaping public health campaigns and messages. Kickbusch et al (2005, p18) argue the importance of cultural relevance and claim that 'health messages and solutions must be placed within settings relevant to their target audiences and encompass both a social and health dimension'. Tailoring health messages so that they are culturally and socially relevant is crucial, especially when targeting vulnerable groups. A one-size-fits-all health campaign may be cost effective in the short term, but not in the long-term, as it will rarely reach its target audience (Kickbusch et al 2005; Zarcadoolas et al 2006).

The socio-cultural aspects of health literacy are not just limited to public health campaigns. Culture shapes language, perceptions, beliefs and behaviours, so it follows that culture also shapes perceptions, beliefs and behaviours around health, including health information, messages, treatment, decisions and actions. Culture is constantly changing and evolving so health care encounters are a mix of differing and evolving perceptions, beliefs and behaviours. This point is highlighted by the Institute of Medicine (2004, p 9) which states that 'these culturally influenced perceptions, definitions and barriers can affect how people interact with the health care system and help determine the adequacy of health literacy skills in different settings'. Furthermore, the Institute claims that health literacy is not just shaped by cultural differences between patients and providers but also between those who create the health messages and those who use them.

#### **f. Who is responsible for developing health literacy?**

Since it is now widely accepted that health literacy reaches beyond the capacity of the individual patient and is a product of the convergence of numerous factors, it follows that the responsibility for improving health literacy levels is shared among the various stakeholder groups in health care. These stakeholders include the individual patients, the health practitioner and the wider health system (Rudd et al 2007; Koh et al 2012).

Bryan (2008) asserts that efforts to curb low health literacy in the United States need to take place at local, regional and national levels, and the United States Institute of Medicine (2004) states that health providers have a key responsibility in this area, suggesting that it is their skills and expectations that actually drive health literacy levels. The central role of health practitioners is reinforced by Edwards et al (2012) who state that it is the capacity of health practitioners to empower or disempower patients that can either facilitate or limit health literacy. From a New Zealand perspective, Kōrero Mārama includes a statement that instead of viewing health literacy as an issue for the individual patient, where the onus is on the individual to lift their skills, the solution lies in a concerted effort from all sectors including, schools, government agencies and the health care system (Ministry of Health 2010).

The ethical dimensions of health literacy (for example health disparities), are reflected in New Zealand by Right 5 of the Code of Health and Disability Services Consumers' Rights Regulation 1996, which gives every consumer the right 'to effective communication in a form, language and manner that enables the consumer to understand the information provided' (Knight 2006, p 4). Clear and effective health communication is a patient's right, so addressing poor health literacy is a responsibility for all stakeholders in the health care system.

Health literacy is more than improving access to information, quality of information and information flow between individuals, communities, health practitioners and the health system. More importantly health literacy is 'about the skills and knowledge of individuals, whānau and communities, so that they synthesise the information they receive from both the health system and other sources, decide whether they have enough information and if not gather more, and then act on the information' (Workbase 2011). This concept of empowered self care runs alongside the process and outcome of becoming more health literate.

### **g. Approaches to health literacy**

Nutbeam (2008) investigates two different approaches, which conceptualise health literacy either as a risk that needs to be managed or as an asset that needs to be built on. The risk model, which earlier was prevalent in the United States, sees low literacy skills as a potential risk factor that needs to be managed and minimised. The risk model focuses on getting patients to become compliant with recommended clinical care and therefore is mostly applied in clinical settings. The asset model is closely linked to health education and sees health literacy as an outcome of personal empowerment in decision making. Improved health knowledge, along with the competence to put that new knowledge into action, will enable individuals to gain greater self control over their health and the health decisions they need to make. This in turn will make them more health literate.

There are key differences in the way the two models view health education. In the risk model, health education is more goal-directed and the health practitioners are focused on what can be done to minimise the risk of their patients not understanding the information or advice they give them. Nutbeam (2008, p 2073) explains that according to this perspective 'the effects of poor literacy can be mitigated by improving both the quality of health communications, and a greater sensitivity among health practitioners of the potential impact of low literacy on individuals and in populations'. The risk model requires an assessment of the individual's literacy levels so that the proper interventions can be put in place. In the United States, health literacy assessment tools such as the Rapid Estimate of Adult Literacy in Medicine (REALM) or the Test of Functional Health Literacy in Adults (TOFHLA) are frequently used to assess patients for low health literacy. The validity of these tests has been criticised as they only measure health literacy in terms of reading at the individual word level and do not include other critical skills such as conceptual knowledge, listening, speaking and numeracy, all of which are needed to get a true picture of a patient's health literacy level (Zarcadoolas et al 2006; Institute of Medicine 2004).

The asset model of health literacy draws on principles of adult education and requires educators to draw on the patient's prior knowledge and experience. Starting with what the patient knows about their condition opens the door to increased interaction, participation and critical thinking, all of which are positive for health literacy (Nutbeam 2008). The asset model can be applied outside health care settings, including schools and community development programmes and offers great potential for enabling positive health actions. The asset model, while powerful in theory, has not yet been widely implemented. This could be due to the fact that the asset model is not as well tested through systematic research as the risk model (Nutbeam 2008).

### **h. Barriers and facilitators in health literacy**

This section outlines barriers and facilitators to health literacy. Information on each barrier also includes how that barrier could be overcome (or what facilitator could be used), to achieve greater health literacy.

Difficulty in reading materials and difficulty in communicating with health care providers are two major health literacy barriers that individuals face when they access and use the health care system (Rudd et al 1999). Kickbusch et al (2005, p 9) assert that 'access to good reliable information is the cornerstone of health literacy' yet most health related material is written at a level beyond what most patients can understand (Kickbusch et al 2005; Levandowski et al 2006; Zarcadoolas et al 2006, Rudd et al 1999; Rudd et al 2007). To minimise the risk of patients not understanding what they read, it is now recommended that all written health care material in the United States be graded to the reading age of a 10 year old (Wilson 2009; Zarcadoolas et al 2006). While using plain language in written material is widely recommended, the validity of this readability approach has been questioned as, apart from the fact that adult patients are not 10 year old children, this approach fails to take

account of the important role that sense, logic, familiarity, tone and cohesion play in the comprehension of a text (Ministry of Health 2012; Rudd et al 2007).

Another major barrier to health literacy is an overload of information. There is a vast amount of health information available to patients, from an equally vast number of information sources, which can make finding and understanding the right information difficult (Kickbusch et al 2005; Zarcadoolas et al 2006; Institute of Medicine 2004). Rethinking how information is given to patients, with the most important information being given first and the rest at a later point can really lessen the cognitive load for all patients and act as a facilitator to improve uptake (Rudd et al 1999).

An additional outcome of an increase in information is a decrease in the consistency of the information. These days it is not uncommon for patients to get conflicting information from their information sources including their health care practitioners, the health system, the media and their family and friends. Even though there is not much that can be done about information that is received from sources outside the health system, consistency in health and medication messages is important. This barrier to health literacy is underscored by Eagle et al (2006) who found that consistency of advice between doctors and pharmacists was rated as very important by a sample of patients.

The quality of oral interactions between patients and their health providers is crucial to health literacy. Spoken language is our main form of communication, so patients who have trouble reading may better understand a spoken message. Spoken interactions are also context-rich and rely on more than words to communicate information and meaning, with tone, body language and gestures all playing an important part (Zarcadoolas et al 2006). On the other hand, speech is ephemeral and once the interaction is over there is nothing left except the memory (which may be incomplete) of what was said (Vandergrift 2006). Zarcadoolas et al (2006, p 90) acknowledge the fleeting nature of spoken interactions and for this reason recommend that spoken messages 'contain facilitators such as brevity, narrative structure and repetition'.

Kelly and Haidet (2007) claim that many health care providers overestimate the health literacy levels of their patients. This leads to a lack of tailored communication which in turn leads to information that is beyond the understanding of the patient, with the potential outcome of non-adherence to a treatment plan. Many experts in the health literacy field now claim that the most effective way to improve patient understanding is to support one form of information with another, i.e. reinforcing spoken explanations with written materials or supporting written materials with visuals (Weiss 2007).

Facilitators for health literacy, which health practitioners can use, include:

- using face to face opportunities to give medical advice as much as possible
- using the teach-back method to check patient understanding, which involves the health practitioner taking responsibility for the clarity of the communication by asking the patient to explain or demonstrate what the health professional has said
- reading written materials with patients or supporting the materials with verbal explanations
- supporting oral explanations with pictorial material or visual aids
- using plain language in spoken and written texts and making materials easier to use through a greater consideration of design, font, layout and pictures (Rudd et al 2007; Weiss 2007).

Rudd (2007, p 183) cites recent medical and public health reports which recommend that future studies in the area of health literacy 'continue to include – but move beyond the doctor-patient encounter ... and include investigations into health-related activities at home, in the workplace, in the community, and in a range of health systems and care settings'. In addition, Rudd highlights the importance of attention to the broad range of skills involved in health literacy, including a closer examination of patient information-seeking skills. Other areas which Rudd considers could facilitate better health literacy, and which require closer attention, include:

- considering the importance of patient background, knowledge and experience in health related activities and paying attention to assumptions that information-givers have about these
- considering the value that new technologies can add to the field of health literacy (Rudd et al 2007).

Although good knowledge of a health condition is essential for good health literacy, improved patient knowledge will not always lead to the desired change in behaviour. Kickbusch et al (2005, p 9) state that 'health information alone will not be useful to people who do not feel they have the power to act'. Confidence and self-efficacy to act on the information and to help others is what counts, and this requires additional inputs such as community development and education (Nutbeam 2008; Kickbusch et al 2005; Zarcadoolas et al 2006). The ultimate goal is greater independence and empowerment in individuals and communities to effectively manage their health. For this to happen a greater understanding is needed around the potential of health education to help focus the health dialogue on the social determinants of health as well (Nutbeam 2008).

Sudore and Schillinger (2009) have developed a framework and description for best practice interventions to improve care for patients with low health literacy in the United States. The framework and description are the result of a comprehensive literature review to identify feasible health literacy interventions at the practitioner-patient level, at the system-patient level and at the community patient level. Although designed to address health literacy in the United States, the framework will provide a useful starting point for analysing and developing effective health literacy interventions in New Zealand (Workbase 2011).

Key messages from interventions at the health practitioner-patient level include:

- patient-centred communication, where existing patient knowledge and experiences are built on
- clear health communication, including use of plain language
- confirmation of understanding, including use of the teach-back method
- reinforcement of information, including using multiple modalities and using the patient's support network
- clear numeracy and risk information, including providing absolute risks instead of relative risks
- medication reconciliation, including simplifying regimens as much as possible and confirming regimen dosage.

Key messages from interventions at the system-patient level include:

- health education materials, including incorporating the target audience in the design of the tools
- medication drug labels, including using concrete examples
- disease self-management support systems which need to be proactive and disease-specific
- creating an empowering environment, including making signs and forms easy to read and encouraging the patients to use the Ask-Me-3 strategy
- clinician training, including health literacy education while clinicians are in training.

Key messages from interventions at the community-patient level include:

- referrals to adult literacy classes
- use of lay health educators/navigators
- use of mass media to disseminate health information (Sudore & Schillinger 2009).

## Health Literacy Reference List

- American Medical Association. 1999. Health literacy: Report on the Council on Scientific Affairs. *Journal of the American Medical Association* 281(6): 552-557.
- Baker DW, Parker RM, Williams MV, et al. 1998. Health literacy and the risk of hospital admission. *Journal of General Internal Medicine* 13(12): 791-798.
- Bryan C. 2008. Provider and policy response to reverse the consequences of low health literacy. *Journal of Health care Management* 53(4): 230-41.
- Eagle L, Hawkins J, Styles E, et al. 2006. Breaking through the invisible barrier of low functional literacy: Implications for health communication. *Studies in Communication Sciences: Special Issue on Health Literacy* 5(2): 29-55.
- Edwards M, Wood F, Davies M, et al. 2012. The development of health literacy in patients with a long-term condition: the health literacy pathway model. *BMC Public Health* 12: 130-157.
- Estrada CA, Martin-Hryniewicz M, Peek BT, et al. 2004. Literacy and numeracy skills and anticoagulation control. *American Journal of Medical Sciences* 328(2): 88-93
- Fetter MS. 2009. Promoting Health Literacy with Vulnerable Behavioral Health Clients. *Issues in Mental Health Nursing* 30: 789-802.
- Institute of Medicine. 2004. *Health Literacy: A prescription to end confusion*. Washington, DC: The National Academies press.
- Kelly PA, Haidet P. 2007. Physician overestimation of patient literacy: A potential source of health care disparities. *Patient Education and Counseling* 66(1): 119-122.
- Kerka S. 2000. *Health and Adult Literacy. Practice Application Brief 7*. Education Resources Information Centre.
- Kickbusch I, Wait S, Maag D. 2005. *Navigating Health: The Role of Health Literacy*. Alliance for Health and the Future, International Longevity Centre: UK. URL: <http://www.ilonakickbusch.com/health-literacy/NavigatingHealth.pdf>
- Knight R. 2006. *Literacy is a Health Issue*. Pharmacy Guild of New Zealand Inc. Wellington: Pharmacy Guild of New Zealand Inc. URL: <http://www.pgnz.org.nz/assets/Uploads/Literacy-is-a-Health-Issue.pdf>
- Koh HK, Berwick DM, Clancy CM, et al. 2012. New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. *Health Affairs* 31(2): 434-443.
- Kripalani S, Henderson LE, Chiu EY, et al. 2006. Predictors of medication self-management skill in a low literacy population. *Journal of General Internal Medicine* 21(8): 852-856.
- Levandowski BA, Sharma P, Lane SD, et al. 2006. Parental Literacy and Infant Health: An Evidence-Based Healthy Start Intervention. *Health Promotion Practice* 7: 95-102.
- Ministry of Education. 2008. *The Adult Literacy and Life Skills (ALLS) Survey: Overview and International Comparisons*. Wellington: Ministry of Education.
- Ministry of Health. 2010. *Kōrero Mārama: Health Literacy and Māori*. Wellington: Ministry of Health.
- Ministry of Health. 2012. *Rauemi Atawhai: A guide to developing health education resources in Aotearoa*. Wellington: Ministry of Health.
- Nutbeam D. 2008. The evolving concept of health literacy. *Social Science & Medicine* 67: 2072-2078.
- Pignone M, Dewalt D, Sheridan S, et al. 2005. Interventions to improve health outcomes for patients with low literacy. *Journal of General Internal Medicine* 20(2): 185-192.

- Rudd RE, Moeykens BA, Colton T. 1999. Health and Literacy: A review of the medical and public health literature. In Comings JP, Smith C, Garner B (eds). *Annual Review of Adult Learning and Literacy*. San Francisco CA: Josey-Bass.
- Rudd RE, Anderson JE, Oppenheimer S, et al. 2007. Health Literacy: An Update of Public Health and Medical Literature. In Comings JP, Garner B, Smith C (eds). *Review of Adult Learning and Literacy, volume 7*. Mahway NJ: Lawrence Erlbaum Associates.
- Speros C. 2005. Health literacy: concept analysis. *Journal of Advanced Nursing* 50(6): 633-640.
- Sudore RL, Schillinger D. 2009. Interventions to Improve Care for patients with Limited Health Literacy. *Journal of Clinical Outcomes Management* 16(1): 20-29
- United States Department of Health and Human Services. (2000). *Healthy people 2010: Understanding and improving health (2<sup>nd</sup> ed)*. Washington, DC: U.S. Government Printing Offices.
- Vandergrift L. 2006. Second Language Listening: Listening ability or language proficiency? *Modern Language Journal* 90 (1): 6-18.
- Vernon JA, Trujillo A, Rosenbaum S, et al. 2007. *Low Health Literacy: Implications for National Health Policy*. University of Connecticut. URL: [http://www.gwumc.edu/sphhs/departments/healthpolicy/dhp\\_publications/pub\\_uploads/dhpPublication\\_3AC9A1C2-5056-9D20-3D4BC6786DD46B1B.pdf](http://www.gwumc.edu/sphhs/departments/healthpolicy/dhp_publications/pub_uploads/dhpPublication_3AC9A1C2-5056-9D20-3D4BC6786DD46B1B.pdf)
- Weiss BD. 2007. *Removing barriers to better safer care. Health literacy and patient safety: Help patients understand. Manual for clinicians. 2nd edition*. Chicago. American Medical Association.
- Wilson M. 2009. Readability and patient education materials used for low-income populations. *Clinical Nurse Specialist* 23(1): 33-44.
- Workbase. 2011. Proposal for Māori Health Research focused on gestational diabetes mellitus. Unpublished tender document. Auckland, New Zealand
- Zarcadoolas C, Pleasant AF, Greer DF. 2006. *Advancing Health Literacy: A Framework for Understanding and Action*. San Fransisco, CA: Jossey-Bass.

## Appendix 3. Health Literacy Demands

### Health literacy knowledge and skills for person at risk of gout (whānau history and/or high uric acid levels but no diagnosis of gout)

#### Knowledge

- Understand the genetic aspects of gout, particularly for Māori and Pacific peoples.
- Understand risks of getting gout because of whānau history.
- Understand that high uric acid levels cause gout - normal uric acid level is 0.36mmol/L.
- Understand that certain foods contain purines that increase uric acid levels.
- Understand that certain drinks, especially beer, orange juice and fizzy drinks, can increase uric acid levels.
- Understand gout can be prevented/delayed by exercising and keeping to a good weight, avoiding foods that increase uric acid levels and eating foods and drinks that do not increase uric acid levels.
- Understand the need for regular checks of uric acid.
- Understand the health benefits of preventing gout.
- Understand that these prevention activities will also assist with preventing other long-term conditions e.g. diabetes.

#### Skills

- Read prevention booklet.
- Read other information either printed or online about gout.
- Ask questions of health practitioners and others in relation to activities to prevent gout.
- Speak to other whānau about what they are doing to prevent gout.
- Speak to other whānau about the genetic aspects of gout.
- Encourage whānau with gout to get treatment for their gout.
- Support whānau with gout to keep taking their uric acid medicines.
- Use numeracy skills to understand how far uric acid levels are from target.
- Read food labels to distinguish which foods to eat and drink.
- Understand the probable risk of getting gout depending on how many risk factors you have – Māori, whānau history and hyperuricaemia.
- Use critical reading and listening skills to synthesise information about the prevention of gout and reject incorrect information.
- Discuss evidence about the prevention of gout with health practitioners and whānau.

The second profile builds on the first profile but there is a significant shift in knowledge needed once a person with gout starts on ULT.

## **Health literacy (knowledge and skills) for person with diagnosis of gout**

### **Knowledge**

First gout attack:

- Understand the genetic aspects of gout, particularly for Māori and Pacific peoples.
- Understand that uric acid crystals in your blood cause gout attacks because you have high uric acid levels – normal uric acid level is 0.36mmol/L.
- Understand that certain foods contain purines that increase uric acid levels.
- Understand that certain drinks, especially beer, orange juice and fizzy drinks, can increase uric acid levels.
- Understand how to treat their gout attack - rest, ice packs, elevate sore joint - until pain is gone.
- Understand the different names for gout attack medicines.
- Understand that only one gout attack medicine should be taken at any one time.
- Understand how gout attack medicines work.
- Understand how to take gout attack medicines.
- Understand side effects of gout attack medicines and what to do if you get side effects.
- Understand that gout attack medicines cannot be taken long-term.
- Understand not to do strenuous exercise while having a gout attack.
- Understand that if they get another gout attack within 12 months, they will have to go on long-term uric acid medicine.
- Understand what actions they can take themselves to prevent gout attacks. Needing to go onto urate lowering therapy (uric acid medicine).
- Understand how uric acid medicines work.
- Understand how to take uric acid medicines – every day, long-term.
- Understand that initial dose will be low and may have to be increased to achieve uric acid level target of 0.36mmol/L.
- Understand side effects of gout attack medicines and what to do if you get side effects.
- Understand that uric acid medicines can cause a gout attack and so also need to take gout attack medicines at the same time.
- Understand not to stop taking uric acid medicine even if you have gout attack.
- Understand how to take gout attack medicines at the same time as uric acid medicines and for how long.
- Understand need for regular appointment and blood tests in the short term until on proper dose of uric acid medicines.
- Understand need to pick up regular repeat prescriptions.
- Understand when you need to come back to get uric acid levels checked in case dose of uric acid medicine needs to be increased again.
- Understand that gout is the only preventable form of arthritis.

### **Skills**

- Read gout booklet and other resources (online, hard copy).
- Speak to other whānau about gout attacks and gout attack medicine.
- Speak to other whānau about uric acid medicines.
- Ask questions of health practitioners and pharmacists in relation to medicines
- Read food labels to distinguish which foods to eat and drink.
- Read medicine labels to follow instructions.
- Use numeracy skills when taking medicine – number, dose and so on.
- Use numeracy skills to understand the need to increase dose of uric acid medicines to achieve target uric acid level
- Use numeracy skills to understand how uric acid levels are decreasing (or not) and actions required.
- Read lab form to go and get blood tests.
- Make a follow up appointment.

- Speak to other whānau about what they are doing to prevent and manage gout.
- Speak to other whānau about the genetic aspects of gout.
- Encourage whānau with gout to get treatment for their gout.
- Support whānau with gout to keep taking their uric acid medicines.
- Read food labels to distinguish which foods to eat and drink.
- Use critical reading and listening skills to synthesise information about treatment and management of gout and reject incorrect information.
- Discuss evidence about the management of gout with health practitioners and whānau.

## Appendix 4. Interviews With People With Gout, Whānau and Community Members

Dr Richard Cooper, who facilitates a number of community groups in Counties Manukau DHB, invited the researchers to talk to members of a group he works with who are training for Iron Māori competitions. Twenty-seven people participated in a group interview. Twenty of these people also volunteered to have their uric acid levels checked,<sup>2</sup> and age, gender and ethnicity data was also collected from them (see Table 2).

Table 2. Iron Māori Group, Maataatua Marae, Mangare, Auckland (N-20)

Gender	Age Range	Ethnicity	Diagnosis of gout	Family history	If gout, taking NSAIDs	If gout, on ULT	High uric acid level (> 0.36 mmol/L)
Female	20-29	Māori/ Samoan		Yes			No
Female	20-29	Māori/Cook Island/Other					Yes
Female	20-29	Samoan					Yes
Male	20-29	Cook Island					
Male	30-39	Māori		Yes			No
Male	30-39	Māori/Cook Island	Yes	Yes		Yes	Yes
Male	30-39	Samoan/ Cook Island					
Female	40-49	Cook Island					Yes
Female	40-49	Māori		Yes			No
Female	40-49	Samoan		Yes			Yes
Male	40-49	Māori/ Cook Island					
Female	50-59	Māori		Yes			No
Female	50-59	Māori		Yes			No
Female	50-59	Māori		Yes			No
Female	50-59	Māori		Yes			Yes
Male	50-59	Māori		Yes			No
Male	50-59	Māori		Yes			No
Male	50-59	Māori	Yes	Yes	Yes	Yes	No
Male	50-59	Māori		Yes			No
Female	60-69	Māori	Yes	Yes	No	Yes	No

Of the 20 people who had their uric acid levels checked, 17 were Māori and three were Pacific. Nine people (45 percent) were over 50 years of age. Two people were taking ULT and had uric acid levels under the treatment target 0.36mmol/L. The one person who was significantly overweight (a risk factor for gout) had a diagnosis of gout and was on ULT.

<sup>2</sup> This was done using a Reflotron machine lent to us by Roche Diagnostics for the length of the project.

Of the 20 people who had their uric acid levels checked, six (30 percent) had levels above the target 0.36mmol/L. Five were women (two of them in their 20s). One of the six people had gout, had been on ULT for two years but now chose to manage their gout through diet only. The other five, who were asymptomatic, were focused on exercise and diet, not to specifically prevent gout, but from the desire for a healthy lifestyle, which was assisting them in preventing the onset of gout.

All people who had their uric acid levels checked were given a card recording their uric acid level at the date of testing. The card recorded the result of the test, the date it was taken, the name and qualifications of the person taking the test, as well as information for the person's GP about the Gout Clinical Pathway and additional resources. Those participants who were tested and had hyperuricaemia were encouraged to take the cards with them to their GP and to have a conversation about preventing and/or managing gout.

This card has now been adapted by Arthritis New Zealand and is being used by all their educators in all their community testing. People who are tested and have high uric acid levels are encouraged to take the card back to their GP to discuss their uric acid levels. (A copy of the card is in Appendix 9.)

The group (which is training for Iron Māori) had a good knowledge of many factors that are detrimental and beneficial for gout (e.g. types of food, drinks, need to exercise and to keep a healthy weight). However 17 (63 percent) of the group thought that all fizzy drinks, including diet fizzy drinks, were bad for gout. None of the group was aware of the genetic link to gout for Māori and Pacific people.

## Appendix 5. Resource Trialling With People With Gout, Whānau and Community Members

### Douglas Manufacturing Limited, West Auckland: 15 August 2012

Workbase has a workplace literacy programme at this company and were aware, from discussions our tutor has had with the company's operational and HR management, that gout impacted on employees' attendance.

We provided a group education session for six staff from all areas of the business (management and distribution). Uric acid testing was offered to the group on site and everyone took up this offer.

Table 3. Douglas Manufacturing Ltd, Henderson, Auckland (N=6)

Gender	Age Range	Ethnicity	Diagnosis of gout	Family history	If gout, taking NSAIDs	If gout, on ULT	High uric acid level (> 0.36 mmol/L)
Male	30-39	Māori	Unsure	Yes	No	No	Yes
Male	30-39	Pakeha	No	No	No		Yes
Male	40-49	Māori	Yes	Yes	Yes	Yes	No
Female	40-49	Indian					No
Male	50-59	Middle East	Yes	Yes		Yes	No
Female	50-59	Pakeha		Yes			No

Two of the staff (one of whom was Māori) were on ULT. Both had uric acid levels under the target of 0.36mmol/L.

One staff member attended on behalf of her husband because he had gout. He was using ULT to treat acute attacks. Another staff member, who had hyperuricaemia but no diagnosis of gout, managed health and safety in part of the company.

Again, all people in this group made strong links between food, drink and gout. The staff member who had hyperuricaemia attributed it to drinking too much beer (he was also significantly overweight). Only one person (non-Māori who was taking ULT) had an in-depth understanding of gout medicines. None of the group were specifically aware of the genetic links to gout for Māori and Pacific peoples although four of the group had a whānau history of gout.

None of this group had visible tophi or reported having tophi.

### CHH Kinleith Mill, Tokoroa: 21 August 2012

Workbase has had a long relationship with the HR Manager at CHH Paper through Workbase's previous longstanding workplace literacy programme at Norske Skog Tasman in Kawerau. We were aware that gout was an issue at Kinleith and approached the company to be involved in the Demonstration phase.

We held a group session with 13 men and one of the health and safety nurses at the Mill. All of the men had their uric acid levels checked.

Table 4. Kinleith, Tokoroa (N=13)

Gender	Age Range	Ethnicity	Diagnosis of gout	Family history	If gout, taking NSAIDs	If gout, on ULT	High uric acid level (> 0.36 mmol/L)
Male	30-39	Māori	Yes	Yes	Yes	No	Yes
Male	40-49	Indian	Yes		No	Yes	No
Male	40-49	Pakeha	Yes		Yes	No	Yes
Male	40-49	Kenyan	Yes		Yes	No	Yes
Male	50-59	Pakeha	Yes		Yes	No	Yes
Male	50-59	Māori		Yes		No	Yes
Male	50-59	Pakeha	Yes		No	No	No
Male	50-59	Māori	Yes	Yes	Yes	No	Yes
Male	50-59	Pakeha	Yes	Yes	No	Yes	No
Male	50-59	Māori	Yes	Yes	Yes	No	Yes
Male	50-59	Māori	Yes	Yes	Yes	No	Yes
Male	50-59	Māori	Yes	Yes	Yes	No	Yes
Male	70-79	Māori	Yes	Yes	No	Yes	Yes

None of the men were overweight. Three of the men were on ULT. One had been prescribed ULT very recently by his Auckland based GP following the employee's first gout attack. This employee lives in Auckland but travels to Tokoroa frequently.

One of the other two men on ULT, had been on ULT for some time. He decided to stop taking ULT because he hadn't had a gout attack for some time (he knew he wasn't meant to stop). Within a short period of time he experienced a significant acute gout attack and was now back on ULT and aware that he needed to take it for life. The third man, who was Māori, was on Probenecid and was aware he had to take it every day (although he also thought his Probenecid was increasing his sex drive). He had a number of other comorbidities and was accustomed to taking medicines on a regular basis.

Two other men had previously been on ULT. One had decided to stop taking it after accidentally putting his ULT medicine in his checked luggage on a long international trip. Because he didn't get a gout attack he had decided to stop taking ULT.

The second man, who was no longer taking ULT, was taken off the medicine by his GP following a short period of a localised rash. This employee had not suffered a rash when commencing ULT and in hindsight realised that his rash was probably attributable to working long hours in hot difficult conditions during a planned maintenance shutdown. This employee remarked that when his GP advised him to stop taking ULT, his GP had mentioned that the ULT was 'toxic'.

Another Māori man (not on ULT), who had had a number of gout attacks and was also on medicine for diabetes, reported that his GP was going to give him a prednisone injection for his next gout attack despite this being clinically contra indicated. We referred this patient to the relevant page of the PHARMAC booklet *Out with Gout* so he could show this page to his GP.

None of this group had visible tophi or reported having tophi.

### **Korowai Aroha Health Centre, Rotorua: 21 August 2012**

We travelled to Rotorua after our visit to Tokoroa to meet with gout patients at a Māori health provider. A nurse from the provider also attended the education session.

Five people attended – three who were on ULT and two women who had strong whānau histories of gout. All of this group were taking medicines for other comorbidities, mainly diabetes.

Table 5. Korowai Aroha Health Centre, Rotorua (N=5)

Gender	Age Range	Ethnicity	Diagnosis of gout	Family history	If gout, taking NSAIDs	If gout, on ULT	High uric acid level (> 0.36 mmol/L)
Male	30-39	Māori	Yes	Yes		Yes	Not tested*
Female	60-69	Māori	Yes	Yes		Yes	No
Female	60-69	Māori	No	Yes		No	Not tested*
Female	60-69	Māori	No	Yes		No	Not tested*
Male	60-69	Māori	Yes	Yes		Yes	No

**Note.** \* Unfortunately the Reflotron machine we used to measure uric acid levels broke down and we were only able to check the uric acid levels of two of the group.

None of this group had visible tophi or reported having tophi. One of the group who did have gout and was on ULT was significantly overweight (a risk factor for gout).

The two people whose uric acid levels were checked were on ULT and were under the treatment target of 0.36mmol/L. The other person taking ULT reported that he was taking his ULT as prescribed.

### **Rheem Industries, Avondale, Auckland: 29 August 2012**

Rheem is another company where Workbase provides a workplace literacy and numeracy programme.

Once again our tutor had made us aware that a number of employees had issues with gout and the HR Advisor was very keen for us to come and provide education sessions for employees who had gout or who had whānau members with gout.

Table 6. Rheem, Avondale, Auckland (N=14)

Gender	Age Range	Ethnicity	Diagnosis of gout	Family history	If gout, taking NSAIDs	If gout, on ULT	High uric acid level (> 0.36 mmol/L)
Female	30-39	Māori	No	Partner	No	No	No
Male	30-39	Cook Island	No	Yes		No	Yes
Female	40-49	Tongan	Unsure	Yes		No	No
Female	40-49	Samoan	No	Partner		No	No
Male	40-49	Niuean	Yes	Yes		No	No
Male	40-49	Cook Island	Yes	Yes	Yes	No	Yes
Male	40-49	Tongan	Yes		Yes	Yes	No
Male	40-49	Samoan	No	No		No	No
Male	50-59	Samoan	No	Yes		No	Yes
Male	50-59	Tokelau	Yes	Yes	Yes	No	No
Male	50-59	Samoan	Yes	No	Yes	Prescribed but not taking	Yes
Male	50-59	Samoan	Yes	No	Yes	No	Yes
Male	60-69	Cook Island	Yes	Yes		No	Yes
Male	60-69	Samoan	Yes	Yes	Yes	No	Yes

The education sessions of an hour each were provided to three small groups of employees. All employees had their uric acid levels checked. 11 men and three women employees attended the sessions. The women attended because they had whānau histories of gout or their partners had gout.

None of this group had visible tophi or reported having tophi. None of the group was overweight.

Two men in this group were currently prescribed ULT. One man was taking his ULT as prescribed. In the past year he had had a stroke and the medicines he had been prescribed to prevent him having further strokes had in fact caused him to have acute gout for the first time in his life. Because he was taking a number of other medicines to prevent strokes he did not find it difficult to add the ULT to his medicine taking regime. However he was not aware of what the medicine was treating (other than gout) or how the medicine worked.

The other man who had been prescribed ULT was not taking it because he did not understand what the ULT was for, how to take it and how to combine it with the Diclofenac he was also prescribed to manage his acute attacks.

This man, who was Samoan and had been in New Zealand for over 20 years, did not speak or read English very well. In March 2012 he had an acute gout attack and went to his local GP practice (a Pacific practice) where he was prescribed both Diclofenac and ULT. His GP, who obviously anticipated that the patient might not return for a follow up appointment, also gave him a prescription for ULT. Written on the label for the ULT was 'Start once 100% pain free. Take one at night.'

The man did not understand the instructions and in fact did not take either the Diclofenac or the ULT prescribed. When he got the prescription filled, the pharmacist did not check to see if the man understood how to take his medicines.

In May he returned to the practice because he was having ongoing acute gout attacks and was again prescribed Diclofenac and ULT. The same instructions were repeated on the ULT prescription. Again, neither his GP nor the pharmacist checked whether he understood the instructions or the complex medication regime he needed to start. Because he did not understand any of the instructions he did not start any of the medicines he was prescribed. On the day we met him his uric acid levels were 0.42mmol because he had recently had an acute gout attack. With his consent, our clinical nurse rang his GP practice and we arranged for the man to attend an Arthritis New Zealand clinic run by George Vea at the GP practice.

This man had also received a written warning from his employer because of the amount of time he has having off due to this acute gout. With the man's consent, we were able to explain to the HR Advisor that he had sought treatment on two occasions and had not had the cause of his gout nor the actions he should take, including medicines, explained to him in a way that he understood. As a result the HR Advisor was going to speak to the man's immediate supervisor and explain the situation. The employee was also going to be offered a place on the literacy programme to assist him to develop his English language skills. The HR Advisor was also talking with company management about contracting a local GP practice to be the company doctor so they could provide consistent information for employees who were experiencing health issues.

Our clinical nurse (with the permission of the patients concerned) contacted practice nurses at the employees' GP practices to encourage the nurses to recall patients for further checks for gout and other non-related health issues.

## Appendix 6. Trialling of Resources with Health Practitioners

The Demonstration activities for the health workforce (which included CME sessions and presentations and seminars) trialled approaches to providing current clinical messages and resources for health professionals about gout. The activities sought ways to constructively engage with health professionals, providing information that they may not have, about the Gout Clinical Pathway and resources, in order to get feedback as well as encourage them to review their current practice.

### a. Tokoroa CME session with health care professionals: 21 August 2012

The CME session was held at the practice of Tokoroa Primary Care for one hour. The session was attended by more than 30 people including GPs, practice nurses, pharmacists and a physiotherapist. Seventeen people requested a copy of the final report from this project.

Dr Peter Jones, a rheumatologist from Waikato DHB, who provides outpatient clinics at Tokoroa Hospital, gave a presentation focusing on the Gout Clinical Pathway. Participants also received hard copies of the pathway and copies of the resources we had used with employees at Kinleith. Leanne Te Karu gave a short presentation about the inequalities in relation to the high incidence of prescribing NSAIDs for gout, particularly for Māori, and the low incidence of prescribing ULT for gout, again particularly for Māori.

None of the health professionals were aware of the Gout Clinical Pathway. The health professionals asked questions of Dr Peter Jones about treatment for individuals in their care. Two pharmacists who were unable to attend the CME session were visited and provided with the Gout Clinical Pathway and the infographics.

We sought feedback from people who had attended the CME session. Feedback included:

- 'I use the Pathway to give advice to patients with gout (Practice Nurse)'
- 'GP is using the Pathway now (Practice Nurse)'
- 'I remember the key message to reduce uric acid is to take Allopurinol rather than focus on food and drink (Practice Nurse)'
- 'Now talking to patients with gout about long-term management and pushing them to start Allopurinol (Practice Nurse)'
- 'I found the session useful and have been referring to the Pathway and more importantly talking to patients about treatment with Allopurinol (GP)'
- 'It has highlighted the fact that we also need to be more pro-active with slightly elevated urate levels whilst the patient is still asymptomatic (Practice Nurse)'
- 'The resources we were given at the session have also been very handy (Practice Nurse)'.

### b. Presentations

The following presentations were provided:

- GRAND (Gastroenterology, Rheumatology and Dermatology) Rounds presentation at Hutt Valley DHB: 24 July 2012
- New Zealand Hospital Pharmacists' Association: 1 September 2012
- GRAND Nurses Conference: 22 September 2012
- Royal New Zealand College of General Practitioners Conference: 22 September 2012.

### c. CME Seminar with Rheumatology Clinical Nurse Leaders: 23 September 2012

This seminar with 25 clinical nurse leaders enabled us to get feedback on the resources developed for this project (*To Stop Gout* resource and prevention leaflet in Appendices 10 and 11 respectively).

#### **d. Interview with GP practising in South Auckland**

This GP has a practice in South Auckland with a large Pacific (60 percent) and Māori (24 percent) client base.

This GP identified that his practice is one of a few that uses Counties Manukau DHB's Chronic Care Management Programme (CCMP) which provides the practice with benefits over and above the Care Plus programme. The benefits, along with funding, include recall and review processes with reports which help monitor progress in treating long-term conditions and provide information about how the practice can improve.

This GP uses practice nurses to provide education for patients because the nurses were able to spend more time with the patient (and their whānau) who often had a range of comorbidities as well as gout.

The GP identified the benefits of hands-on assistance and support from Dr Peter Gow, Counties Manukau DHB rheumatologist, and Arthritis New Zealand educator George Veal, in ways which maintained the mana of the GP. Patients (and their whānau) benefitted because they didn't have to travel to clinics and also learnt more about gout. The practice team benefitted because they learnt more about gout and how to manage it, as well as how to seek help from secondary services, which meant issues were resolved more quickly and patients got prompt access to secondary services if required.

This GP was the only health professional interviewed for this research project who identified that his first question in a consultation is to ask patients (and their whānau) what they know about gout and what causes it. In health literacy terms, this GP is activating his patients' schema and is then able to reinforce existing knowledge and link new knowledge to what the patient already knows. Understanding the patient's schema also enables this GP to address the common beliefs about gout in relation to food and drink being the main cause; that gout is the acute attack (rather than a chronic condition); and that there is no long-term treatment apart from NSAIDs.

#### **e. Hutt Valley DHB Tane Ora projects in Wainuiomata and Naenae focused on gout**

We liaised with the Hutt Valley DHB Tane Ora facilitator Harley Matthews who provided us with information from these two workshops. The Tane Ora workshops about gout were held on 21 and 22 August 2012 supported by Arthritis New Zealand, two Hutt Valley DHB rheumatologists and community organisations. A total of 42 tane (men) with gout and/or their whānau attended both workshops.

Tane at both workshops identified the four top causes of gout as being food, fizzy drinks, alcohol and medications (taken to manage existing comorbidities).

Tane (particularly those at the Naenae workshop) were aware that gout was associated with genes and arthritis; that gout was a risk factor for heart disease; and that you needed to take medicine (Allopurinol) for life. Key factors in managing gout were food management and taking long-term medicines.

Even though these tane were aware of the need to take long-term medication, they still held entrenched beliefs about the causes of gout which mirror the findings in this research project. Knowing the need to take long-term medicine can produce useful behaviour (adherence) but with little understanding of why a medicine is helping, or how gout (rather than acute attacks) affects the body means that the adherence may be unconscious rather than conscious.

As a result of these workshops, and the fact that more of the tane had cardiovascular disease (CVD) than gout, the Tane Ora project has been refocused from gout to CVD and related conditions. Stand alone dietary/food management workshops are to be provided.

These workshops also showed that the number of tane diagnosed with gout and then prescribed ULT (properly titrated) is low. In view of this it seems a missed opportunity that the focus of the Tane Ora project shifted so quickly to CVD rather than continue to ensure that tane get correct messages about gout and receive appropriate treatment. Dietary management workshops, while helpful, will also reinforce the beliefs about food and drink being the primary causes of gout.

## **Appendix 7. List of Those Involved in Resource Development**

The following people have been directly involved in the development of the resource, provided feedback and endorsed it:

Dr Karen Lindsay, rheumatologist

Dr Natalia Valentino, Research Manager, Arthritis New Zealand

Leanne Te Karu, prescribing pharmacist with a large practice of gout patients

Dr Peter Gow, rheumatologist

Dr Nicola Dalbeth, rheumatologist

Dr Peter Jones, rheumatologist

Dr Doone Winnard, Public Health specialist

Dr Tony Merriman, gout researcher

Dr Gary Reynolds, GP

Dr Bruce Arroll, GP and Associate Professor, General Practice, University of Auckland

Donna Snell, primary care practice nurse

Gabrielle Sexton, gout research nurse

Caran Barratt-Boyes, Maaori Gout Action Group

Georgina Greville, George Veal, Jane Messer and Amelia Peihopa, Arthritis New Zealand educators.

Jennie Harre-Hindmarsh, research co-ordinator, Ngati Porou Hauora

Shirley Green, long-term conditions nurse, Ngati Porou Hauora

Te Miringa Huriwai, practice nurse, Ngati Porou Hauora

This same group of people also assisted with the development of, or gave feedback about and/or endorsed, the prevention leaflet.

## Appendix 8. 1-12 Stages of Gout

### Stages of gout for people at risk of, or with, gout and their whānau

1	2	3	4	5	6
<p>Whānau history of gout and your uric acid levels are normal</p>	<p>Whānau history of gout and/or high uric acid levels but no diagnosis of gout</p>	<p>Has had first gout attack: no family history of gout</p>	<p>First gout attack: family history of gout and/or high uric acid levels</p>	<p>Having a gout attack maybe once every two years</p>	<p>Managing gout attacks using pain medicine only</p>
<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Get pain medicine from your GP or pharmacist.</li> <li>• Go to your GP two weeks after the attack to check your uric acid levels.</li> <li>• Talk to your GP about why you have gout.</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Get pain medicine from your GP or pharmacist.</li> <li>• Go to your GP two weeks after the attack to check your uric acid levels.</li> <li>• Talk to your GP about when you should start taking uric acid medicine because you have a family history and/or high uric acid levels.</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Get your GP to check your uric acid levels.</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Get your uric acid levels checked.</li> <li>• Talk to your GP or nurse about how gout is affecting your life, work and your health, especially long term damage to your joints.</li> <li>• Talk to your GP about taking uric acid medicine to get rid of gout.</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>



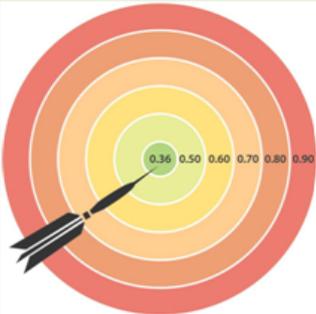
## Stages of gout for people at risk of, or with, gout and their whānau

7	8	9	10	11	12
Has had two or more gout attacks within one year	Had to stop taking uric acid medicine because of side effects e.g. skin rash	Having gout attacks but not taking uric acid medicine because it made your gout worse	Taking uric acid medicine every day but still having gout attacks	Taking uric acid medicine every day and your uric acid levels are still above 0.36 mmol/L but you are not getting gout attacks	Taking uric acid medicine every day and your uric acid levels are below 0.36 mmol/L (below 0.30 mmol/L if you have tophi)
<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Get your GP to check your uric acid levels.</li> <li>• Your GP will give you uric acid medicine to take every day. Keep taking the medicine even if you have a gout attack.</li> <li>• Go back to your GP regularly to get your uric acid levels checked. Your GP might have to increase your dose of uric acid medicine.</li> <li>• Make sure you get a new prescription before your pills run out.</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Get your GP to talk to a rheumatologist or specialist nurse about other uric acid medicine you can take.</li> <li>• Take your new uric acid medicine every day even if you have a gout attack.</li> <li>• Make sure you get a new prescription before your pills run out</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Get your GP to check your uric acid levels.</li> <li>• Talk to your GP or nurse about how gout is affecting your life, work and your health, especially long term damage to your joints.</li> <li>• Talk to your GP or nurse about your options - start uric acid medicine again as well as pain medicine in case you get another gout attack.</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Keep taking your uric acid medicine every day, even if you have a gout attack.</li> <li>• Get your GP to check your uric acid levels.</li> <li>• Talk to your GP about increasing your dose of uric acid medicine.</li> <li>• Talk to your GP about taking pain medicine when you start your increased dose of uric acid medicine.</li> <li>• If you get another gout attack, keep taking your uric acid medicine and your pain medicine and go back to your GP.</li> <li>• Ask your GP to talk to a specialist at your local hospital about your gout.</li> <li>• Eat healthy food (not too much meat or seafood).</li> <li>• Be active.</li> <li>• Exercise.</li> <li>• Try to lose weight if you need to.</li> <li>• Drink water and other fluids (not sugary or fizzy drinks, orange juice or beer).</li> <li>• If you get gout in your foot or toe, make sure your shoes have a wide toe, deep heel to fit your foot, cushioned insole, velcro or laces and a firm sole that isn't worn.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Keep taking your uric acid medicine every day.</li> <li>• Make sure you get a new prescription before your pills run out.</li> <li>• Get your GP to check your uric acid levels once a year.</li> <li>• Talk to your GP about increasing your dose of uric acid medicine.</li> <li>• You can now start eating <b>small</b> amounts of seafood and meat.</li> <li>• You can now drink a <b>small</b> amount of beer.</li> <li>• Keep eating a healthy diet.</li> <li>• Drink water and other drinks e.g. low fat milk (not sugary or fizzy drinks or orange juice).</li> <li>• Do some exercise.</li> <li>• Enjoy life with your whānau.</li> </ul>	<p>Things to do:</p> <ul style="list-style-type: none"> <li>• Keep taking your uric acid medicine every day.</li> <li>• Make sure you get a new prescription before your pills run out.</li> <li>• Get your GP to check your uric acid levels once a year. If your levels are low, ask your GP if you can reduce your dose of uric acid medicine.</li> <li>• You are now eating <b>small</b> amounts of seafood and meat.</li> <li>• You are now drinking a <b>small</b> amount of beer.</li> <li>• Keep eating a healthy diet.</li> <li>• Keep drinking water and other drinks e.g. low fat milk (not sugary or fizzy drinks or orange juice).</li> <li>• Do some exercise.</li> <li>• Enjoy life with your whānau. Congratulations, you are now in control of your gout.</li> </ul>

## Appendix 9. Uric Acid Card

Front of card:

Your uric acid was checked on \_\_\_\_\_ 2012.



**Talk to your GP about your uric acid level.**

Your uric acid level was checked by Christine Lynch, RN, RM, CTT, BHS<sub>c</sub>, MN Nursing (Hons), Primary Healthcare Specialist as part of a research project about the prevention, early diagnosis and management of gout.

Lead investigator: Susan Reid  
Email: sreid@workbase.org.nz  
Ethics approval no: MEC/12/EXP/038



Back of card:

As part of a research project my blood was tested and I have been told my uric acid level is high.

Please talk to me about starting allopurinol together with colchicine to bring my uric acid level down to stop gout.

Do I need to have a heart and diabetes check?

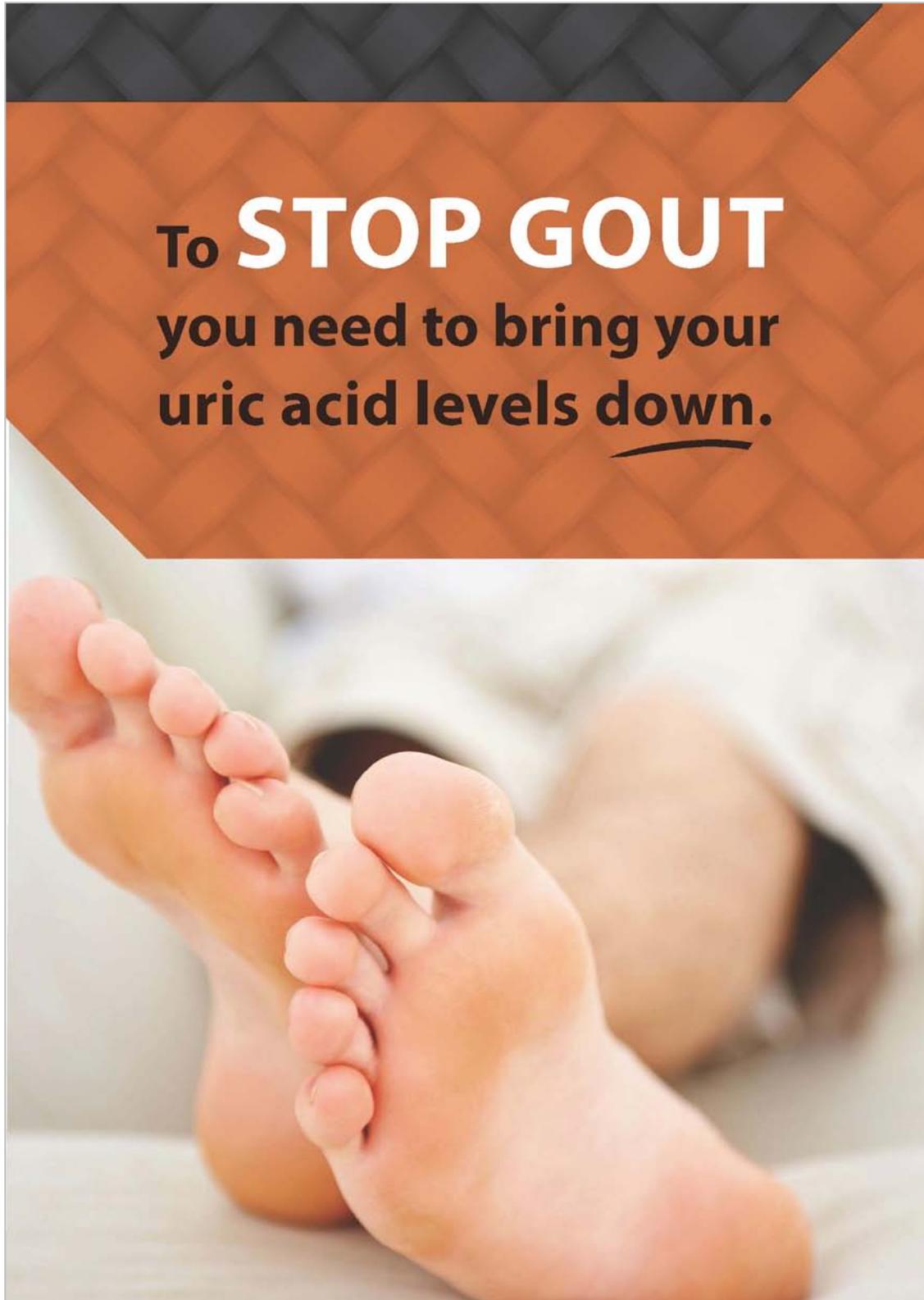
New Gout Clinical Pathway  
Acute gout:  
<http://www.healthpointpathways.co.nz/acute-gout>

Gout prevention:  
<http://www.healthpointpathways.co.nz/gout-prevention>

More information about gout on Health Navigator:  
<http://www.healthnavigator.org.nz/health-topics/gout/>

## Appendix 10. Booklet - To Stop Gout

(This is printed as an A5 stapled booklet)



## Why do I get gout?

You might think that gout is caused by drinking too much beer and fizzy drinks and eating too much meat and shellfish. In fact, gout is caused by having too much of a chemical called uric acid in your blood.

Your body makes uric acid when you eat food. It is normal and healthy to have some uric acid in your body. Most people get rid of uric acid through their urine.

However, if you eat food, such as meat, seafood, beer, fizzy drinks and orange juice, your body can make too much uric acid.

## How does gout affect you?

Gout can be a sign you could get diabetes, heart disease and kidney problems.

Gout can be very painful and can stop you doing all the things you enjoy. Gout can stop you playing sport and spending time with your family or whānau.

Gout can stop you feeling good about yourself and your life.

# What causes your gout attacks?

If there is too much uric acid in your blood, the acid turns into crystals in your joints especially your toes, knees, elbows, wrists and fingers.

The crystals are very sharp, like needles, and your joint gets very sore and painful. This is called a gout attack.

Crystals can cause damage to your joints.

The crystals cause lumps which are called tophi (you say toe-fy). If tophi get too big they can make it hard for you to wear shoes, use a knife and fork, write and walk easily.

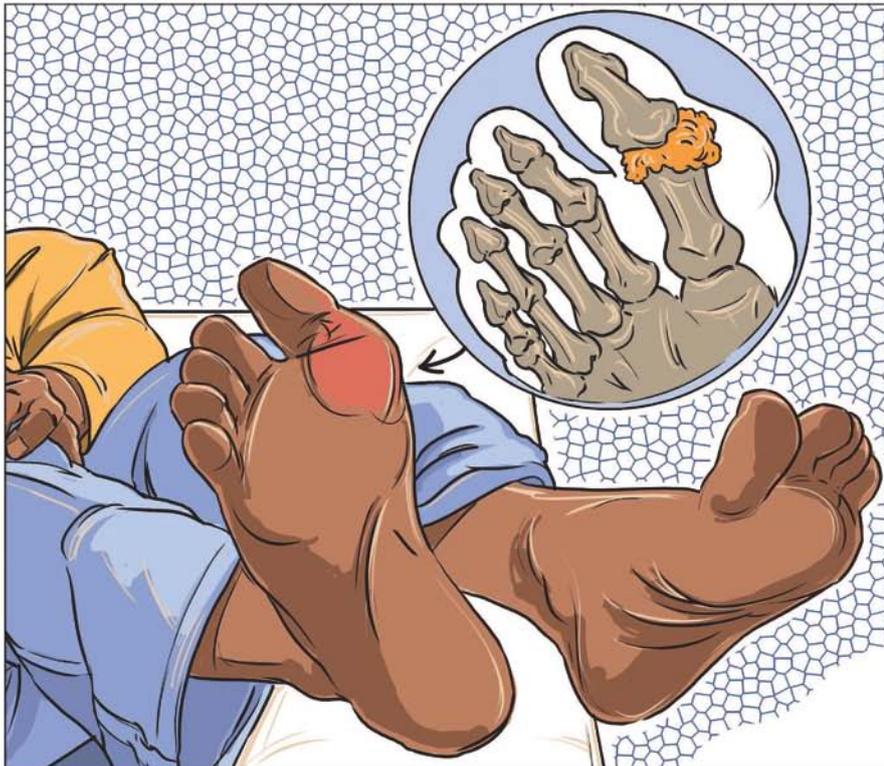


Image supplied by PHARMAC

## What causes high uric acid in your body?

**80%**

of high uric acid is caused by your body not getting rid of uric acid properly.

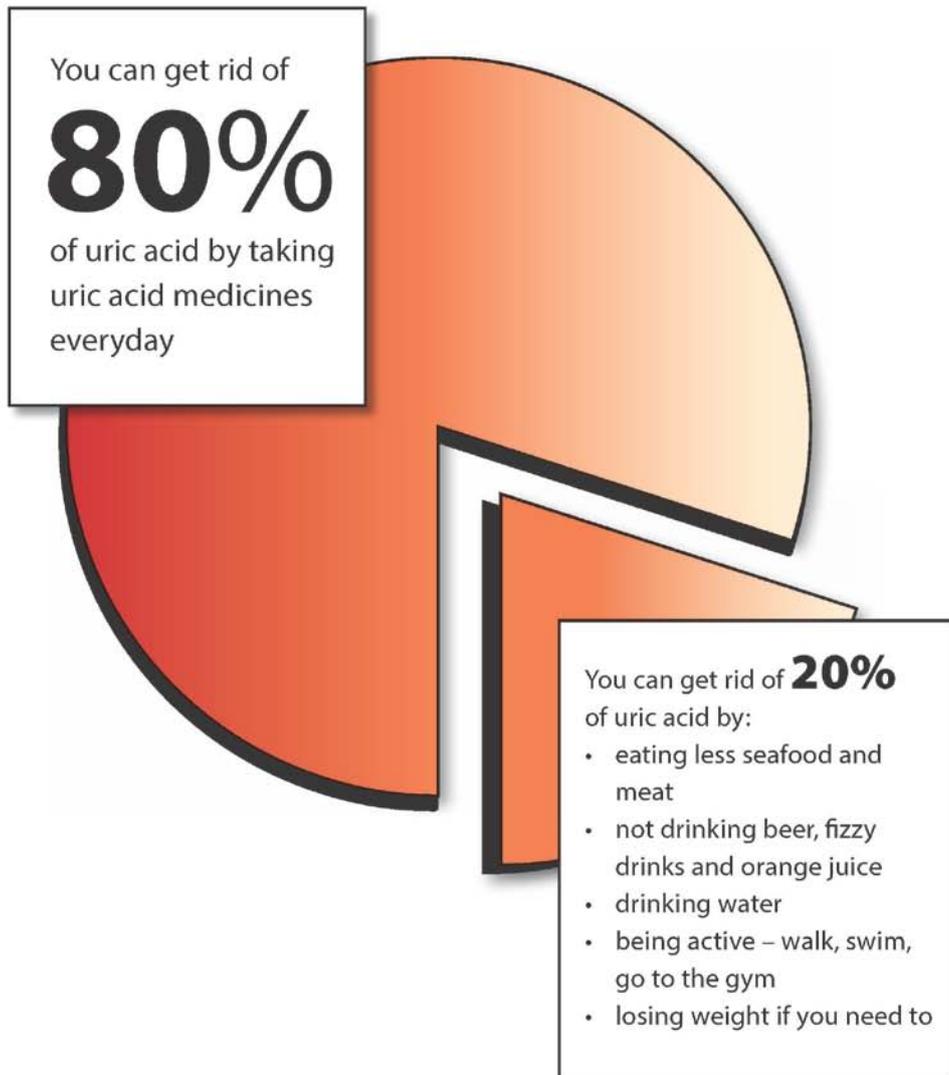
This could be because of:

- your genes
- your weight
- kidney problems

**20%**

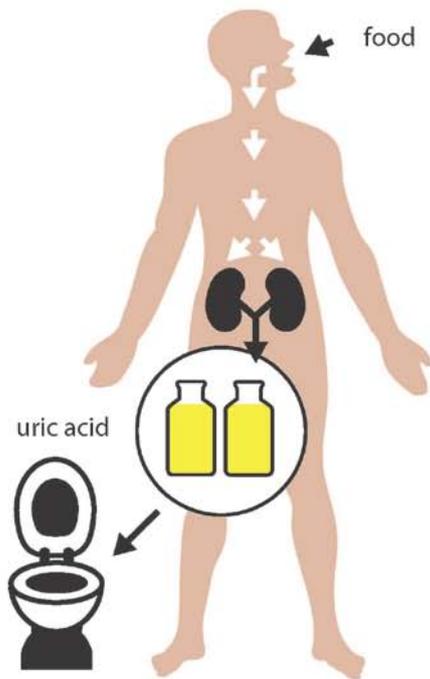
of high uric acid is caused by what you eat and drink

## How can you get rid of uric acid in your body?

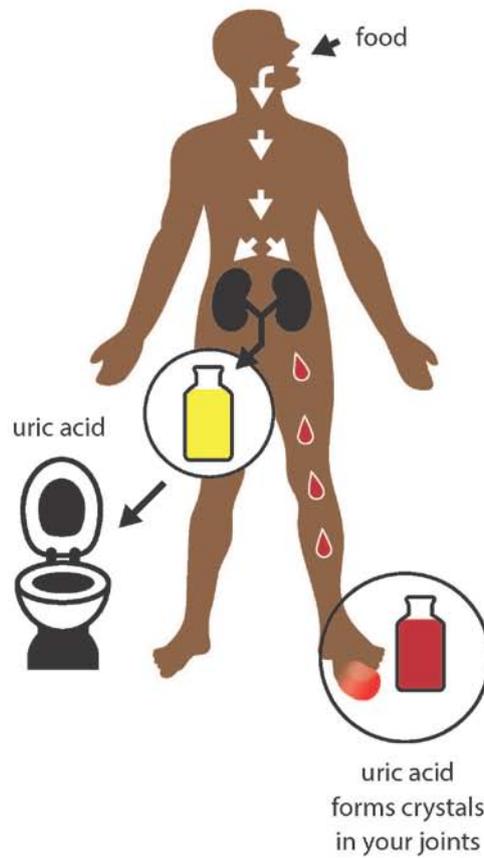


# How you get rid of uric acid

Most people get rid of uric acid through their urine

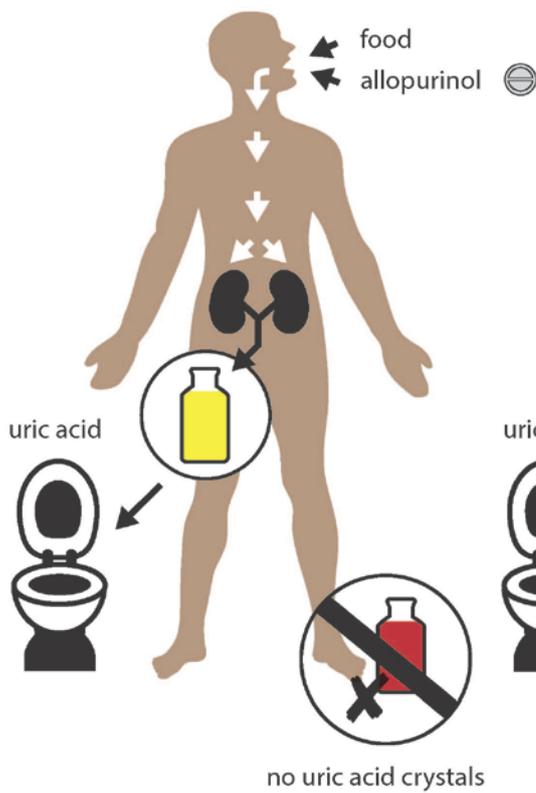


Some people, including many Māori and Pacific people, get rid of some of their uric acid, and the rest stays in their blood

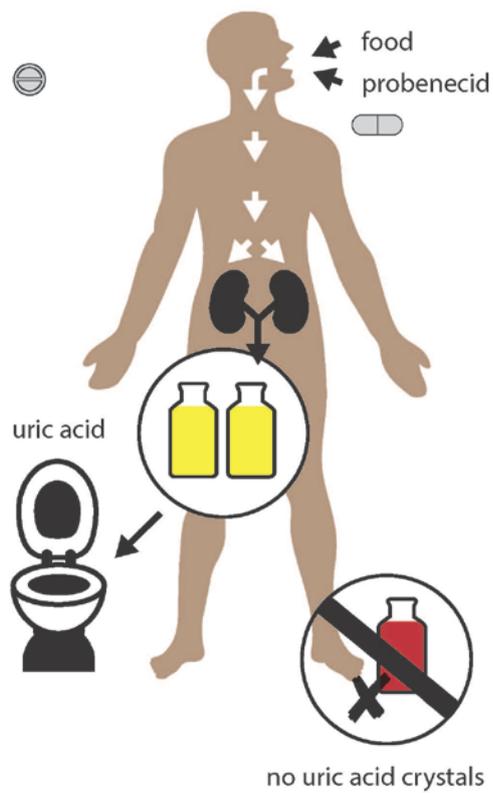


# How uric acid medicines help you

**Some uric acid medicines stop your body making too much uric acid**



**Some uric acid medicines help your body get rid of uric acid through your urine**



# Medicines for gout

There are two types of medicines for gout:

## 1. Uric acid medicine

*Uric acid medicines bring your uric acid levels down. You need to take them every day.*



Common uric acid medicines are allopurinol and probenecid. There are other uric acid medicines as well.

You need to take uric acid medicine every day, even if you are having a gout attack. When you start taking uric acid medicines, you might get a gout attack. So make sure your doctor also gives you medicine to treat the pain from a gout attack.

### Side effects

Make sure you ask your doctor, nurse or pharmacist what the side effects of uric acid medicine could be and what you should do if you get side effects.

## 2. Gout attack medicines

*Gout attack medicines treat gout attacks. You take these medicines when you feel a gout attack coming on or if you are in pain.*

Common gout attack medicines are colchicine, prednisone, naproxen, diclofenac (Voltaren®) and ibuprofen.

Gout attack medicines only treat pain and swelling. Gout attack medicines do not stop gout because they do not bring your uric acid levels down.

### Side effects

Most gout attack medicines should not be taken for a long time. People with tophi may need to take colchicine for a long time.

Taking gout attack medicines all the time can cause side effects such as stomach problems.

*Always ask your doctor, nurse or pharmacist how long you should take your gout attack medicine for.*

# Starting on uric acid medicine

**Your doctor should start you on a low dose and slowly build up to a stronger dose. When you start on uric acid medicine you also need to take gout attack medicine. You will be taking two medicines.**

## 1st medicine

Your uric acid medicine is called \_\_\_\_\_

You take:

\_\_\_\_\_ mg a day for \_\_\_\_\_

*Remember, keep taking your uric acid medicine every day even if you get an attack. Tell your doctor or nurse if you get an attack. Stop taking uric acid medicine immediately if you get a bad skin rash. Tell your doctor or nurse immediately if you get a bad skin rash.*

Take your uric acid medicine every day even if you get a gout attack.

## 2nd medicine

Your gout attack medicine is \_\_\_\_\_

You take:

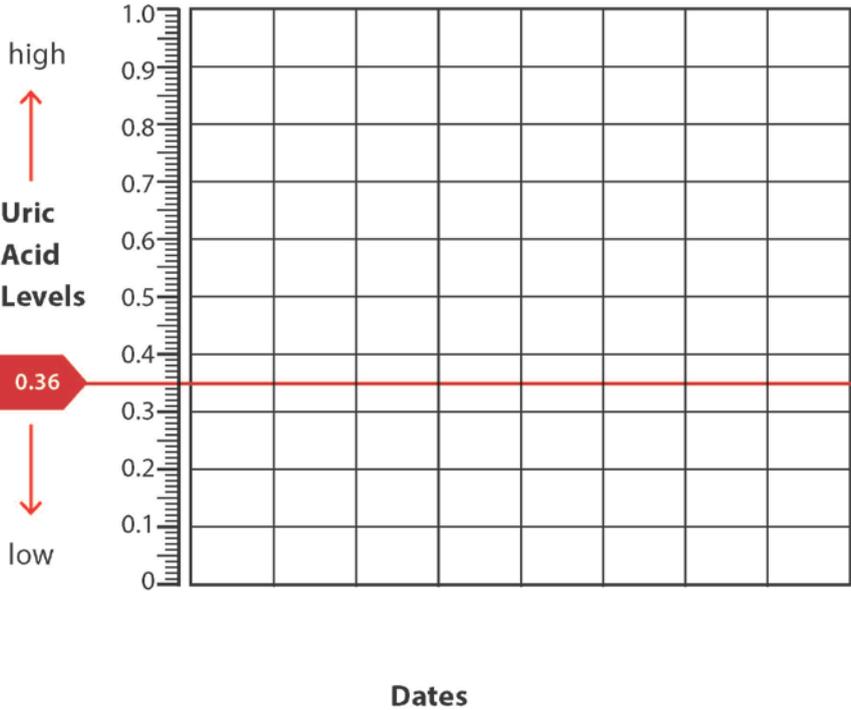
\_\_\_\_\_ mg a day for \_\_\_\_\_

*Remember, you shouldn't take most gout attack medicines for a long time as they can cause stomach problems.*

# Checking your uric acid level

When you take uric acid medicine your target is to get your uric acid levels down to 0.36. You need to get your uric acid level checked regularly. You might need to take a stronger dose of your uric acid medicine if your levels don't come down. If you have tophi you might need to get your uric acid levels down to 0.30 to get rid of your tophi.

Fill in your uric acid levels on this graph



# Choosing the right shoe

If you get gout in your foot, try not to wear:



sandals



jandals



slippers



old shoes

These shoes don't support your feet properly when you are walking or standing. This can affect your balance and make your pain worse.

People with gout in their feet need to wear shoes that:

1. are comfortable (not too tight), so there is room if your foot swells up
2. have a wide toe to leave room for your sore toe
3. have laces or velcro so you can tighten or loosen your shoe
4. have a cushioned insole that supports your foot
5. have a deep heel so your foot fits into your shoe properly
6. have a small heel because high heels can cause problems with your feet, knees and legs
7. have a firm sole that is not worn.



You need to buy a good quality shoe but your shoes don't have to be expensive.

If you are not sure about what shoes to buy, take this list with you and talk to the salesperson in the shop.

**Ask**

## your doctor, nurse or pharmacist

*What is my uric acid level?*

*When do I need to get my uric acid level checked again?*

*What are the possible side effects from this new medicine?*

*What else can I do to bring my uric acid levels down?*

*When do I need to call you if I have any side effects?*

*This medicine doesn't seem to be working for me – I am still getting gout attacks and my uric acid level isn't going down. Can you talk to a rheumatologist or specialist nurse and ask them what else we can do?*

*Should I stop taking this medicine if I get side effects?*

*Do I need to get my heart and diabetes checked as well?*

*Do I need to take more uric acid medicine to get my uric acid level down?*

*What can I say to my family so they don't get gout?*

### Want to know more about gout:

#### Health Navigator:

[www.healthnavigator.org.nz/health-topics/gout/](http://www.healthnavigator.org.nz/health-topics/gout/)

**Arthritis NZ:** Phone: 0800 66 34 63  
(freephone for cell phones and landlines)  
[www.arthritis.org.nz](http://www.arthritis.org.nz)

This booklet was developed by Workbase Education Trust as part of a research project funded by the Ministry of Health.

Workbase would like to thank the Maaori Gout Action Group, Dr Peter Jones, Leanne Te Karu, Arthritis New Zealand and PHARMAC for feedback on this resource.

Your question



## Appendix 11. Draft Prevention Leaflet<sup>3</sup>

**→ Three risk factors for gout:**

- 1. You are Māori or Pacific**  
Many Māori and Pacific people have genes that make it harder to get rid of uric acid from their bodies.
- 2. Your doctor has told you you have high uric acid levels**  
Uric acid is a chemical that everyone has in their body. Some people have higher uric acid levels than others. High levels of uric acid can turn into gout.  
You can reduce your uric acid levels by keeping active, staying fit, keeping your weight down, eating a healthy diet and not drinking beer and sugary drinks.
- 3. You have a family history of gout**  
If people in your family have gout then you have a higher chance of getting gout.

**If you do get a gout attack:**

Talk to your doctor, nurse, pharmacist or Arthritis NZ educator about medicine to treat the gout attack and about taking medicine every day to bring down your uric acid levels and prevent further attacks.

**Want to know more about gout:**

**Health Navigator:**  
[www.healthnavigator.org.nz/health-topics/gout/](http://www.healthnavigator.org.nz/health-topics/gout/)

**Arthritis NZ:**  
Phone: 0800 66 34 63 (freephone for cell phones and landlines)  
[www.arthritis.org.nz](http://www.arthritis.org.nz)

This leaflet was developed by Workbase Education Trust as part of a research project funded by the Ministry of Health.

 **MINISTRY OF HEALTH**  
MANATŪ HAHIORA

 **Workbase**  
Leading health literacy

**Are you at risk of gout?**

**Are you:**

- Māori?
- Pacific?

**Or do you have:**

- high uric acid levels?
- a family history of gout?

**Things you can do to reduce your chances of getting gout** →

<sup>3</sup> This prints as a double-sided pamphlet folded into 3 sections



## Things you can do to reduce your chances of getting gout by bringing down your uric acid levels



### Exercise

- ▶ Keep active.
- ▶ Stay fit.
- ▶ Keep playing sport.
- ▶ Keep going to the gym.
- ▶ Keep your weight down.



### Food

- ▶ Keep eating a healthy diet.
- ▶ Eat lots of vegetables and some fruit.
- ▶ Eat low fat yoghurt or cheese such as Edam.
- ▶ Eat only small amounts of red meat or seafood. Eat chicken and white fish.
- ▶ Eat takeaways only once a week.



### Drink

- ▶ Keep drinking water, coffee and tea, diet soft drinks and lite blue and green milk.
- ▶ **Don't drink** too much beer, RTDs or other alcohol.
- ▶ **Don't drink** sugary drinks such as energy drinks, ordinary soft drinks, orange juice and powdered drinks.



*Being overweight increases your uric acid levels.*



*Some foods, such as red meat and seafood, increase your uric acid levels.*



*Alcohol, sugary soft drinks and fruit juice increase uric acid levels.*

## Appendix 12. Talking Points

➔ Talking Points for health professionals when using leaflet: *Things you can do to reduce your chances of getting gout*

### Scenario 1

## Person at risk of gout (whānau history and normal uric acid level)

- Find out what they know about gout – who in their whānau has had gout, their experiences, how are their whānau managing their gout.
- Show them the page about risk factors for gout. Explain they have two of the risk factors – whānau history and Māori.
- Explain that there are things they can do to stop getting gout – show inside of leaflet.
- Go through each part of the leaflet – exercise, food and drink. Find out what they are doing for each area by asking what food and drink they think are good for gout, not so good for gout and so on.
- Check they know what to do if they do get a gout attack.
- Use Teachback to check understanding (I want to check I have been clear – can you tell me what you need to do to stop getting gout and I will listen to make sure I explained it properly).
- Schedule an annual blood test to check uric acid levels.



### Scenario 2

## Person at risk of gout (whānau history and/or high uric acid level)

- Find out what they know about gout – who in their whānau has had gout, their experiences, how are their whānau managing their gout.
- Show them the page about risk factors for gout. Explain they have all of the risk factors – whānau history, high uric acid levels and Māori. This means it is really important they take action to stop getting gout. (If they are not concerned, show them pictures of tophi or show them the video on the Health Navigator Gout web page).
- Explain that there are things they can do to stop getting gout – show inside of leaflet.
- Go through each part of the leaflet – exercise, food and drink. Find out what they are doing for each area by asking what food and drink they think are good for gout, not so good for gout and so on.
- Check they know what to do if they do get a gout attack.
- Use Teachback to check understanding (I want to check I have been clear – can you tell me what you need to do to stop getting gout and I will listen to make sure I explained it properly).
- Schedule an annual blood test to check uric acid levels.



**Talking points for health professionals when using the *To Stop Gout* booklet with patients and their whānau**  
**Find the scenario that best describes your patient and their whānau**

Scenario 1 First gout attack: no whānau history	Scenario 2 First gout attack: whānau history of gout and/or high uric acid levels	Scenario 3 Having a gout attack maybe once every two years	Scenario 4 Managing gout attacks using gout attack medicine only	Scenario 5 Has had two or more gout attacks within one year
<ul style="list-style-type: none"> <li>Find out if person knows what is happening.</li> <li>Prescribe gout attack medicine.</li> <li>Show page 8 and talk about gout attack medicines you are prescribing, side effects etc.</li> <li>If patient not in too much pain and still interested, show page 6 (shows uric acid in blood).</li> <li>Key points. Make sure they understand:               <ol style="list-style-type: none"> <li>They need to get a blood test after 2 weeks (and why they need to wait 2 weeks).</li> <li>They need to come back and talk to you about blood results.</li> </ol> </li> <li>If patient wants more information, go over pages 2, 3, 4 and 5 - what is gout, gout attacks, causes of uric acid and how medicines work.</li> <li>If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>Use page 12 to check if they have any questions.</li> <li>Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> </ul>	<ul style="list-style-type: none"> <li>Find out if person knows what is happening.</li> <li>Prescribe gout attack medicine.</li> <li>Show page 8 and talk about gout attack medicines you are prescribing, side effects, etc.</li> <li>Find out what they know about gout, genes, urate lowering therapy, etc.</li> <li>If patient does know about genes then mention they are at higher risk of more gout attacks because of whānau history/hyperuricaemia - might have to go on long term medicine.</li> </ul> <p>Key points:</p> <ul style="list-style-type: none"> <li>If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>Use page 12 to check to see if they have any questions.</li> <li>Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> </ul>	<ul style="list-style-type: none"> <li>Ask them what they know about gout – uric acid, genes, etc.</li> <li>Explain that according to guidelines doctors follow, this person doesn't have to go on gout attack medicine unless has more attacks in a year. So need to manage gout attacks through food, drink, exercise and weight (where relevant).</li> <li>Go through pages 2, 3, 4 and 5 with particular focus on page 5.</li> <li>Ask them if they know what their trigger foods are.</li> <li>Mention that big servings are often an issue.</li> <li>Ask them to explain how they are managing gout attacks and their gout attack medicine.</li> <li>Check their understanding of side effects.</li> <li>If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>Use page 12 to check if they have any questions.</li> <li>Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> <li>Make a regular appointment for blood tests.</li> </ul>	<ul style="list-style-type: none"> <li>Ask them what they know about gout – uric acid, genes, etc.</li> <li>Check if they recall that long term use of gout attack medicine can cause stomach problems, etc.</li> <li>Depending on their responses, use open questions to find out how gout is affecting them – <i>how is gout affecting your work, relationships, sport, family, enjoyment of life?</i></li> <li>Listen for the factor that might change the patient's mind about going on uric acid medicine.</li> <li>Check their uric acid levels regularly. If over 0.36mmol, show picture on page 3 and explain how uric acid is eating into their joints.</li> <li>If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>Use page 12 to check if they have any questions.</li> <li>Schedule follow-up telephone call/ appointment to check how they are doing.</li> <li>Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> <li>Make an appointment.</li> </ul>	<ul style="list-style-type: none"> <li>Ask them what they know about going onto uric acid medicine because they have had more than 2 attacks in a year. Go through pages 4 and 5 and emphasise now need to reduce uric acid levels.</li> <li>Go through page 7. Circle uric acid medicine they will be taking and explain how it works.</li> <li>Go to page 8. Ask them if anyone else in their whānau is on uric acid medicine. What do they know about it? Depending on their responses confirm how long they need to take it. Fill in page 9 with their dosage. Mark uric acid level on page 10. Talk person through these pages.</li> <li>Use Teach-back to check you have been clear, especially about side effects, taking every day even if have attack and taking gout attack medicine (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> <li>If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>Use page 12 to check if they have any questions.</li> <li>Make appointment for blood test and follow-up to titrate to higher dose if necessary.</li> </ul>



**Talking points for health professionals when using the *To Stop Gout* booklet with patients and their whānau (continued)**  
**Find the scenario that best describes your patient and their whānau**

<p><b>Scenario 6</b></p> <p>Has had to stop taking uric acid medicine because of side effects e.g. skin rash</p>	<p><b>Scenario 7</b></p> <p>Having gout attacks but not taking uric acid medicine because made their gout worse</p>	<p><b>Scenario 8</b></p> <p>Taking uric acid medicine every day but still having gout attacks</p>	<p><b>Scenario 9</b></p> <p>Taking uric acid medicine every day and their uric acid levels are still above 0.36 mmol/L</p>	<p><b>Scenario 10</b></p> <p>Taking uric acid medicine every day and uric acid levels are now below 0.36 mmol/L (or 0.30 mmol/L if they have tophi)</p>
<ul style="list-style-type: none"> <li>• Find out if person knows what is happening.</li> <li>• Acknowledge that patient has had side effect from uric acid medicine.</li> <li>• Ask them what happened and acknowledge that they came off their uric acid medicine when they got side effect.</li> <li>• Ask them if they remember there is another uric acid medicine. Go to page 7. Explain this medicine works a bit differently.</li> <li>• Print off page 9 and fill it in with patient. Explain side effects of new uric acid medicine. If effects are different from what is written on page 9 then write in correct information about side effects.</li> <li>• Check if they have got enough gout attack medicine and how they are taking that medicine.</li> <li>• Congratulate them for keeping going with uric acid medicine.</li> <li>• Fill in graph on page 10.</li> <li>• If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>• Use page 12 to check if they have any questions.</li> <li>• Make another appointment.</li> <li>• Remind person they have to take uric acid medicine every day.</li> <li>• Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> </ul>	<ul style="list-style-type: none"> <li>• Ask what they know about gout – uric acid, genes, etc.</li> <li>• Check if they recall that long term use of gout attack medicine can cause stomach problems, etc.</li> <li>• Depending on their responses, use open questions to find out how gout is affecting them - <i>how is gout affecting your work, relationships, sport, enjoyment of life?</i></li> <li>• Listen for the factor that might change the patient's mind about going onto uric acid medicine.</li> <li>• Check their uric acid levels regularly. If over 0.36mmol, show picture on page 3 and explain how uric acid is eating into their joints.</li> <li>• If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>• Use page 12 to check if they have any questions.</li> <li>• Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> <li>• Schedule follow-up telephone call/appointment to check how they are doing.</li> </ul>	<ul style="list-style-type: none"> <li>• Empathise with patient and check if they know why this is happening. If not, explain still too much uric acid so will need to increase dose of uric acid medicine.</li> <li>• Check uric acid levels. Write level on page 10.</li> <li>• Explain about new increased dose. Dose is still safe but still need to check for side effects.</li> <li>• Check they have gout attack medicines and explain they should start taking these again as they are taking increased dose of uric acid medicine.</li> <li>• Fill in page 9 together.</li> <li>• Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> <li>• If your patient gets gout in their toe or foot talk to them about the best footwear (page 11).</li> <li>• Use page 12 to check if they have any questions.</li> <li>• Finish by congratulating patient for keeping on taking their uric acid medicine as really important for long term health.</li> </ul>	<ul style="list-style-type: none"> <li>• Empathise with patient and check if they know why this is happening. If not, explain still too much uric acid so will need to increase dose of uric acid medicine.</li> <li>• Check uric acid levels. Write level on page 10.</li> <li>• Explain about new increased dose – still safe but need to check for side effects.</li> <li>• Check they have gout attack medicines and explain they should start taking these again as they are taking increased dose of uric acid medicine.</li> <li>• Fill in page 9 together.</li> <li>• Use Teach-back to check you have been clear (<i>I want to check I have been clear - can you tell me what you need to do to prevent gout and I will listen to make sure I explained it properly</i>).</li> <li>• Use page 12 to check if they have any questions.</li> <li>• Finish by congratulating patient for keeping on taking their uric acid medicine as really important for long term health.</li> </ul>	<ul style="list-style-type: none"> <li>• Congratulate patient for achieving 0.36 mmol/L (or 0.30 mmol/L).</li> <li>• Fill in page 10 together.</li> <li>• Check their understanding about need to take uric acid medicine every day.</li> <li>• Ask them what their understanding of gout is now and if necessary use booklet as prompt.</li> <li>• Explain that there are still important messages for them to pass on to whānau and friends about prevention of gout.</li> <li>• Check if they have tried small amounts of trigger foods. If not, encourage them to do so if they want.</li> <li>• Check they know how to use gout attack medicine. If necessary, go through it again.</li> <li>• Congratulate patient – remind them about regular prescriptions and annual blood tests.</li> </ul>

## Appendix 13. Summary of Current and Earlier New Zealand Gout Research Projects

### Research in progress 2012

Author	Year	Location	Ethnicity	Basic Summary/Findings
McQueen, et al (University of Auckland/AMRF)	Current	Not specified	Not specified	An observational study of MRI, dual energy CT (DECT), plain radiography and digital tomography for advanced imaging in gout.
Dalbeth, et al (University of Auckland/HRC)	Current	Not specified	Not specified	An RCT of zoledronate for prevention of bone erosion in patients with tophaceous gout and an imaging sub-study of the high dose allopurinol study.
Dalbeth, et al (University of Auckland/Arthritis NZ)	Current	Not specified	Not specified	A longitudinal observational study of patients with recent onset of gout to determine the clinical factors associated with joint damage and other outcomes.
Dalbeth, et al (University of Auckland)	Current	Not specified	Not specified	Laboratory studies to determine the mechanisms of joint inflammation and damage in gout.
Fernandez, et al (University of Auckland/AMRF)	Current	Not specified	Not specified	An imaging and bioengineering project to understand the role of biomechanical strain on deposition of urate crystals and development of joint damage in gout.
Lindsay, et al (CMDHB)	Current	Not specified	Not specified	Qualitative studies examining impact of gout and barriers to treatment.
Dalbeth, et al (University of Auckland/AMRF)	Current	Not specified	Not specified	Laboratory studies examining the interaction between adipokines and gouty inflammation.
Stamp, et al (University of Otago/HRC)	Current	Not specified	Not specified	An RCT of the efficacy and safety of a 'treat to urate target' approach for allopurinol dosing.
Rome, et al (AUT/HRC)	Current	Not specified	Not specified	A short term intervention study to determine optimal footwear for people with gout.
Stamp, et al (University of Otago/HRC)	Current	Not specified	Not specified	A randomised controlled trial of Vitamin C for serum urate lowering in patients with gout.
Harper, et al (Malaghan Institute of Medical Research/Arthritis NZ)	Current	Not specified	Not specified	Laboratory studies on the effects of hyperuricaemia on macrophage inflammatory responses.
Arroll, et al (University of Auckland/MPIA)	Current	Not specified	Pacific	A randomised controlled trial of immediate versus delayed usage of allopurinol for the prevention of gout flares.

Merriman, et al (University of Otago/ HRC/Arthritis NZ)	Current	Not specified	Māori, Pacific, European	A large nationwide study examining the genetic basis of gout. Three case-control cohorts have been studied (Māori, Pacific and European). This project also includes analysis of the interaction between environmental factors and genetic variants, with recent completion of a fructose feeding study.
Taylor, et al (University of Otago/ACR/EULAR/ OMERACT)	Current	Not specified	Not specified	An international initiative to determine optimal outcome measures for use in clinical trials of gout.
Taylor, et al (University of Otago/ACR/EULAR)	Current	Not specified	Not specified	An international initiative to develop a new classification criteria for gout.
Gow & Dalbeth (University of Auckland/CMDHB)	Current	Not specified	Not specified	Commercial clinical trials examining the efficacy and safety of lesinurad, a new uricosuric agent.
Stamp, et al (University of Otago)	Current	Not specified	Not specified	A case controlled study examining the prevalence of fructose malabsorption in patients with gout.
Stamp & Kettle (University of Otago/ HRC)	Current	Not specified	Not specified	A laboratory based study of the role and actions of myeloperoxidase in gout.
Harper, et al (Malaghan Institute of Medical Research/Lottery Health Research)	Current	Not specified	Not specified	Investigating how hyper-inflammatory cells develop to drive inflammation in gout.
Merriman, et al (University of Otago/ HRC/Arthritis NZ)	Current	Not specified	Māori	A local study of gout together with Ngāti Porou Hauora examining the genetic basis of gout for people in the Tairāwhiti region. One case-control cohorts has been studied. This project also includes analysis of the interaction between environmental factors and genetic variants.
Rome & Gow (AUT/CMDHB)	Current	Not specified	Not specified	Describe the foot wound characteristics of a cohort of chronic gout patients.
Rome & Dalbeth (AUT)	Current	Not specified	Not specified	To investigate ultrasonographic characteristics of Achilles tendon in chronic gout with altered biomechanics at the foot and lower limb.

## Earlier research

Taylor, Smeets, Hall & McPherson	2004	National	European, Māori, Pacific	Older people, males, people who lived in more deprived areas and Europeans were more likely to consult with a doctor about a rheumatic disorder. Māori were more likely than Europeans to consult about gout. Most of these conditions seen in general practice are non-inflammatory and non-surgical. If a community-needs approach was taken, it is likely that the workload and associated costs would be even greater.
Rose	1956	East Cape	Māori (Te Whānau-A-Apanui)	Of the 88 people who complained of rheumatic conditions, 20 were diagnosed with hyperuricaemia but only 3 were thought to have developed gout.
Queen Elizabeth Hospital and the School of Social Sciences of Victoria University	1958	Rotorua	European, Māori	186 Māori and 641 Non-Māori were surveyed. 5 Māori and 2 non-Māori were found to have clinical gout.
Prior & Rose	1966	Carterton	European	Gout Prevalence: Men, 1.98 percent; Women, 0 percent.
Klemp, Stansfield, Castle & Robertson	1992	Rotorua	European, Māori	342 Māori and 315 European men and women aged 15 years and older were studied by personal interview and a musculoskeletal system examination. Gout was significantly more common in Māori (6.4 percent) than Europeans (2.9 percent) and in Māori men (13.9 percent) than in European men (5.8 percent). Hyperuricaemia was significantly more common in Māori men (27.1 percent) than in European men (9.4 percent) and in Māori women (26.6 percent) than in European women (10.5 percent).
Bauer and Prior	1962/ 1968/ 1974		Māori	Longitudinal study of gout in New Zealand Māori based on a sample of 388 males and 378 females. The prevalence of hyperuricaemia was 49 percent in males and 42 percent in females.
Gibson, Waterworth, Hatfield, Robinson & Bremner	1984	Not stated	Māori	A survey of 115 Māori men of working age revealed a history of gout in 10 (8 percent) and asymptomatic hyperuricaemia in 26 (23 percent).
Wrigley, Prior, Salmond, Stanley & Pinfold	1987	National	Tokelauans	Tokelauan migrants to New Zealand were surveyed over a 20 year period for rheumatic issues. Results show that people in the islands have much lesser rates of gout than migrants. Island Men: 1.3 percent; Migrant Men 5.3 percent, Island Women 0 percent; Migrant Women 0.6 percent.

Lindsay, Gow, Vanderpyl, Logo & Dalbeth	2011	South Auckland	Māori, Pacific, European	Qualitative investigation into 'living with gout'. Results find that gout is often trivialised through shame and embarrassment. Stigma may lead to a reduction in help-seeking behaviour. Lack of knowledge may lead to under treatment with ULT.
Hollis-Moffatt, Xu, Dalbeth, Merriman, Topless, Waddell, Gow, Harrison, Highton, Jones, Stamp & Merriman	2009	Auckland, Wellington and Christchurch	Māori, Pacific, European	Objective: To examine the role of genetic variation in the renal urate transporter SLC2A9 in gout in New Zealand sample sets of Māori, Pacific Island and European ancestry, and to determine if the Māori and Pacific Island samples could be useful for fine-mapping.
Phipps-Green, Hollis-Moffatt, Dalbeth, Merriman, Topless, Waddell, Gow, Harrison, Highton, Jones, Stamp & Merriman	2010	Not specified	Māori, Pacific, European	Unlike SLC2A9, which is a strong risk factor for gout in both Māori and Pacific Island people, ABCG2 rs2231142 has a strong effect only in people of Western Polynesian ancestry.
Arroll, Bennett, Dalbeth, Hettiarachchi, Cribben & Shelling	2009	<i>South Auckland</i>	Not specified	Trial of two interventions to improve gout control with people with serum uric acid above 0.36 mmol/L. Intervention #1 took place in the clinic and did not produce significant results. Intervention #2 was conducted via phone and mail and was found to have positive results.
Gow & Dalbeth	2006	<i>Auckland</i>	Māori, Pacific, European	Gout is often emphasised as an important factor in the development of gout. This study shows that 75 percent of patients with gout are not drinking excessive alcohol and that it is indeed over emphasised.
Lennane, Rose & Isdale	1960	Not specified	Māori	Population surveys show a much greater prevalence of gout among the Māori people of New Zealand than among people of European stock. Historical evidence strongly suggests a real and recent increase in incidence. It is suggested that the marked economic and dietary changes in the Māori cultural environment in the last two hundred years could sufficiently explain this without postulating any alteration in the necessary genetic constitution.

Martini, Bryant, Te Karu, Aho, Chan, Miao, Naidoo, Singh & Tieu	2012	Not specified	Not specified	The objectives of this study were to explore the knowledge and perceptions of people with gout toward the disease and to determine the impact gout has on lifestyle including possible barriers to treatment. There were substantial gaps in the knowledge about gout and its causes and management. All healthcare providers could help identify patients with suboptimal knowledge and improve the management of gout.
Kumar & Gow	2002	South Auckland	All ethnicities	Surgery for tophaceous gout is associated with a relatively high rate of complication when sepsis is the main indication. Patients with gout in this study population had several associated medical co-morbidities, which contributed to the high complication rate. Gout control was poor as evidenced by a high rate of hyperuricaemia, and less than one third of the study population were on allopurinol.
Dalbeth, Kumar, Stamp & Gow	2006	South Auckland	Not specified	Published guidelines state that allopurinol doses should be adjusted according to creatinine clearance. The authors investigated whether such dosing provides adequate control of hyperuricaemia. Adherence to published allopurinol dosing guidelines led to suboptimal control of hyperuricaemia in this population of patients with gout.