

Review of Health Education Resources on Gout Medication

Summary of report to the Ministry of Health

It's not just about reading and writing. Workplace literacy is the communication, numeracy, problem solving and computer skills essential for a productive workforce. When you develop the literacy skills for work, you're developing your staff to their full potential.

A black and white photograph of a pen resting on a piece of paper. The text on the paper is slightly blurred and tilted, matching the text in the image block above. The pen is a simple, dark-colored ballpoint pen, positioned diagonally in the lower right corner of the frame.

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Executive summary

Content of this report

This report summarises the findings of a health literacy review of publicly available resources on gout that focus on treatment with medication. This report also describes how these resources could be improved.

Reviewers

Workbase carried out the review at the end of 2011 with support from the Maaori Gout Action Group, Arthritis New Zealand (Greater Auckland Branch), Leanne Te Karu (a clinical pharmacist) and Ngāti Porou Hauora.

How the review was carried out

The review team looked at five dimensions that interact to influence the use and effectiveness of resources.



Workbase collated and reviewed more than 80 resources. It also held interviews and focus groups with 29 health professionals and 13 individuals (10 Māori, 2 Samoan, and 1 Cook Island Māori) with personal experience of gout to discuss how they used resources and what they would like resources to contain.

Workbase then developed a description of the literacy demands of managing gout and compared these needs with the literacy skills of the population with, or most at risk of getting, gout. The Maaori Gout Action Group then helped Workbase to develop a draft list of messages that are essential in patient-focused resources.

Findings

How people with gout use resources

People with gout seldom read the available resources because, for example:

- resources are too long
- resources are densely worded and hard to navigate
- resources include pictures with which people may not relate
- they believe gout and gout attacks are self-inflicted, are not serious or require unappealing life changes (such as dietary changes).

How health professionals use resources

Resources provide an opportunity to improve a patient's understanding of gout.

Health professionals frequently use two publications: *Out with Gout* (PHARMAC 2008) and *Starting on Allopurinol* (Counties Manukau District Health Board (DHB) 2007). However, they are more likely to give these resources to patients after a discussion rather than use them actively during a discussion.

Literacy demands of managing gout

Initially, the medication and management process for gout and gout attacks is complex, with a lot of new information, experiences and decisions for people with gout. It is during this initial phase that managing medication is most complicated and people form incorrect medication habits and beliefs. Poor medication management can lead to a refusal to use preventive medication. This initial phase is more successful when people are closely monitored, with adequate follow-up, by a health professional.

Literacy skills of people with gout

Research into the health literacy skills of people with, or most at risk of getting, gout shows that Māori and Pacific peoples have, on average, low document literacy (difficulty reading tables, maps and forms) and low prose literacy (difficulty reading booklets and brochures) (such as reading a brochure, for example, PHARMAC *Out with Gout*). As well, these groups generally have low numeracy skills (difficulty reading and processing mathematical information) (Satherley and Lawes 2007). The research has also found that the health literacy skills of the adult population start to decline from the age of 55. Men have slightly better document literacy, better numeracy skills and poorer prose literacy than women.

Messages most relevant to Māori and Pacific peoples, many of whom have an inherited tendency to develop gout, are not prioritised within resources. For example, messages emphasising managing gout through diet and exercise are misleading for people with a genetic predisposition to a high uric acid level, and support the myth that gout and gout attacks are self-inflicted. Such messages may prevent people with gout from seeking the treatment they need.

Resource content

The messages, advice and language used throughout the resources are not particularly consistent.

A few resources use plain language descriptions of gout and build patients' health literacy by clearly explaining gout-related terms and processes (for example, the 2008 PHARMAC *Out with Gout* booklet, which is available in English, Māori, Samoan, Niuean and Tongan). However, most of the resources that are meant to be patient focused are difficult for most people with gout to understand (especially

when they have been newly diagnosed). These resources include complex descriptions about the workings of the body and use unfamiliar language, including terms specific to the health sector, that is not explained.

People retain only a certain amount on their first exposure to new information. Therefore, if messages about diet are put at the beginning of an interaction or resource people are likely to focus on this information rather than later information about medication, which is more important.

Resources typically contain two types of material: **information** about gout that helps a reader to build a general understanding about the disease and **instructions** that explain what to do to manage and prevent gout. People read information and instructions in different ways. People are more likely to quickly skim and scan information. However, people usually need to carefully and thoroughly read and reread instructions. It can be confusing to include instructions and information in the same resource.

The emphasis in most resources is on providing information. However, the Counties Manukau DHB resource, *Starting on Allopurinol*, emphasises instruction and is adapted to each individual with gout to show the type, timing and quantity of medications they need to take. Several health professionals used this resource.

Fear is not a successful motivator to get and maintain treatment. Pictures of abscesses and tophi (deposits of crystallised uric acid) may stop people without these symptoms of gout from looking at a resource. Conversely, these images may help to engage people who have tophi that have not yet progressed to abscesses, as these people can recognise their own condition in the graphics.

People with gout as well as health professionals found instructional material useful to reinforce processes and remind them what to do, when and why.

Misperceptions about gout impede successful management

There is a persistent belief among people with gout and the wider public that gout is not a long-term (chronic) illness but instead is present when a person is experiencing an attack. This misperception makes it hard for people to understand the need for long-term medication.

Some confusion is caused by the use of the word 'gout' to mean the long-term condition as well as a gout attack. People diagnosed with gout are likely to have gout for the rest of their lives and may suffer ongoing gout attacks if their condition is not managed effectively.

When management of gout is most successful

The most successful management of gout occurs in communities where clear instructions about medication are provided and health professionals monitor people with gout and support their families and whānau to ensure the instructions are understood and followed.

1 Introduction

Content of this report

This report summarises the findings of a health literacy review of publicly available gout education resources, focusing on treatment with medication. The report also makes recommendations for improving these resources (see section 12).

Reviewers

Workbase, with support from the Māori Gout Action Group, Arthritis New Zealand (Greater Auckland Branch), Leanne Te Karu (a clinical pharmacist) and Ngāti Porou Hauora, carried out the review at the end of 2011.

Review purpose

The intent of the review was to assess the suitability of information on gout medication for users and practitioners. This arose from concerns about people not understanding that gout is a serious condition that can be treated effectively and then managed through appropriate use of relevant medication.

Without exception, the resources reviewed had been created with good intent by resource developers who recognised that people needed more information to better understand and manage gout. We hope that the findings and recommendations in this report will provide ideas and information to support resource developers as they continue to produce and improve resources for their communities.

Populations most affected by gout

Research has established that gout is more common among:

- Māori and Pacific peoples
- males
- people living in the most socioeconomically deprived areas
- people aged over 65 (Merriman and Dalbeth 2011).

Some people, including many Māori and Pacific peoples, have an inherited tendency to develop gout.

The prevalence of gout in older Māori and Pacific men is particularly high (more than 25 percent of the population).

Risks associated with untreated gout

The length of time that people have gout before starting urate-lowering medication is of concern. The longer gout goes untreated with such medication, the higher the chance of a person with gout developing major and irreversible joint damage (Dalbeth et al 2009). Poorly treated gout is also associated with greater risk of developing chronic kidney disease and cardiovascular disease. (Research is under way to identify the length of time that Māori and Pacific peoples suffer from gout attacks before being prescribed urate-lowering medication.)

Role and importance of education resources

Also of concern is the poor adherence to medication regimes that prevent gout and manage the pain of gout attacks. This review looked at how gout education resources do (and could better) contribute to patients' and health professionals' understanding of gout, gout attacks, preventive measures, medication, and medication adherence.

He Korowai Oranga: Māori Health Strategy requires the health and disabilities sector to deliver culturally appropriate services to Māori to improve health outcomes and reduce inequalities (Minister of Health and Associate Minister of Health 2002).

The review supports the Code of Health and Disability Services Consumers' Rights that says all New Zealanders have the right to receive 'effective communication in a form, language, and manner that enables the consumer to understand the information provided' (Right 5) and the right 'to be fully informed' (Right 6).

2 Explanation and importance of health literacy

Health literacy is about people's capacity to access, understand and use health information in ways that promote and maintain good health. Health literacy is also about how health systems and health professionals enable people to make informed health-related decisions and take appropriate actions (US Department of Health and Human Services 2010).

Strong relationship between health literacy and health status

A strong relationship exists between a person's health literacy and their health status. Research shows that health literacy is a stronger indicator of health status than is education level, ethnicity, gender or socioeconomic status (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs and American Medical Association 1999; Ministry of Health 2012).

Determinants of health literacy

The adequacy of a person's health literacy is determined by two broad factors: the health literacy skills and knowledge of that person and the complexity of the health literacy demands they face. When these two things align, people are in a position to make informed decisions about their health.

Health literacy skills and knowledge include reading, writing, speaking, listening, numeracy and critical thinking. Matters that affect a person's literacy skills include the:

- person's familiarity with the health topic and system
- stress the person is under
- time and resources the person has available
- person's confidence, attitudes, values and beliefs.

The **health literacy demands** of the health condition are created by the:

- complexity of a health issue and management regime
- communication skills of the health workforce
- consistency of advice and information provided
- difficulty of texts given to consumers (for example, forms, letters, publications, websites, labels and instructions)
- design and funding of health services and media messages (Ministry of Health 2012).

Benefits of good health literacy

If a person has good health literacy, they can find, understand, influence and evaluate health information and services to make effective health decisions and access appropriate services. As well as the skills and knowledge mentioned earlier, health literacy includes the ability to send and receive oral and written communication, comprehension, and problem solving (Ministry of Health 2012). Good health literacy also includes a person having a good knowledge of how the human body works, as well as knowledge of specific health conditions.

New Zealanders have poor health literacy

New Zealanders in general have poor health literacy. Groups with particularly 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 skills than non-Māori regardless of age, gender, income, employment status, education level and location (Ministry of Health 2010).

3 Resources and health literacy

Resources need to be written or scripted using language and concepts that work for the target audience. Making a resource understandable is not about 'dumbing down' or reducing information; it is about health professionals being more responsive to the needs of their patients and taking a patient- and whānau-centred approach to all forms of information. It is about giving people the information they need, when they need it, in a form that makes sense to them. This may mean that initially less information is shared with people rather than more. However, this approach means information needs to be built up over time. Once people have acquired the most important concepts and knowledge, then new information can be added to develop a person's understanding of their condition and treatment.

How health education resources can address health literacy

Health education resources can address health literacy by:

- ensuring the main audience can easily use and understand the information and messages in the resources
- helping the audience develop the health literacy skills they need to understand and manage their health issues.

However, a resource alone is unlikely to be the answer to raising health literacy. It is crucial that resources are supported by interactions such as discussions between a health professional and patient when the professional is introducing new and complex ideas.

Health education resources provide an opportunity for patients to develop their health literacy skills by:

- building their understanding of the main events in a health process
- explaining how to read labels and instructions
- building their understanding of essential health terms
- building their understanding of who they can talk to for support and advice
- demonstrating how to have a conversation with health professionals
- explaining and demonstrating how to fill in forms
- building their numeracy skills such as how to work out dosage amounts and the timing of medications (Ministry of Health 2012).

Making gout health education resources effective

To be effective from a health literacy perspective, gout resources must:

- be easily understood by the person interacting with the resources, including being in the language and using cultural contexts to which audiences can relate
- be engaging by looking interesting, having a helpful rather than hectoring tone, and containing the right amount of information with the right amount of detail
- focus on what the audience wants and needs at that particular time
- be accurate, containing correct and current information about the condition
- emphasise key messages about gout
- be accessible, being easy to get hold of and use
- build the health literacy skills and knowledge of the person so they can better understand a health condition, for example, by explaining the words used to describe the symptoms and effects of gout.

4 Gathering gout resources to review

Sources of gout resources

The health education resources for gout medication were found primarily through the internet. Google was used as the search engine, and the search terms used to imitate a person looking for information about gout medication were gout, gout medication, and gout treatment.

Most resources found on the internet were targeted at people with gout, with a minority targeted at health professionals.

We also asked health organisations to identify resources they were using with gout patients. We emailed the communication departments of all district health boards and the chief executives of all primary health organisations as well as the Pharmacy Guild, the Pharmacy Society, Whitecross and Medsafe. The email asked them to send us a file or link to the gout education resources they used.

We followed up the email with phone calls and supplementary emails. We allowed up to two weeks for organisations to reply, but responses were difficult to get. Those who responded from organisations were rheumatologists, nurses, pharmacists and gout educators. Most of the additional resources these people identified were targeted at health professionals.

We also sourced resources from pharmacies and general practices, and through interviews with the Maaori Gout Action Group, Arthritis New Zealand and Ngāti Porou Hauora.

Resources grouped for analysis

The gout resources were organised into three groups for analysis.

- Resources about gout and medication for people with gout, and their families or whānau.
- Resources for health professionals to assist with the diagnosis and treatment of gout.
- Resources containing medical or pharmaceutical information for health professionals, for example, medication data sheets.

5 Review of resource content

This section summarises the framework we used to analyse each resource.

Review criteria

The details of each resource were recorded and the content analysed using the following criteria.

- Publication – the name of the resource.
- Produced by – the author(s) of the resource.
- Published – the date the resource was published or otherwise released.
- URL – the uniform resource locator or online address of the resource if relevant.
- Purpose – the explicit or implicit purpose of each resource.
- Audience – who the resource is targeting: patients and whānau; individuals and health professionals; or a combination of patients, whānau and health professionals.
- Description – what the resource is, its format, how it prints, and its content.
- Availability – where the resource is available (all the resources are publicly available, but some are available in specific areas of New Zealand).
- SMOG (Simple Measure of Goobledygook) and Flesch-Kincaid – two tests of readability where the resulting scores are based on American school grade levels. As an example, a score of 6.4 means an average student in sixth grade (the equivalent to age 11 or year 7 in a New Zealand school) can understand the text (Kincaid et al 1975; McLaughlin 1969).
- Health literacy elements and opportunities – how the resources could be improved to be build the health literacy skills of the users.
- Māori framework (discussed later in this section).
- Key messages about gout.

A clinician from the Maaori Gout Action Group also analysed the resources for health professionals in terms of their clinical accuracy and their purpose.

Rauemi Atawhai

As requested by the Ministry of Health, we used the framework developed in *Rauemi Atawhai: A guide to developing health education resources in New Zealand* to inform the review of the resources (Ministry of Health 2012). *Rauemi Atawhai* provides best-practice advice and guidance for developing health education resources.

Rauemi Atawhai can be used to review resources and inform recommendations for improvement. In particular, we used *Rauemi Atawhai*'s definitions of health literacy and its examples of the ways health literacy skills can be improved through health education resources. We also used the plain language checklist from *Rauemi Atawhai* as a guide when reviewing the language, tone and design of resources.

Readability tests

The readability of the resources was measured using the SMOG Index and Flesch-Kincaid grade levels. Both of these readability tests involve taking a section of text from each resource and measuring a mix of variables, such as the number of syllables per word and sentence length, to approximate reading difficulty. The underlying principle is that longer sentences and words are usually harder to comprehend than shorter ones. Generally, the higher the score (or grade) the harder the text is to read.

These tests cannot, however, measure sense, logic, familiarity, tone and cohesion within a text, so the results need to be viewed with caution. SMOG has traditionally been used when assessing health literacy levels in health education resources. However, we chose to include Flesch-Kincaid results as this tool is commonly available in Microsoft Word.

Māori framework

We developed a Māori framework for reviewing the gout resources. This framework was based on Te Whare Tapa Whā, a model for understanding Māori health (Ministry of Health, no date).

The model describes four dimensions of health and wellbeing, symbolising the four walls of a whare (house). Should one of the four dimensions be missing or damaged, a person or a collective may become 'out of balance' and subsequently unwell. Within each dimension, we developed a series of questions that demonstrated what to look for in gout education resources.

6 Specific findings from the review

Readability levels

Over 26 percent of patient-focused resources were rated at grade 10 or above (ages 15–16) on the SMOG index and Flesch-Kincaid grade levels. A further 50 percent of resources were rated between grades 7 and 9.9 (ages 12–15). These resources are likely to be too difficult for quick and easy comprehension by most of the target audience. This is especially true for people newly diagnosed with gout who are unfamiliar with the language and management processes of gout. Many resources also contained complex descriptions about the workings of the body and explained health sector terms poorly.

A few resources used plain language to describe gout and built health literacy by providing clear explanations of terms and processes. These resources were part of the 24 percent of resources scoring between grades 5 and 6.9 (ages 10–12) and included the following.

- *Starting on Allopurinol*, the Counties Manukau DHB resource, demonstrated effectively when and how to take allopurinol (a drug used in the treatment of gout). One page of this resource can be personalised to include a person's details, specified dosage and medication names. This means people are more likely to understand the relevance of this resource for them and refer to the form at home.
- The Health Navigator New Zealand webpage on gout provides general information (www.healthnavigator.org.nz).
- MedlinePlus (an online US resource) provides general information that is linked to other overseas information (www.nlm.nih.gov/medlineplus).
- Warrant of Fitness – Gout (Series 5, Episode 11) is on Youtube (www.youtube.com). This online resource provides general information in a three-part video about gout and its implications for family life.

The English language version of the PHARMAC resource, *Out with Gout* (2008), has a readability grade of between 8 and 9 (ages 13–14), but it is a good example of how readability results alone are not always an indication of complexity. The high score is largely because the resource contains many technical terms. However this resource provides excellent plain language explanations of these terms so the resource is easier to understand than the score indicates.

Resources for patients

Across the resources for patients and their family and whānau there was generally not a lot of consistency in the messages, advice, language and priority of messages about gout. Nevertheless, most of these resources covered what gout is, how it is diagnosed, its symptoms, and treatment for it. Each explanation was slightly different in content but followed a similar structure. Often information about uric acid, crystals and tophi was also found towards the beginning of the resources. Information about preventive medication, if included, was usually presented towards the end of resources.

Many resources contained a combination of instructional and informational material. People need to read instructions differently to information. In particular, people need to read instructions thoroughly and sequentially whereas they can skim informational material. When these types of information are combined in a document, it can be difficult for a reader to recognise the different types and determine how best to read the document.

By contrast, *Starting on Allopurinol* had instructional material (such as which medication to take) on one side of a single page with general information on the other side. Several practitioners used this resource.

When information about the role of diet and exercise in preventing attacks and managing gout makes up the first few messages in resources, most readers will assume these are the most important messages. The emphasis on managing gout through diet and exercise for people with a genetic disposition to high uric acid levels is misleading and supports the myth that gout and gout attacks are self-inflicted. This messaging may discourage people with gout from seeking the preventive treatment they need. It also means that messages most relevant to Māori and Pacific peoples are not prioritised within resources.

Resources for health professionals

Resources developed for health professionals have a different audience and purpose to patient-focused resources, so resource developers feel they can provide information in more complex language. These resources provide specific information about gout and gout medication for health professionals to use in their diagnosis and treatment of gout. However, health professionals also benefit from resources being written simply and clearly. In these resources, key messages about gout as well as health literacy elements need to be included not only to build the understanding of health professionals, but to demonstrate how health professionals can build patient understanding during their interactions. These messages could be supported by suggested scripts for discussions or questions to be used with patients (to elicit information and check understanding).

Factors on resource effectiveness

Common factors affecting the effectiveness of resources included:

- too much information and too many instructions, especially for people receiving a new diagnosis or medication for the first time
- plain language not always being used
- medical terms and situations that were not always explained
- resources that are too long or densely worded, making them hard to read and navigate
- inconsistent messages among resources for patients, which may indicate that the information for managing gout is not current, accurate, or best-practice in some resources
- a lack of active language and conversational tone in resources for people with gout
- an emphasis on fear (for example, images of tophi and abscesses) that may discourage readers who do not have tophi or abscesses from reading further or changing their behaviour, but, for a reader with tophi or abscesses, may help them to relate to the resource
- a strong focus on diet and exercise to prevent attacks and manage gout
- preventive medication often mentioned only at the end of resources
- poor quality photo images or pictograms (for example, drawings of brown people did not resonate with the people interviewed)
- resources for health professionals that varied in their treatment guidelines.
- a lack of appeal to, and understanding of, Māori audiences
- webpages that do not print well and include advertising and other distracting information
- information and instructions in many overseas online resources that are different from, or incorrect for, the New Zealand situation
- a lack of summarised information in the resources
- inconsistent font sizes, too many capitalised terms and basic formatting problems in resources, making them difficult to read.

7 Summary of health literacy skills in the population with, or most at risk of developing, gout

The International Adult Literacy Survey and Adult Literacy and Lifeskills Survey measure prose literacy, document literacy and numeracy (OECD and Ministry of Education 2007; Satherley and Lawes 2007, 2008; Satherley et al 2008).

Prose literacy measures a person's ability to search, comprehend and use information from continuous texts such as newspapers. Document literacy measures a person's ability to search, comprehend and use information from non-continuous texts in different formats such as tables, forms and charts. In this context, the PHARMAC *Out with Gout* resource is an example of prose, and the Counties Manukau DHB *Starting on Allopurinol* resource is an example of a document. Numeracy measures a person's ability to effectively manage the mathematical and numerical demands of different situations.

Findings from the Adult Literacy and Lifeskills Survey

The Adult Literacy and Lifeskills Survey found that particular groups within the target population for gout resources have particular skills in relation to prose and document literacy, and numeracy (Satherley and Lawes 2007, 2008; Satherley et al 2008). This information complements the limited audience analysis undertaken earlier in this review.

When we refer to poor health literacy skills we mean skills measured at levels 1 and 2 on a five-point scale. Level 3 is the level at which people are deemed to have the skills for everyday life and work.

Māori and Pacific peoples

Māori generally have similar prose and document literacy levels: 63 percent had poor prose literacy and 64 percent had poor document literacy.

Pacific peoples have slightly better document literacy than prose literacy: 76 percent had poor document literacy skills compared with 79 percent with poor prose literacy.

Seventy-five percent of Māori and 86 percent of Pacific peoples had low numeracy skills.

Age

Age has a negative impact on prose literacy, document literacy and numeracy. Of adults aged 55–65:

- 48 percent had poor prose literacy
- 52 percent had poor document literacy
- 57 percent had poor numeracy skills.

Gender

Women had relative strength in prose literacy, and men had relative strength in numeracy and document literacy.

Labour force status

Labour force status has an impact on literacy skills. People who were unemployed or retired had poorer literacy and numeracy skills than those who were employed:

- 65 percent of unemployed people and 54 percent of retired people had poor prose literacy skills compared with 40 percent of employed people
- 66 percent of unemployed people and 58 percent of retired people had poor document literacy skills compared with 40 percent of employed people
- 76 percent of unemployed people and 65 percent of retired people had poor numeracy skills compared with 46 percent of employed people.

Income levels

Income levels also have an impact on literacy skills with higher document and numeracy skills associated with higher incomes:

- 48 percent of people on the lowest income and 52 percent of people on the next income band had poor document literacy skills compared with 20 percent of people on the highest income
- 58 percent of people on the lowest income and 62 percent of people on the next income band had poor numeracy skills compared with 20 percent of people on the highest income.

8 Health literacy skills required by a person with gout

A person with gout needs to understand key messages for gout, assuming that the person also understands how their body processes food and eliminates waste (such as uric acid, a by-product of the digestive system).

In addition, introducing long-term medication to lower uric acid to the management regime for gout can be a challenging process. People need to manage a mix of regular and increasing medication as well as pain medication taken 'as required' while managing a gout attack caused by the introduction of the uric acid-lowering medicine. Managing medication during the first 3–6 months of treatment is complicated and people easily form incorrect medication habits and beliefs. Poor medication management can also lead to a refusal to use preventive medication. Regular blood tests and doctor and pharmacy visits need to be planned. Medication needs to be continued despite all the symptoms of the gout attack disappearing. Following preventive medication regimes for gout is poor amongst Māori and Pacific peoples, particularly in the long term.

The health literacy demands of managing gout and preventing further attacks are highest when the person is first diagnosed with gout and when the person is first prescribed medication to lower uric acid levels. This is because:

- the person is often unfamiliar with gout at this point
- the person may have to manage multiple medications, depending on how the condition responds to treatment
- there are several myths or common misconceptions about gout.

Gout requires patients to have good numeracy skills so they can understand their uric acid level target and calculate the appropriate dosages for their medications.

In specific terms, people with gout need the following literacy and numeracy skills.

Reading and writing – People need to be able to read, understand and synthesise information from multiple sources and in multiple formats such as online and in print. These abilities are needed to understand the following (some of which also require writing skills):

- clinic forms
- medication labels
- patient information sheets
- health education resources
- letters from health professionals
- uric acid level readings
- internet searches about gout
- notes about uric acid levels and medication.

Speaking and listening – People need skills in speaking and listening to health professionals and others to gain information, check understanding and clarify messages. These receptive (listening) and productive (speaking) processes are usually interactive. People also need to understand verbal and non-verbal language, and to have confidence to speak. The different situations patients face include:

- clinical interactions
- arranging and altering appointments
- interacting with educators (Arthritis New Zealand or others)
- talking with pharmacists
- speaking to whānau about gout and its causes and treatment.

Numeracy skills – People need to be able to add, subtract, multiply and divide whole and part numbers as well as to apply measurement, for example, to:

- understand their uric acid levels and uric acid target
- monitor their fluid intake and food portions
- manage multiple medications and medication doses (including maximum and varying doses based on blood test results).

9 Findings from focus groups with patients and whānau

Arthritis New Zealand (Greater Auckland Branch) was contracted to organise focus groups of Māori with gout for the review. Focus groups were held at Ruapotaka Marae, Glen Innes, (21 November 2011) and Papakura Marae, Papakura, (25 November 2011).

To engage with additional Māori with gout and their whānau, a project team member attended two half-day clinics at Papakura and Clendon (30 November 2011) that Arthritis New Zealand was contracted to provide for Te Raukura Hauora o Tainui, a Māori health provider. By attending these two clinics, the team member could observe how the Arthritis New Zealand educator engaged with people in relation to gout and the resources.

From the clinics, two people with gout were taking their medications regularly without having much understanding about gout. One of these people was taking medication because it was expected of them, and the other because it made them feel physically better (and they had other medical conditions requiring them to take medication).

People with gout, and their families, made few attempts to seek out resources about gout or to read those they had been given without a health professional first explaining the resource and referring to specific sections of the text. Only one of the people with gout interviewed recalled receiving resources about gout but reported he had not read them or could not recall what he had read.

People come to read resources with their own purpose, sense of truth and pre-existing views (known as a person's 'schema'), which may not be factually correct (for example, the myth that gout is not a serious condition). Therefore, when a person with gout is introduced to a resource, a connection needs to be made between the person's schema and the resource. Does the resource align with the patient's schema? Can the person recognise their situation in the resource? If the first thing a person sees is a picture of tophi or an abscess and they do not have them, they might reject the resource because it does not match their schema. Alternatively, if a person is told that their uric acid level is high but has no idea what uric acid is and how it links to gout, then they will have difficulty linking this information (and the accompanying resource) to their schema.

People's schema are built over time. Changing a person's schema means health professionals first have to find out what that schema is and then build a link between it and a new piece of information that should be added.

Managing gout requires a significant change to a widely held belief in the community: that if you are well then you do not need to be on medication. To be well with gout, a large number of people, particularly Māori and Pacific peoples, need to be on medication.

10 Focus groups with health professionals

Four focus groups and one interview were held with health professionals.

Questions asked of health professionals

Health professionals were asked:

- what resources they use when they talk to people about gout
- how they use those resources (for example, during discussions)
- what they know about the health literacy of their patients
- what feedback they have from people about resources
- what they think would be more useful for people with gout and their family and whānau and why?

Where the time for the focus group was restricted (because of other clinical matters), questions were limited to resources used, how they were used, what the health professionals think would be more useful for people with gout and their whānau and why.

Analysis

The two resources health professionals use most are PHARMAC's *Out with Gout* and Counties Manukau DHB's *Starting on Allopurinol*.

Health professionals said they wanted changes to both these resources to:

- simplify *Out with Gout*
- have different versions of *Starting on Allopurinol* that could be used in different contexts.

Suggestions about changes to *Out with Gout* related to health professionals consistently using a limited number of pages from the resource. This does not mean the rest of the information is not important, but it indicates that the most frequently used pages could be put at the front of any new resource and the rest of the material provided as supplementary information.

Most health professionals refer to specific pages in *Out with Gout* (for example, the uric acid graph) and use that page to remind people with gout of a key message. Health professionals suggest that people with gout could read the rest of the book but no one checks whether this happens. Health professionals from both Arthritis New Zealand and Ngāti Porou Hauora are aware that many of their patients would find it difficult to read all of *Out with Gout*.

Because questions about food and exercise are asked early in Arthritis New Zealand's interaction with patients, this may mean that people assume managing gout is about diet and exercise. A focus on dietary issues was also evident in the interactions Ngāti Porou Hauora staff have with people with gout.

Starting on Allopurinol is easier for health professionals to use than *Out with Gout* because, as a patient card, it summarises key messages in a short document. Health professionals can speak to people with gout about the key messages while they are filling in the card. An advantage of *Starting on Allopurinol* is that a discussion between a health professional and a person using this resource can take place within a 15-minute appointment.

Health resources are never neutral. The messages in the resource influence how a reader feels about themselves, the resource and gout. The different ways that health professionals use gout resources with people with gout showed that:

- the resources are not necessarily fit for purpose
- health professionals are not clear about the key messages to be given to people with gout and reinforced over time (that is, different people need different messages at different times).

Health professionals need to reframe resources as tools to identify the extent of a patient's schema and, once that has been identified, to use those resources to gradually build a patient's schema about gout (as alluded to earlier). This means health professionals need to change their current expectations that resources are useful to reinforce a key point, or for the patient to read in their own time so that the patient can learn more and change their behaviour.

11 Conclusion

There is low public awareness, and patient and whānau understanding, of the facts about gout, gout prevention and management. Gout education resources need to be a vehicle for building the health literacy skills and knowledge of people with gout, and their whānau.

During this review, interviews carried out with health professionals as well as people with gout and their whānau highlighted a lack of patient engagement with existing gout education resources. This could be addressed, in part, with resource developers engaging with the intended audience during resource development to ensure the look and content of resources is patient-focused. Another approach is to prioritise and target the messages in resources to better meet the needs of specific audiences, as they have particular information and instruction needs, depending on the cause and symptoms of their gout and the most appropriate actions for them in the short term.

Plain language, separating instructional text from information content, shorter resources, consistent and accurate messaging, and better design will also improve audience engagement. Developing and distributing a set of key messages for preventing and managing gout will help with consistency, accuracy and plain language.

However, the most significant influence on engagement with resources appears to be the way in which health professionals use and discuss the content of gout education resources with people with gout, and their whānau. Resources also provide an opportunity to guide the advice and information provided by health professionals. Any resources that are distributed to patients and whānau without explanation and support are likely to go unread.

12 Recommendations

These recommendations describe how existing resources could be improved.

- 1 Explain health terms in resources to build people's health literacy.
Resources need to be a vehicle for building the health literacy of people with gout and their whānau. There is a significant mismatch between the health literacy of people diagnosed with gout and the literacy demands they face to understand how to prevent attacks and manage gout. For example, gout-specific terms and words such as inflammation, prevention and management need to be explained to build health literacy.
- 2 Make the first resources people receive as short as possible – preferably no more than one or two double-sided pages – and provide additional information during future consultations as people become more health literate.
The messages people are first given need to vary according to whether the person is experiencing a gout attack. There needs to be an understanding between health professionals and people being diagnosed with gout that learning about preventing attacks and managing gout long term is an ongoing process.
- 3 Produce resources that separate **instructions** for preventing and managing gout from general **information** about gout.
- 4 Develop a short, clear instructional resource that provides an individualised gout plan for a person with gout.
The plan would include pain management medication names and dosage, preventive medication names and dosage, blood test dates and results, doctor's visits, clinic visits, and contact numbers for assistance.
- 5 Ensure resource developers work with the target audience when developing, and revising and testing resources.
Developers need to ask the audience what they want from a resource and, when drafts of the resource are available, ask the audience what the draft is telling them. (These practices are described in *Rauemi Atawhai: A guide to developing health education resources* (Ministry of Health 2012).)
- 6 Write resources in clear language, avoid jargon, and follow clear design principles.
- 7 Produce culturally appropriate resources in multiple languages for readers for whom English is not a strong written language.
This requires developers to have language and cultural knowledge and understanding rather than simply providing direct translations of English resources.
- 8 Consider short DVDs, especially featuring people with gout explaining what they do to manage their gout, rather than written material.
DVD resources could also be available online. However, access in rural areas with limited broadband services means that DVDs are often more accessible.
- 9 Prioritise messages about managing gout and preventing attacks, based on the needs of the main audience for a resource.
This could mean producing two versions of a resource: one for people (and their whānau) who need treatment and another for people (and their whānau) who could, in the first instance, try to prevent gout attacks through diet and exercise.
- 10 Develop and reinforce consistent key messages for gout across all resources.
This includes the consistent use of gout language such as triggers, attacks, acute attacks, flares, preventers and relievers. Sub-groups of key messages may be needed to target people

at different stages and with different symptoms of gout. For example, a patient with tophi going on medication for the first time may need a different set of messages than a person who is newly diagnosed with gout and able to prevent attacks through short-term medication and lifestyle changes.

- 11 Reflect the realities of the main audience in the resource.
People need to relate to the pictures and information in a resource if they are to believe it is relevant to them. For example, pictures of large tophi and abscesses may not be relevant for most people with gout.

The next two recommendations take a different approach to gout resources and address the need to extend a person's existing schema concerning gout.

- 12 Reframe resources as tools to help health professionals identify the extent of a person's existing schema about gout, and then to use the resources to add new knowledge to that schema so that the person can manage their gout effectively.
- 13 Develop visual aids to explain high levels of uric acid and crystals (examples of existing visual resources may provide a basis for new resources).

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