National Institute for Health and Care Excellence

Guideline version (Final)

Gout: diagnosis and management

[A] Evidence review for patient information

NICE guideline NG219

Evidence reviews underpinning recommendations 1.2.1 and 1.2.2 in the NICE guideline

June 2022

Final

National Institute for Health and Care Excellence

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ISBN: 978-1-4731-4603-7

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1.1 Review question: What information and support is needed by people with gout and their families or carers in relation to gout, and when should this be provided?

1.1.1 Introduction

People with gout (and their families and carers) require information that explains the causes, diagnosis, treatment and self-management options including dietary advice to support active participation in their care and engage in shared decision making.

As gout is a long-term condition, ongoing support may be required not only during acute episodes, but also to ensure the efficacy of life-long drug treatment such as urate lowering therapy. In current practice the provision of information and support varies widely and dependent on many factors including the knowledge and time available to the clinician.

This evidence review evaluates the information and support needs of people with gout and their families or carers and when this should be provided.

1.1.2 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	• To determine what information and support should be provided to people with gout and their families or carer, for example: Methods of diagnosis • Long-term impact of gout • Treatment options • Timing • Causes of gout (risk factors) • Pathophysiology (hyperuricemia, crystal deposition disease)
Population and setting	Inclusion: Adults (18 years and older) with gout and their families or carers, and health care professionals. Opinions of adults with gout and their families or carers, and health professionals. Exclusion: People with calcium pyrophosphate crystal deposition, including pseudogout.
Context	The context will depend on what is found within the studies.
Review strategy	Synthesis of qualitative research. Results presented in narrative and table format. Quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

1.1.3 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in Appendix A and the methods document.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

1.1.4 Qualitative evidence

1.1.4.1 Included studies

We searched for qualitative studies looking at information and support needed by people with gout and their families or carers and when this should be provided.

Eighteen qualitative studies were included in the review [2, 3, 7, 13, 15-17, 26, 27, 29, 40-42, 46, 53, 56, 58, 59]. These are summarised in Table 2 below.

Three studies[27, 41, 42] conducted separate qualitative analyses using data from one population of patients, therefore we have amalgamated these three studies within this review.

Most of the studies used semi-structured interviews with a mixture of grounded theory or thematic analysis. One study[56] used the Kaupapa Maori approach. One study[2] used focus groups.

Key findings from these studies are summarised in the clinical evidence summary below Table 2. See also the study selection flow chart in Appendix C study evidence tables in Appendix D, and excluded studies lists in Appendix F.

Studies included populations with gout on different treatments. Four studies included a population in an area with a higher prevalence of gout (Humphrey 2016),[16] (Martini, 2012),[29] (Rebello, 2016),[40] (Te Karu, 2013).[56] Most studies interviewed patients with gout or their partners, however some studies examined the experience and views of health care professionals.

One study examined patient perceptions of a nurse-led package of care (Latif, 2019)[26] One study interviewed pharmacists (Counsell, 2018)[3], four studies interviewed GPs or as part of a mixed group Jeyaruban, 2016,[17] Vaccher, 2016[58], Humphrey, 2016[16] and Spencer, 2012.[53] Two studies recruited patients from other studies (Howren 2018)[15] which included patients who were participating in an eHealth supported collaborative care study (Virtual Gout Study) and Latif 2019[26] which included patients from the nurse-led care arm of an RCT.

As a lot of papers were identified for this review, inclusion was halted once saturation was reached. Saturation is the point at which no new information emerged from studies that were found to match the review protocol.

A narrative summary of the evidence synthesis is provided in Table 3.

1.1.4.2 Excluded studies

See Appendix F for details of excluded studies.

1.1.5 Summary of studies included in the qualitative evidence

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Chandratre 2016[2]	Focus groups with thematic analysis	Patients from the baseline phase of a cohort study of HRQOL in gout. n= 17; 15 M/2F; mean age 71 years UK	To examine the impact of gout and its treatments on health-related quality of life using focus group interviews.	Exclusively Caucasian and mainly male. Study was focused on HRQOL in gout.
Counsell, 2018[3]	Qualitative, semi-structured interviews with thematic analysis	Community pharmacists n=15; 11F/4M Australia	To explore the views of Australian pharmacists on their roles in gout management and to identify factors influencing their involvement in gout management.	Selection bias: the pharmacists were known to the researchers.
Deprouw, 2019[7]	Qualitative, semi-structured interviews with grounded approach	Nurses (n=20), 9 rheumatology, 11 internal medicine; and partners of gout patients n=12; 11F/1M France	To explore partners' of gout patients and nurses' knowledge and representations of gout.	Partners of gout patients and nurses
Harrold 2010[13]	Qualitative, semi-structured interviews with thematic analysis	Patients with gout (n=26) and providers who care for gout patients (n=15). USA	To examine patients' and health care providers' views on the treatment of gout to better understand why management is suboptimal.	Patients and health care providers
Howren 2018[15]	Qualitative, semi-structured interviews	Patients with gout n=12; 10 M/2 F mean age 66.5 ± 13.3 years	To use patients' perspectives to construct an explanatory framework to understand how patients become engaged in the management	Patients who were participating in a proof-of-concept study (Virtual Gout Study) were recruited. Patients had a SUA>360µmol/l in the past 2 months.

Study	Design	Population	Research aim	Comments
		Canada	of their gout.	
Humphrey 2016[16]	Qualitative, semi-structured interviews	N=14 professionals who had regular interactions with patients with gout (six general practitioners (GPs),four nurses, and one pharmacist.) New Zealand	To explore the experience of treating gout among primary care clinicians and understand the perceived barriers to effective therapy.	HCPs
Jeyaruban, 2016[17]	Qualitative, semi-structured interviews with thematic analysis	N=14 providers (GPs) Australia	To explore management of gout from the perspective of GPs, while identifying the barriers and possible strategies for improvement.	GPs
Latif, 2019[26]	Qualitative, semi-structured interviews	Patients with gout N=30; 26M/4F Age: 65.17 (11.51) years (mean), 36-85 years (range). UK	To explore patient perception of the role of a nurse-led complex package of care in facilitating engagement with urate-lowering therapies (ULTs) in the management of gout.	Participants were recruited from an RCT investigating a nurse-led package of care for gout.
Liddle, 2015[27] Richardson, 2016[41] Richardson, 2015[42]	Qualitative, semi-structured interviews	Patients with gout N=43 67%M Age range 30-89 years (Richardson 2015 n=14 age range 32 to 82) UK	(Richardson 2016) To explore reasons for the low prescription rate for urate lowering therapy (ULT) and the low adherence to treatment through an exploration of patient experience and understanding of ULT treatment for gout. (Liddle 2015) To explore patients' experiences from initial	Liddle 2015 and Richardson 2016 had the same population but had different analyses performed. Richardson 2015 was based a subset of female patients.

Study	Design	Population	Research aim	Comments
			symptoms to receiving a diagnosis of gout. (Richardson 2015) To explore the perspectives of females on receiving a diagnosis of gout and of female-specific issues related to the diagnosis.	
Martini, 2012[29]	Qualitative, semi-structured interviews with thematic analysis	Patients with gout N= 60 54M/6F Age range: 23-93 years New Zealand	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.	All of the patients had been prescribed allopurinol or colchicine.
Rebello, 2016[40]	Qualitative, semi-structured interviews with thematic analysis	N=30 patients 24M/6F Age range 28-76 years New Zealand	To explore patients' knowledge on the use of gout medicines, and in particular their awareness of the maximum dose of colchicine, the dangers of colchicine overdose, and their opinions on restricting colchicine dispensing.	Patients were from an area with a high prevalence of gout
Seow, 2020[46]	Qualitative, semi-structured interviews with thematic analysis	Patients with gout N=15 15M Age range 32-85 years Ethnicity: 12 Chinese, two Malay, and one Filipino Singapore	To explore the perceptions regarding living with gout of patients with gout in Singapore	All participants were male

Study	Design	Population	Research aim	Comments
Spencer, 2012[53]	Qualitative, semi-structured interviews with grounded theory analysis	20 patients with gout (15M/5F) and 18 health care professionals Mean age: 61 years UK	To explore patient and provider illness perceptions and barriers to effective management of gout in general practice.	Patients had an SUA level >360µmol/l (i.e., were sub-optimally treated)
Te Karu, 2013[56]	Qualitative, semi-structured interviews with thematic analysis	Maori population. N=12 67%M Age range: 48-79 years, New Zealand	To explore the perceptions, understanding and treatment of gout among Maori	Kaupapa Maori approach for methodology
Vaccher, 2016[58]	Qualitative, semi-structured interviews with thematic analysis	15 GPs (6M/9F) 22 patients with gout (19M/3F) Median age: 59 years Australia	To explore the understanding of gout and its management by patients and general practitioners (GP), and to identify barriers to optimal gout care.	Patients and GPs
Van Onna, 2015[59]	Qualitative, semi-structured interviews with grounded theory analysis	Patients with gout attending primary or secondary care. N=15 14M/1F Mean age 63 years The Netherlands	To explore the health literacy of patients dealing with gout and to understand perceptions that might account for non-adherence to urate lowering therapy.	7 were using colchicine or NSAIDs plus ULT, 3 were using only colchicine or NSAIDs, 5 were using only ULT

See Appendix D for full evidence tables.

1.1.6 Summary of the qualitative evidence

Table 3: Review findings: information and support needs

Main findings	Statement of finding
Information needs	
Causes of gout 8 studies Patients: Chandratre 20162, Liddle, 201527, Martini, 201229, Partners and nurses Deprouw, 20197, Patients and HCPs Harrold 201013, Spencer, 201253, Vaccher, 201658 HCPs Jeyaruban, 201617	Causes of gout were poorly understood and many alternative causes were suggested, including alternative pathophysiologies, injury and ageing.
Dietary advice 8 studies (from 7 populations Patients Chandratre 20162, Latif, 201926, Liddle, 201527, Martini, 201229, Richardson, 201641, Seow, 202046, Partners and nurses Deprouw, 20197,, Patients and HCPs Vaccher, 201658	Many patients requested dietary advice, commonly wanting to know which foods and drinks were ‘safe’ and what were to be avoided.
Long-term impact of gout 8 studies Patients Chandratre 20162, Howren 201815, Liddle, 201527, Martini, 201229, Richardson, 201641, Van Onna, 201559 Partners and nurses Deprouw, 20197, Patients and HCPs Vaccher, 201658,	Gout is often treated as an acute condition and the long-term consequences were not frequently understood or discussed.

Main findings	Statement of finding
Tailored information for females 4 studies (from 3 populations): Patients Liddle, 201527, Martini, 201229, Richardson, 201542, Patients and HCPs Spencer, 201253	Delays in diagnosis due to gender, poor provision of female specific information.
Online information 5 studies: Partners and nurses Deprouw, 20197, Patients Howren 201815, Liddle, 201527, Van Onna, 201559 Patients and HCPs Vaccher, 201658,	Patients commonly searched the internet for information following diagnosis. Information online was often found to be incorrect, contradictory or ambiguous.
Information preferences 8 studies (from 7 populations): Patients and HCPs Harrold 201013, Vaccher, 201658, Patients Latif, 201926, Liddle, 201627, Rebello, 201640, Richardson, 201641, Seow, 202046, Van Onna, 201559	Patients wanted more time for discussion during consultations, especially at diagnosis, more oral and written information and to be involved in the decision- making process.
Support needs	
Role of GPs 4 studies: Patients Martini, 201229, Te Karu, 201356#1216, Patients and HCPs Spencer, 201253, Vaccher, 201658	Need for improved and continuing medical education. GPs felt they didn’t have enough time or appropriate material to provide to patients. Language/ cultural barriers were cited as a barrier to providing education and resulted in different understandings of gout. There was a lack of awareness of guidelines on gout. Most information was provided verbally and there was a lack of resources for providing information about gout, such as reading material, websites, and video resources.
Role of nurses 3 studies: Partners and nurses Deprouw, 20197,	Nurses felt that with more training they would be better placed to educate and monitor patients.

Main findings	Statement of finding
HCPs Humphrey 201616, Patients Latif, 201926,	
Role of pharmacists 2 studies: Pharmacists Counsell, 20183, Patients Martini, 201229	Pharmacists had a good understanding of medication related issues and of dietary information. Able to 'bridge the gap' between patient and GP due to having more time. Opportunity to offer information at each prescription.
Referral to specialists 5 studies (from 4 populations): Partners and nurses Deprouw, 20197, Patients and HCPs Harrold 201013, Patients Liddle, 201527, Richardson, 201641, Seow, 202046	A variety of views on specialist referral were found, both from patients, family/ friends and their GPs.

See Appendix E for full GRADE-CERQual tables.

Narrative summary of review findings

Review finding 1: Patient knowledge of causes of gout

The causes of gout were in general poorly understood by patients. Despite many patients having a family history of the condition, very few believed there to be a genetic link. Some stated they had no idea of possible causes. There was also a lack of knowledge in relation to medication and renal factors linked to gout.

The lack of understanding of the causes of the disease created some doubt about the diagnosis. There was a general view that it was self-inflicted and therefore ‘not a disease’ and this caused people to hesitate in seeking medical help.

Explanation of quality assessment: minor methodological limitations in six of the eight contributing studies due to the unclear role of the researcher and moderate limitations in two studies due to the recruitment process and data analysis; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate/ high confidence in this finding.

Review finding 2: Patient knowledge of dietary advice

Many patients were unsure of dietary advice citing a variety of beliefs on the subject, as found in the causes of gout theme, the lack of knowledge of pathophysiology of the disease gave rise to confusion about dietary triggers. Diet was a frequent topic for discussion, particularly at GP appointments. Published information provided was not always clear and sometimes in contradiction to verbal information given by HCPs. Patients especially wanted to know what their personal triggers where, and how to cope with eating outside of the home.

Explanation of quality assessment: minor or very minor methodological limitations in five of the seven studies due to the unclear role of the researcher and moderate limitations in two due to the recruitment process and data analysis and one study with moderate concerns about the role of the researcher.; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate/ high confidence in this finding.

Review finding 3: Long-term impact of gout

Many GPs focussed on acute attacks and acknowledged that they do not give enough information on the possible long-term consequences of gout, and this leads many patients to be unaware of the chronic nature of the disease. Some GPs appeared reluctant to prescribe allopurinol, citing reasons such as it was better to wait until the patient experience a flare, or that it could cause a flare. Nurses and partners of patients with gout highlighted the need for a better understanding of ULT. Patients who did take ULT often discontinued early as they were unaware of its preventative nature. Compliance with preventative medication appeared to improve when patients were made aware of the long-term issues and possible complications. Patients also expressed a desire to know more about long-term medication.

Explanation of quality assessment: minor or very minor methodological limitations in the contributing studies; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance due to some contributing studies; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of high confidence in this finding.

Review finding 4: Tailored information specifically for females

Often, women with symptoms suggestive of gout were dismissed due to their gender, or their age. This caused delays in diagnosis. There was also not much information specifically tailored to females available. There was a general belief among patients and HCPs that women did not suffer from gout, leading to patients believing that there was something else wrong with them. Female patients wanted information tailored to them and wanted to know how medications could affect female specific issues.

Explanation of quality assessment: minor methodological limitations in the contributing studies; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of high confidence in this finding.

Review finding 5: Online sources of information

Patients mainly stated that the first thing they did after receiving the diagnosis was to check for more information online. While many websites, NHS and others provided helpful information, and patient forums provided a sense of community, patients frequently found conflicting, incorrect, or ambiguous advice. Some patients found the information they retrieved alarming. As a consequence, some patients changed their diets based on online advice and even bought monitoring equipment.

Explanation of quality assessment: minor methodological limitations seven of the eight contributing studies, with the exception of moderate concerns in one study due to recruitment and data analysis; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate/ high confidence in this finding.

Review finding 6: Information/ education preferences

Some HCPs wrongly assume patients know more about the gout than they do, due to it being a well-known condition. Many patients found the information provided contradictory and difficult to follow. Most people got their information from their GP, although some mentioned receiving information from their pharmacist. Most asked for extra information, and preferred written information that they could read at home with their family or carers. This was especially true in cases where the GP did not speak the patient’s first language. When oral advice was given, it was difficult for patients to recall. Some people highlighted that information using pictures was particularly helpful.

Many patients stated that at the point of diagnosis, they would like to have enough time to discuss the implications of their condition and receive information on medication and diet.

Explanation of quality assessment: minor methodological limitations in the contributing studies, with the exception of moderate concerns in one study due to recruitment and data analysis; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate/ high confidence in this finding.

Review finding 7: Role of GPs

With consultation times being so short, it was difficult for many GPs to devote enough time to educating their patients about gout. GPs reported feeling insufficiently trained and lacking confidence in providing gout care and education. They reported that undergraduate and postgraduate training in the area had been poor and most of their knowledge was through self-directed learning. Often, GPs did not manage gout as a long-term condition, and prescribed medication only for acute attacks.

Most GPs questioned were not aware of existing guidelines relating to gout, but suggested flowcharts and websites would be helpful. In certain populations some GPs stated feeling uncomfortable with providing dietary advice due to cultural issues; and language barriers could also hinder the process of providing information.

Explanation of quality assessment: minor methodological limitations in two of the contributing studies and moderate concerns in two studies due to recruitment and data analysis; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this finding.

Review finding 8: Role of nurses

Most nurses described having poor knowledge of gout, citing similar experiences to GPs with regards educational opportunities. They expressed a strong desire to learn more about the condition. Many nurses encounter patients with gout as a comorbidity in chronic disease management clinics, but felt they were well-placed to offer monitoring for patients on ULT and provide information to patients during monitoring.

Explanation of quality assessment: all studies had minor methodological limitations due to the unclear role of the researcher; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of high confidence in this finding.

Review finding 9: Role of pharmacists

Pharmacists stated that they usually only provided information and advice at the first prescription but acknowledged that the nature of medication dispensing provided an opportunity for providing further advice and monitoring the condition. Some patients reported receiving information from the pharmacist

Explanation of quality assessment: moderate concerns in both studies due to recruitment and data analysis; no concerns about the coherence of the finding with nothing to lower our confidence; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this finding.

Review finding 10: Specialist referral

In some cases, patients asked for a referral to a rheumatologist as soon as they received a diagnosis, or prior to commencing allopurinol. Friends and family of patients with a history of gout would advise them to see a rheumatologist, in some cases instead of seeing a GP. In other cases, patients were unaware of the option of seeing a specialist.

Some GPs referred patients relatively frequently, to a rheumatologist or a dietician, others said it was not necessary when asked.

Explanation of quality assessment:

All studies had minor methodological limitations due to the unclear role of the researcher; moderate concerns about the coherence of the finding with a variation in reported experiences; no concerns about relevance; no concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of low confidence in this finding.

Qualitative evidence summary

1.1.7 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

1.1.8 The committee's discussion and interpretation of the evidence

1.1.8.1 The quality of the evidence

Overall, the quality of the evidence was mostly graded by GRADE-CERQual as moderate/high confidence in the findings. An exception was for referral to a specialist which was graded low due to minor methodological limitations as well as a lack of coherence because of variation in experiences reported by patients requesting referral at first diagnosis. The committee thought that this was due to the varying expectations of people with gout but that referral to a rheumatologist is unlikely to be required at diagnosis. The rest of the evidence had only study limitations and no concerns about coherence, applicability or adequacy of the findings. The methodological limitations were mostly due to the unclear role of the researcher and sometimes due to the recruitment process or data analysis. This meant that overall, the committee had confidence in the findings and agreed they were reliable enough to make recommendations. However, they did think there was some limitation in the relevance of the role of GP, nurses and pharmacists as this included the education, they required to improve health practitioner knowledge. Although health professionals were included in the protocol this was regarding what information and support, they thought should be provided to the patient.

1.1.8.2 Findings identified in the evidence synthesis

One of the information needs identified in the review included the 'causes of gout', which were found to be often poorly understood by people with gout, their families, and health care professionals even when the patient had a family history of the condition. The prevailing belief was that gout was a self-inflicted disease brought on by dietary habits, rather than occurring as a result of genetics, obesity, comorbidities or medications. This was thought to make people resistant to seeking medical help. This belief linked to the second finding 'dietary advice'. Many people requested dietary advice at their G.P. appointment to know what foods were advisable and which to avoid. The misconceptions about the effect diet had on the condition demonstrated the lack of knowledge of the pathophysiology of the disease and over emphasis placed on the role diet has in managing the condition. The evidence found people with gout thought that information available on dietary modifications was not always clear and sometimes contradicted the information provided by healthcare professionals. The committee agreed advice on diet was commonly asked for and acknowledged there was a lot of misleading information on diet available. The committee discussed the general lack of understanding of gout by patients and agreed provision of information on the causes of gout, and the signs and symptoms to look out for should be provided. The committee also discussed the importance of an awareness of risk factors when undertaking history taking and discussion of these with the person. Genetic links had been highlighted in the review, but the committee also raised obesity, comorbidities such as chronic kidney disease and hypertension, and polypharmacy were other risk factors that people should be informed about and included within the recommendation.

The theme around the 'long-term impact of gout' included the finding that more often GPs focused on acute flares and didn't provide enough information about the long-term consequences of gout. This could contribute to poor adherence as patients may discontinue their medication earlier because they are unaware that gout is a chronic condition requiring long-term treatment. The evidence reported people discontinuing urate lowering therapy unaware that it is a preventative medication, but also that adherence improved when people were made aware of the long-term consequences of not continuing on ULT. Generally, people wanted more information on long-term medication. The committee agreed with the conclusions of this finding, and it reflected their own experience that there is a lack of understanding about gout being a condition requiring long-term treatment amongst health professionals as well as patients. They acknowledged there is often more focus by clinicians on treating a flare rather than managing the condition in the long-term, and patients will often look to altering diet or lifestyle as a means to improve their condition. The committee wanted to highlight that although a healthy diet and lifestyle should be promoted it will not stop the progression of gout without medication. The committee agreed people needed to be made aware that gout is a life-long condition requiring long-term medication in order to control urate levels, reduce flares and prevent permanent damage to joints.

The themes of ‘online sources of information’ and ‘information preferences’ were linked in that both highlighted conflicting, incorrect or ambiguous information being reported by gout patients. After receiving a diagnosis many people will seek further information via websites. The committee concurred with this and noted people should be signposted to reputable, trustworthy online sources such as NHS websites and recognised gout charities and organisations. People stated they wanted more time to discuss their condition particularly around the time of diagnosis. Generally, there was a preference for having written information that could be read in the person’s own time and shared with family or carers.

There were a few studies that looked at the requirement for ‘tailored information specifically for females. Often the possibility of women having gout was dismissed by health care professionals because of the belief it is not a condition that affects women, and this can lead to delays in diagnosis. Female patients wanted information tailored more towards them and their specific issues such as gout within younger age groups and links with menopause. The committee agreed that there was an embedded belief that gout was primarily only found in older males and that women could be mis-diagnosed because of this.

Generally, GPs and nurses reported that they lacked training in the condition and consequently believed they had insufficient knowledge to provide education and information to patients with any confidence. Nurses related their experience of caring for people with gout who have other chronic conditions and believed with the correct training they were well placed to monitor and provide information on medication such as ULT as part of monitoring a person’s other conditions. Pharmacists also stated they could bridge the gap between the GP and patient, providing advice on medication and directing people to other sources of information or back to their GP.

From the findings presented the committee decided to recommend providing tailored information as what was required would vary according to the needs of the individual and the stage of the care pathway they were on. They agreed it was important to highlight that this was best provided not only at the time of diagnosis but also at follow-up appointments, as the flare may not be the best time for patients to take in information when they are in acute pain. Providing information at subsequent appointments provides the opportunity to reinforce important messages and this allows the patient time to think about subsequent questions to ask to get the information they require. The committee reflected on the themes found within the evidence and used this as a basis to detail the key information that should be provided within the recommendation.

1.1.8.3 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this was a qualitative review. The recommendations made as a result of this review question provide guidance on what topics should be covered within a patient review. The committee agreed that this provision of information would not require an additional appointment and would likely be provided at the time of diagnosis or scheduled follow-up appointments. Therefore, this recommendation is not expected to result in a substantial resource impact.

1.1.8.4 Other factors the committee took into account

The committee noted that information on how to manage gout flares was not a theme that had emerged strongly from the evidence, however providing a person with information on the treatment options available was very important in order that the person can act quickly and bring their symptoms under control. Therefore, based on committee consensus this was included in the recommendation.

The committee agreed cross reference should be made to the recommendations within the NICE guidance Patient experience in adult NHS services and Shared decision making

The committee identified UK gout society as a useful online resource to use.

1.1.9 Recommendations supported by this evidence review

This evidence review supports recommendations 1.2.1 to 1.2.2.

1.1.10 References

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Appendices

Appendix A – Review protocols

Review protocol for patient information

ID	Field	Content
0.	PROSPERO registration number	Not applicable
1.	Review title	Information and support needed by people with gout and their families or carers in relation to gout, and when should this be provided
2.	Review question	What information and support is needed by people with gout and their families or carers in relation to gout, and when should this be provided?
3.	Objective	To determine what information and support should be provided to people with gout and their families or carer, for example: • Methods of diagnosis • Long-term impact of gout • Treatment options • Timing • Causes of gout (risk factors) • Pathophysiology (hyperuricemia, crystal deposition disease)
4.	Searches	The following databases (from inception) will be searched: • Embase • MEDLINE • CINAHL • PsycINFO Medline search strategy to be quality assured using the PRESS evidence-based checklist (see methods chapter for full details) Searches will be restricted by: • English language studies • Human studies

		The searches may be re-run 6 weeks before the final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Gout (including people with gout and chronic kidney disease)
6.	Population	Inclusion: Adults (18 years and older) with gout and their families or carers, and health care professionals. Exclusion: People with calcium pyrophosphate crystal deposition, including pseudogout.
7.	Phenomena of interest	Views, opinions, and experiences relating to information, education, or support.
8.	Comparator	Not applicable
9.	Types of study to be included	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology, or other appropriate qualitative approaches). Survey data or other types of questionnaires will only be included if they provide analysis from open-ended questions, but not if they report descriptive quantitative data only.
10.	Other exclusion criteria	Non-English language studies. Conference abstracts will be excluded as it is expected there will be sufficient full text published studies available.
11.	Context	It was thought important for people with gout to have more understanding of gout and how to manage it. This was thought best investigated within a qualitative review. This would uncover what people with gout and their families and carers think relevant information and support is and when it should be provided. Such a review would highlight information that should be covered within consultations such as methods of diagnosis, causes of gout, impact of gout, treatment options. Furthermore, whether specific timing of this information was important.
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and not pre-specified, but areas of interest include:

		Who will provide information? (preference) Format (written, internet) Delivery (face-to-face, telephone, video conferencing, one-one one versus group) How often? And when delivered?
14.	Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations, and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract data from studies (see Developing NICE guidelines: the manual section 6.4). Additional qualitative studies will be added to the review until themes within the analysis become saturated, i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes. The point at which data saturation is reached will be noted within the review. 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: • papers were included /excluded appropriately • a sample of the data extractions • correct methods are used to synthesise data • a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary.
15.	Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual - Critical Appraisal Skills Programme (CASP)

<table>
<tr><td></td><td></td><td colspan="3">qualitative checklist</td></tr>
<tr><td>16.</td><td>Strategy for data synthesis</td><td colspan="3">The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings.
GRADE CERQual will be used to synthesise data from qualitative studies.</td></tr>
<tr><td>17.</td><td>Analysis of sub-groups</td><td colspan="3">• Patients versus family and carers
• Those with and without CKD</td></tr>
<tr><td rowspan="7">18.</td><td rowspan="7">Type and method of review</td><td>☐</td><td colspan="2">Intervention</td></tr>
<tr><td>☐</td><td colspan="2">Diagnostic</td></tr>
<tr><td>☐</td><td colspan="2">Prognostic</td></tr>
<tr><td>☒</td><td colspan="2">Qualitative</td></tr>
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<tr><td>☐</td><td colspan="2">Service Delivery</td></tr>
<tr><td>☐</td><td colspan="2">Other (please specify)</td></tr>
<tr><td>19.</td><td>Language</td><td colspan="3">English</td></tr>
<tr><td>20.</td><td>Country</td><td colspan="3">England</td></tr>
<tr><td>21.</td><td>Anticipated or actual start date</td><td colspan="3">14th January 2020</td></tr>
<tr><td>22.</td><td>Anticipated completion date</td><td colspan="3">13th June 2022</td></tr>
<tr><td rowspan="6">23.</td><td rowspan="6">Stage of review at time of this submission</td><td>Review stage</td><td>Started</td><td>Completed</td></tr>
<tr><td>Preliminary searches</td><td>☑</td><td>☑</td></tr>
<tr><td>Piloting of the study selection process</td><td>☑</td><td>☑</td></tr>
<tr><td>Formal screening of search results against eligibility criteria</td><td>☑</td><td>☑</td></tr>
<tr><td>Data extraction</td><td>☐</td><td>☐</td></tr>
<tr><td>Risk of bias (quality)</td><td>☐</td><td>☐</td></tr>
</table>

		assessment		
		Data analysis	☐	☐
24.	Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail managementofgout@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and National Guideline Centre		
25.	Review team members	From the National Guideline Centre: Gill Ritchie [Guideline lead] Julie Neilson [Senior Systematic reviewer] Audrius Stonkus [Systematic reviewer] Alexandra Bonnon [Health economist] Amber Hernaman [Project manager] Joseph Runicles [Information specialist]		
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.		
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: [NICE guideline webpage].		

29.	Other registration details	[Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.]	
30.	Reference/URL for published protocol	[Give the citation and link for the published protocol if there is one.]	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE. [Add in any additional agree dissemination plans.]	
32.	Keywords	[Give words or phrases that best describe the review.]	
33.	Details of existing review of same topic by same authors	[Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible. NOTE: most NICE reviews will not constitute an update in PROSPERO language. To be an update it needs to be the same review question/search/methodology. If anything has changed it is a new review]	
34.	Current review status	☒	Ongoing
		☐	Completed but not published
		☐	Completed and published
		☐	Completed, published, and being updated
		☐	Discontinued
35..	Additional information	[Provide any other information the review team feel is relevant to the registration of the review.]	
36.	Details of final publication	www.nice.org.uk	

Appendix B – Literature search strategies

- What information and support is needed by people with gout and their families or carers in relation to gout, and when should this be provided?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[32]

For more information, please see the Methodology review published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 4: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 06 July 2021	Qualitative studies Exclusions (animal studies, letters, comments)
Embase (OVID)	1974 – 06 July 2021	Qualitative studies Exclusions (animal studies, letters, comments)
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 06 July 2021	English language studies
PsycINFO (ProQuest)	Inception – 06 July 2021	English language studies

Medline (Ovid) search terms

1.	exp Gout/
2.	gout*.ti,ab.
3.	toph*.ti,ab.
4.	podagra.ti,ab.
5.	pseudogout.ti,ab.
6.	or/1-5
7.	letter/
8.	editorial/
9.	news/
10.	exp historical article/
11.	Anecdotes as Topic/
12.	comment/
13.	case report/
14.	(letter or comment*).ti.
15.	or/7-14

16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animals/ not humans/
19.	exp Animals, Laboratory/
20.	exp Animal Experimentation/
21.	exp Models, Animal/
22.	exp Rodentia/
23.	(rat or rats or mouse or mice).ti.
24.	or/17-23
25.	6 not 24
26.	Limit 25 to English language
27.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
28.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
29.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
30.	or/27-29
31.	26 and 30

Embase (Ovid) search terms

1.	exp Gout/
2.	gout*.ti,ab.
3.	toph*.ti,ab.
4.	podagra.ti,ab.
5.	pseudogout.ti,ab.
6.	or/1-5
7.	letter.pt. or letter/
8.	note.pt.
9.	editorial.pt.
10.	case report/ or case study/
11.	(letter or comment*).ti.
12.	or/7-11
13.	randomized controlled trial/ or random*.ti,ab.
14.	12 not 13
15.	animal/ not human/
16.	nonhuman/
17.	exp Animal Experiment/
18.	exp Experimental Animal/
19.	animal model/
20.	exp Rodent/
21.	(rat or rats or mouse or mice).ti.
22.	or/14-21
23.	6 not 22

24.	Limit 23 to English language
25.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
26.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
27.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
28.	or/25-27
29.	24 and 28

CINAHL (EBSCO) search terms

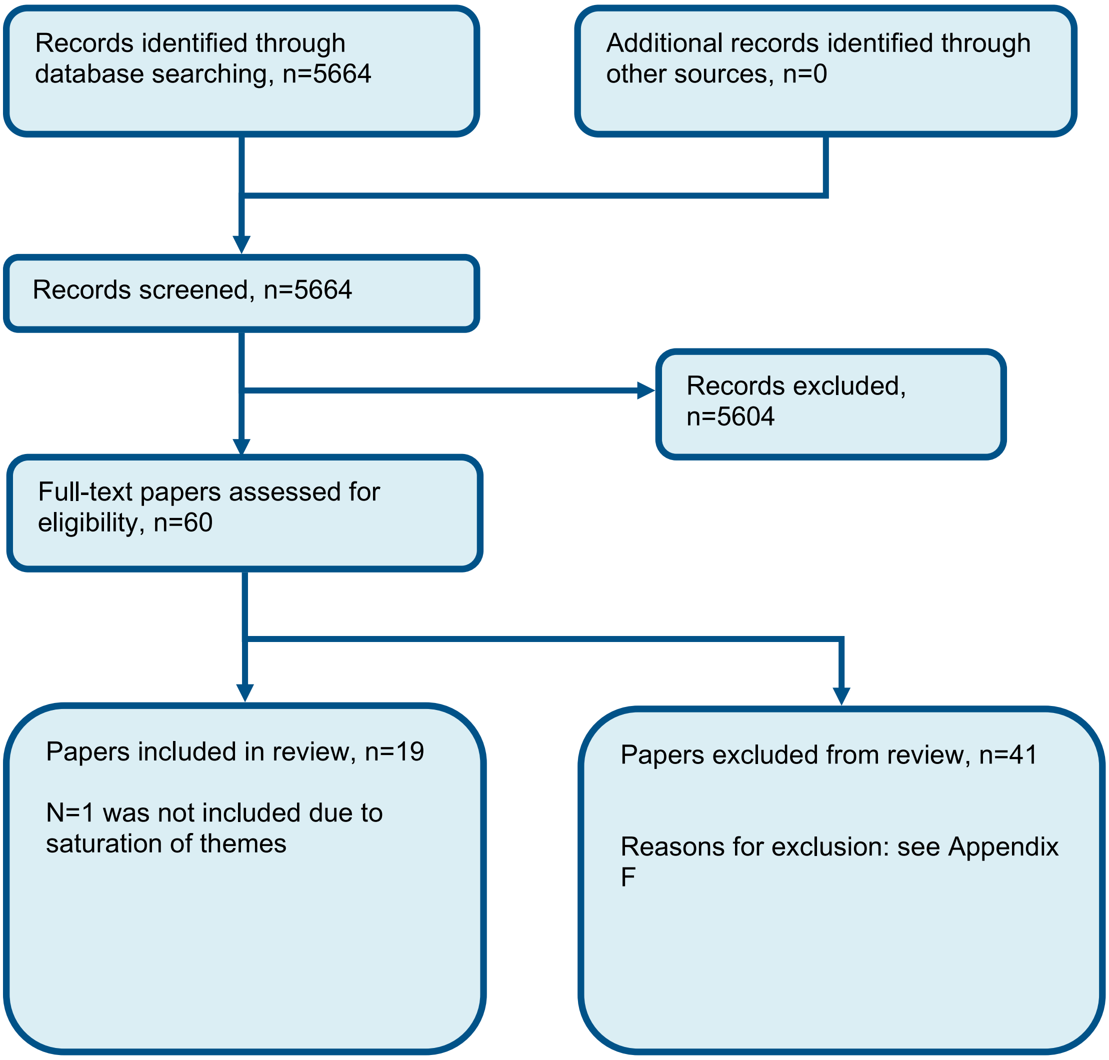
S1.	(MH "Gout")
S2.	gout*
S3.	toph*
S4.	podagra
S5.	pseudogout
S6.	S1 OR S2 OR S3 OR S4 OR S5
S7.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT “questions and answers” or PT response or PT software or PT teaching materials or PT website
S8.	S6 not S7
S9.	(MH "Qualitative Studies+")
S10.	(MH "Qualitative Validity+")
S11.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S12.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S13.	S9 or S10 or S11 or S12
S14.	S8 and S13

PsycINFO (ProQuest) search terms

1.	(Gout* OR toph* OR podagra OR pseudogout) NOT ((su.exact.explode("rodents") OR su.exact.explode("mice") OR (su.exact("animals")) NOT ((su.exact("human males") OR su.exact("human females") OR ti(rat OR rats OR mouse OR mice))
2.	((su.exact.explode("qualitative methods") or su.exact("narratives") or su.exact.explode("questionnaires") or su.exact.explode("interviews") or su.exact.explode("health care services") or ti,ab(qualitative or interview* or focus group* or theme* or questionnaire* or survey*) or ti,ab(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* near/3 analys*) or theoretical-sampl* or purposive-sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*))
3.	1 and 2

Appendix C –Qualitative evidence study selection

Figure 1: Flow chart of qualitative study selection for the review of patient information



Appendix D – Qualitative evidence

Study	**Chandratre, 2016**[2]
Aim	To examine the impact of gout and its treatments on health-related quality of life using focus group interviews.
Population	From the baseline phase of a cohort study of HRQOL in gout, participants with varying attack frequency and treatment with and without allopurinol participated in one of four focus group interviews. A sub-sample of 120 baseline responders with a primary care Read code diagnosis of gout or prescription of colchicine allopurinol in the preceding 2 years were invited to participate. n= 17 patients with gout (one was a carer who did not have gout themselves); 15 M/ 2F; mean age 71 years
Setting	University and general practice, UK
Study design	Qualitative- focus group interviews
Methods and analysis	Focus groups containing 3-5 participants. The moderator used a topic guide to guide the interview, which had been developed in conjunction with 5 expert patients with gout from the research centre's Research Users Group. The topic guide was pre-determined but not prescriptive, and participants were encouraged to lead the discussion. The main question of the focus group enquiry was: 'What impact has gout and its treatment had on your Quality of Life?'. All interviews were audio-recorded and transcribed verbatim. Thematic analysis was based on Braun and Clarke's framework, modified by combining reviewing and defining themes into one stage. The original transcripts were scrutinised by three researchers for data relevant to the impact of gout (and its treatment) on all aspects of quality of life, which were then coded. Codes used to annotate the main text that were similar in nature were clustered together into themes. Similar themes were organised under one overarching theme or higher order descriptive label. Thematic analysis was data driven (inductive) as far as possible. Data analysis and interpretation were iterative as new themes developed on repeated reading of the transcripts, until no new themes could be identified (data saturation).
Findings	**Understanding of gout** Over-indulgence as a cause for gout and dietary modifications: some reported uncertainty regarding diet and its role in causing and treating gout. There was a lack of information from 'trusted' sources such as health care practitioners, and participants relied on NHS endorsed and unendorsed websites for detailed dietary information. Self- discovered sources of information were considered to be overwhelming and frightening. 'when I looked onto NHS Direct, after I'd got it, that frightens the life out of you if you do anything because you get five pages' Gout not a disease: some participants did not consider personal actions such as lifestyle choices to be a key cause of gout as they saw it as an illness resulting from a 'natural' accumulation of metabolites in the body rather than a disease. Gout considered humorous and only understood by close contacts: not taken as seriously as other conditions, particularly by HCPs, particularly in contrast to 'self-inflicted' conditions such as drug misuse. Awareness and understanding were considered better amongst

Study	Chandratre, 2016[2]
	family and friends due to care and observation. Lack of information from HCPs: prompted participants to conduct their own internet searches on causes and treatments of gout. They were concerned about the quality and authenticity of information available via internet sources. Participants felt that HCPs assumed their gout was due to excessive consumption of alcohol. 'I found out for myself basically. [okay] So the doctor didn't really explain it that well'. 'We've all got ignorance of it. Doctors don't sort of explain exactly what it is' 'I'd like to know the side effects though, properly [yeah] from a doctor, and not from the internet'. 'I would say my GP almost dismissed my view that [yeah] the attacks were brought on when I stressed the joint, but on the NHS site, definitely it states [yeah] that if you stress a joint it can instigate the gout'. 'But you couldn't talk to my doctor about it, he wasn't interested'.
	Beliefs about treatment of gout: Lack of contact with HCP: a participant reported that her GP was reluctant to refer her to a specialist even her gout was sub-optimally controlled. Reluctance to prescribe and take allopurinol: 'he says I wouldn't really recommend it if you can get away with it, just come in if you start getting an attack'. Concerns about side effects of treatment: 'my medic said that Allopurinol can actually cause gout to flare up again…'
Funding	Authors funded by NIHR School for Primary Care Research, NIHR Collaborations for Leadership in Applied Health Research and Care West Midlands, the NIHR School for Primary Care Research and a NIHR Research Professorship in General Practice (NIHR-RP-2014-04-026).
Limitations and applicability of evidence	Applicability: exclusively Caucasian and mainly male. Directness: study was on HRQOL in gout and not education directly.

Study	Counsell, 2018[3]
Aim	To explore the views of Australian pharmacists on their roles in gout management and to identify factors influencing their involvement in gout management.
Population	Community pharmacists known to the research team (11F/4M) n=15 Average 11 years' experience (range 1-38 years), practicing tin 11different pharmacy practices in Sydney. Pharmacists had contact with people living with gout and dispensed some form of gout medication at least 2-3 times a week.
Setting	Australia
Study design	Qualitative- semi-structured interviews using an interview guide.
Methods and	Interview questions focused on the participant's experiences of managing gout, interactions with people living with gout and the perceived role and responsibilities of a pharmacist in gout management. Questions were written with input from a rheumatologist, a

Study	Counsell, 2018[3]
analysis	pharmacist, and a qualitative researcher. One on one interviews were conducted and lasted 20-30 minutes, and participants were reimbursed for their time. All interviews were conducted by one researcher, a Medical Science Honours student. Interviews were practiced beforehand to ensure competence in interview delivery and adequate participant understanding of the questions. Interviews were de-identified, audio-recorded, and transcribed verbatim. Transcripts were not returned to participants for comment. Thematic analysis of transcripts was undertaken concurrently with conduct of interviews to determine theme saturation. Once theme saturation was achieved, no further participants were invited to join the study. Each transcript was analysed independently by two reviewers using an inductive approach whereby researcher do not analyse transcripts with a pre-determined coding framework. Instead, after analysis of five transcripts, they convened to discuss emerging themes. Emerging themes were categorised into pharmacist's current role and the barriers and facilitators to pharmacist involvement in gout management. A framework was then developed based on the theme that emerged. This framework was used for analysis of all subsequent transcripts and for reanalysis of the first five transcripts and allowed the most commonly appearing themes to be noted.
Findings	**Current role of pharmacists in gout management** <u>Advice and education</u> Pharmacists reported that they provided both pharmacological, diet and lifestyle advice to people with gout. Only a small number reported that they provided education about the pathogenesis of gout. All pharmacists explained that they provided advice when they first dispensed gout medication but rarely thereafter. One pharmacist said, 'To be honest if they've used it before and they've got a history of using [gout medications] regularly I don't generally give them advice'. All pharmacists also reported providing some form of written educational material to people with gout, especially if it was the person's first visit to the pharmacy or it was a new medication for the patient (In Australia, most commonly this is the Consumers Medicines Information, a plain language summary of Australian Therapeutics Goods Administration approved relevant information available for every prescription medicine in Australia). <u>Filling patients' knowledge gaps</u> Most pharmacists felt that GPs often did not have the time to provide sufficient education to people living with gout in a consultation. Consequently, pharmacists reported that the education they provided filled this gap in gout patients' knowledge. For example, 'I think the majority of the time doctors don't [provide enough gout education] and we'll do that for them'. <u>Medication adherence monitoring</u> Not something that is done actively or regularly, however it was recognised as something that should be done.
	Facilitators to pharmacists' involvement in gout management <u>Good pharmacist understanding of gout and its management</u> The majority of pharmacists reported having a good understanding of gout medications and their appropriate use, including knowledge of when to initiate allopurinol, appropriate dose and its dependence on renal function. They also appeared to have a sound understanding of the impact of diet and lifestyle on gout and gave appropriate advice regarding diet.
	Barriers to pharmacists' involvement in gout management <u>Difficulty monitoring gout medication adherence</u>

Study	**Counsell, 2018[3]**
	This was the most common barrier. Tracking the intake of gout medications, particularly allopurinol was said to be difficult from examination of the patient's medication dispensing history because of the sizes of gout medication packs. <u>Lack of specific training in gout and its management</u> The majority reported a lack of specific professional training or continuing professional education in up to date gout management. For example, one pharmacist stated, 'There is no training [in gout] …I get a lot of information by drug reps for every disease under the sun except gout'. Another reported 'The only training I've done [on gout] was when the dosing recommendations changed'. They also reported relying on what was learnt at university or through their own research. <u>Gout viewed as being less important than other conditions</u> Gout was not given a lot of focus or high priority in comparison to other chronic conditions such as hypercholesterolaemia.
Funding	Lexy Davies Bequest at St Vincent's Hospital, Sydney.
Limitations and applicability of evidence	Reliance on self-reporting Selection bias

Study	**Deprouw, 2019[7]**
Aim	To explore partners' and nurses' knowledge and representations of gout.
Population	Nurses (n=20), 9 rheumatology, 11 internal medicine (3M/17F); and partners of gout patients (n=12), 11F/1M. Ethnicity: 11/12 Caucasian, 1/12 Asian.
Setting	Rheumatology and internal medicine departments (nurses); general practice (partners), France
Study design	Qualitative grounded approach with semi-structured face-to-face individual interviews
Methods and analysis	Two semi-structured interview guides were designed by 6 investigators. Face-to-face individual interviews were conducted in a dedicated room in rheumatology and internal medicine departments of Lariboisière hospital for nurses and at home for partners. The interviews were audio-recorded after oral and written consent was obtained from participants. Investigators used open questions and let participants describe their knowledge, perceptions, and feelings about gout. Involved themes explored the causes and consequences of gout disease, gout symptoms, impacts on daily life and family, emotional and psychological impacts, gout treatments, diet, relation with care providers, information and advice received or given. When themes were not mentioned spontaneously, participants were directed with sub questions to explore all covered areas. Interviews were conducted in parallel to the analysis and continued until data saturation (data collection was completed when no new idea/opinion emerged during the last interview). Each interview was transcribed verbatim. Participants agreed to quote the interviews in anonymized form. Using Nvivo 10® software data analysis was performed after each interview. This software stores the qualitative data, allows for coding data and sorting codes, and illustrates data by "word clouds," for example, whereby the size of the word is proportional to its frequency mentioned during the

Study	Deprouw, 2019[7]
	interview. Data encoding was performed by groups of 2 to 6 investigators, checking that the verbatim interpretation was similar, to ensure internal validity. To ensure credibility several participants were interviewed with prolonged engagement until theme saturation; methodological triangulation was made with in-depth interviews and investigator triangulation with regular meetings to perform coding, analysis, and interpretation decision. Wherever necessary, consensus was reached after discussing specific verbatim.). The codes were regrouped inductively into different categories based on the grounded theory approach. Once an interview was performed, the encoded verbatim were compared to previous themes and categories until the theoretical saturation. The constant comparative analysis between encoded data and new interviews permitted to generate themes and models from the data alone. Codes, concepts, and the core category were recoded and relabelled, until a final theory provided the insight.
Findings	**Knowledge gaps on gout disease and care** Causes of gout For some partners gout was considered as a “spontaneous” disease or secondary to excess walking, increase of urea level or acid level in the body. Other partners and rheumatologic nurses believed that gout was a diet-related disease and incriminated excess intake of meat, delicatessen foods, seafood, sodas, some vegetables (cabbage, cauliflower lentils) or salt. Alcohol was cited but as an afterthought and some nurses pointed out the role of beers and hard alcohols. Only few partners and nurses mentioned the role of genetic, medication or renal factors. Although nurses knew that gout was secondary to hyperuricemia, most of them did not distinguish hyperuricemia from urate crystal deposition. Only few nurses working in the rheumatology department said that gout was related to urate crystal deposition. Similarly, no partner was aware of the relation between gout, hyperuricaemia, and crystal deposition. “It's salted water which enters in the toe, and bones, joints.” (partner) “It's phoric acid overproduced.” (nurse) “I told myself: it's too much acid.” (partner) “Avoid eating too salty, too fat, too acid.” (nurse) “Especially not to eat cabbage.” (nurse) “Avoid sardines and asparaguses.” (partner) “He stops coffee. And I discover that tea is ten times worse than coffee.” (partner) Consequences of gout Nurses and partners did not know that crystal deposition continued to accumulate and could lead to irreversible joint destruction. Thus, tophus formation, joint destruction, kidney involvement and cardiovascular risks were barely mentioned. How gout is diagnosed was unknown. Partners and some nurses thought that it could be done by blood analysis, clinical signs, or joint fluid aspiration but they did not specify the exact target. Treatment of gout The understanding of gout management was poor and mainly focused on flare treatment and foods to avoid. In fact, many partners believed that gout was a chronic and incurable condition with painful and recurrent flares. Most of them reported that gout was neither a severe nor life-threatening disease. A majority was unaware of the existence of ULT and admitted that they had never heard about these treatments. Partners and nurses who knew about ULT still had misunderstandings and confusion with flare treatments. Some

Study	**Deprouw, 2019**[7]
	rheumatology nurses knew the purpose of ULT. However, they were not aware of the possibility of gout flare under ULT initiation neither the possibility of severe cutaneous adverse reactions. In contrast to the ignorance of urate crystal burden and efficiency of ULT, nurses and partners all knew the efficacy of flare treatments, especially colchicine, as the role of alcohol and diet to trigger flare. “You can’t heal from gout. When you get it, it's for all the time and it trigger or not.” (2 partners) “We can diminish all symptoms and live with it, but I don’t think it can be really treated.” (4 nurses) “I know it's always colchicine in first intention, I think. Allopurinol is more depending on gout cause.” (2 nurses)
	Lack of information and education on gout All partners and nurses complained about the lack of education on gout. Nurses reported that gout was not well taught during their scholarship. Their knowledge was mostly acquired during their professional practice and experiences. Partners said that general practitioners did not give necessary information about gout pathophysiology and management and that they did not take sufficient time to educate patients. Most of them had never heard about rheumatologists or the need to have a specialist care. Their knowledge on gout were acquired from internet, TV, radio, family, or relationship experiences and, of course, their own history. Thus, some partners said they learned to manage gout flares from the behaviour of relatives who had gout. Similarly, they said that after the first flare they learned how to manage the next one. Moreover, some partners knew that flare treatment was more efficient when initiated at the onset of symptoms. All nurses expressed the desire to participate in an education program. They were interested to improve their knowledge on gout symptoms, treatment, and management. Partners were interested to learn about gout causes and diet. Desire for more knowledge “A formation will be interesting. We are more focused on rheumatoid arthritis and spondyloarthritis but concerning gout it's true that there is some degree of lack.” (4 nurses) “I think this program is a good idea. In term of information because we are ignorant, we don’t know anything.” (3 partners) “We have less time to listen. Patient don’t have time to speak, we need to do nursing quickly.” (nurse) Incompetency feeling “I don’t know enough to educate patient.” (2 nurses)
Funding	None
Limitations and applicability of evidence	Moderate limitations due to role of the researcher not being addressed and applicability. For nurses the interviewer was a rheumatology resident who had previously worked in the department where the nurses worked. For partners, the interviewer was the GP both of which could have affected the interview. Applicability: relates to nurses and partners information needs. Nurses were from a specialised gout clinic.

Study	**Harrold, 2010**[13]
Aim	To examine patients’ and providers’ views on the treatment of gout to better understand why management is suboptimal.

Study	**Harrold, 2010**[13]
Population	Gout patients (n=26) who initiated treatment with a urate-lowering drug (ULD) in the prior 6 months and with providers who care for gout patients (n=15). Patients Inclusion criteria: those aged 18 years or older with a diagnosis code for gout (ICD-9 code 274.XX) in the prior 5 years, continuously enrolled in the health plan, new users of a ULD within the last 6 months (180 days) and who had no prior use. n= 26 patients with gout (20M/6F), mean age was 73 (±11). Most rated their overall health as good or very good. Ethnicity: all Caucasian. Twenty-four of the 26 patients reported that their diagnosis of gout was made based on the clinical presentation and serum uric acid result. Only two patients reported that they had had a joint aspiration confirming gout through visualization of monosodium urate crystals. Fifteen reported rare gout attacks with the rest having attacks weekly to every few months. Only a few patients reported receiving prophylaxis with colchicine or NSAIDs prior to initiation of a ULD. Almost all patients had vivid recollections of their first episode of gout with symptoms of pain, swelling and discoloration. Most were limited in terms of daily activities or ambulation when they had a gout flare. Providers Inclusion criteria: adult primary care physicians, rheumatologists, podiatrists, nurse practitioners and physician assistants who saw patients at the Fallon Clinic at least one day a week were identified. While these providers may have cared for the patient participants, the authors did not specifically match providers to the patient participants. n= 15 providers (7M/8F), all but 2 were aged 40–59. Ethnicity: 13 Caucasian, 1 Asian and 1 Southeast Asian. Eleven were primary care providers with 2 podiatrists and 2 rheumatologists. Thirteen providers were physicians; 2 were nurse practitioners. Most providers cared for 5 or fewer patients with acute gouty flares in a typical month
Setting	Multispecialty group practice, USA
Study design	Qualitative, cross-sectional design involving in-depth telephone interviews
Methods and analysis	An initial draft of both the provider and patient interview guide was developed by the authors and pilot tested with 2 providers (one rheumatologist and one internist) and 2 patients. The guide included questions in each of the following topic areas: 1) clinical experiences, 2) treatment, 3) knowledge and beliefs, 4) self-management, 5) barriers to management, 6) facilitators of gout management, and 7) suggestions to improve care. Follow-up questions were used to elicit more detail based on responses. The telephone interviews were conducted by interviewers after training (patient interviews and provider interviews were conducted by different investigators). Those patients contacted who consented to the study participated in individual in-depth interviews lasting approximately 30 to 60 minutes and were compensated $25. Providers who consented to the study participated in individual semi-structured interviews lasting 20 to 30 minutes and were compensated $100. The interviews were audio taped and transcribed verbatim. Recruitment for both the patient and provider interviews was terminated once saturation on themes was achieved.

Study	**Harrold, 2010**[13]
	Qualitative analysis of the transcripts was done using an iterative process. One investigator read several transcripts and generated an initial list of themes and coding categories based on the interview guide. A second investigator read 5 additional transcripts and suggested modifications. Tis process was repeated with successive readings of the transcripts. Two additional investigators read 4 to 6 transcripts each to assess completeness of the coding categories. This process continued until all investigators agreed that the listing captured all major issues raised by the interviewees. Interviewee responses were coded through application of the coding categories with modifications suggested and discussed. After coding, interviewee responses were sorted by question and response code and reviewed them for additional themes or subthemes. Any questions or discrepancies which were not easily resolved were brought to the full team for resolution. Two investigators reread the entire set of transcripts to ensure that no relevant themes had been missed. The major thematic categories identified included education and knowledge regarding gout, treatment strategies and response to treatment for both the acute and chronic management of gout.
Findings	**Acute gout management** Most providers thought patients understood how to manage acute gouty flares. Only a few thought patients had a difficult time grasping the behaviours necessary to prevent an attack. In fact, most patients did have a regimen that they followed when they had an acute attack
	Chronic gout management Most primary care providers as well as the 2 rheumatologists stated that their patients had a good understanding on the cause of gout and the need for chronic medications In fact, many patients understood that allopurinol was prescribed to reduce serum uric acid and prevent gout attacks; however, several patients reported that their provider did not provide details on what causes gout. Patient comments included “I get very little information on this from doctors”, “they don’t tell you what the pills are for,” “if I call there with some problems, sometimes she makes me feel bad” and “I sometimes wonder why the heck I even go to the doctors…he just wants to get rid of you.”
	Strategies to improve gout management Virtually all providers mentioned that patient education was vital for ensuring optimal care. All but a few thought they were sufficiently trained and able to provide the necessary education. The competing priorities of patient volume and patient education were mentioned by one primary care provider. He stated that he had taken “a huge financial hit” in order to spend “a huge amount of time per patient” for clinical care including patient education. Other strategies proposed included involving patients and their families in the decision-making process, providing advice on how to incorporate medications into their routine, giving educational handouts and describing the risks associated with nonadherence. Suggestions from patients on how to improve care included providing more information (both orally and through written materials), more time for patient-provider interactions and follow-up after initiating treatment. One patient suggested that providers should tailor their messages based on the specific needs of the patient. Additional comments from patients included “wait until a patient experiences symptoms before giving allopurinol,” “be aware of alternative methods such as cherry juice” and “tell the patient if they are taking a

Study	Harrold, 2010[13]
	medication than can cause gout." Several patients, when asked what recommendations they would make to other patients afflicted with gout, suggested seeing a rheumatologist rather than the primary care physician.
Funding	Drs. Harrold, Mazor and Yood are investigators in the HMO Research Network Center for Education and Research on Therapeutics (Agency for Healthcare Research and Quality HS10391). Dr. Harrold was supported by Grant Number K23AR053856 from the National Institute of Arthritis and Musculoskeletal and Skin Diseases.
Limitations and applicability of evidence	Minor limitations due to role of researcher being unclear Applicability: all patients were Caucasian, findings only generalisable to one specific care plan in one group practice

Study	Howren 2018[15]
Aim	To use patients' perspectives to construct an explanatory framework to understand how patients become engaged in the management of their gout.
Population	Individuals with gout who were participating in a proof-of-concept study (Virtual Gout Study) of an eHealth-supported collaborative care model for gout: n= 12; 10 M/2 F; mean age 66.5 ± 13.3 years Individuals from the Virtual Gout Study were invited, which included patients with confirmed gout who were seen in one of four participating rheumatology practices and had at least one flare in the past year and serum uric acid (SUA) level > 360 μmol/L in the past 2 months
Setting	Telephone interviews, Canada
Study design	Qualitative, semi-structured interviews
Methods and analysis	Semi-structured interviews (average duration 33 minutes), using adaptable probes and prompts, were conducted with participants by a single author over the telephone. Each interview was started by briefing the participant on the subject matter and purpose and situating the participant as the expert early in the interview. A topic guide with open-ended questions was developed and revised by study authors, and the interview was focused on exploring participants' experiences with gout before and during the Virtual Gout Study, management of gout, perceptions of disease activity, and beliefs and behaviours surrounding gout medications. Interviews were recorded and professional. Transcription service providers transcribed each audio-recorded interview. Analysis Three main steps of the coding process of constructivist grounded theory were followed: initial coding, focused coding and categorizing, and theoretical coding. For the initial coding phase, line-by-line coding was conducted. Focused coding narrowed the scope of the qualitative analysis by identifying initial codes that held analytical significance or were repetitive. Last, theoretical coding was done with the aim of interpreting relationships between constructed categories. Analytical techniques such as the constant comparative method and memo writing were applied throughout. Data gathering and

Study	Howren 2018[15]
	analysis were carried out in an iterative process such that participants were interviewed until saturation was achieved.
Findings	**Insufficient education about gout or the medications being prescribed.** Narratives expressed by participants included the misconception of thinking there is no "cure" for gout, believing that ULT has a cumulative effect to prevent against future gout attacks, and misunderstanding medication directions. A common experience shared by participants was the decision to discontinue their ULT early because they seemed unconvinced of the need for daily medication and were unaware of the preventive nature of ULT. For one participant, forgetting seemed to be connected to lacking knowledge, with the belief that ULT is "built up after, you know, a week of taking it straight, missing it one day is probably not going to be detrimental, right?" (male participant).
	Participants having an active role in managing their gout. Participants relayed a sense of personal responsibility such as being proactive and taking initiative, acknowledging the importance of knowing one's own body (e.g., triggers of gout flares), and feeling that "my health is my concern",(male participant). Also mentioned by participants was being proactive in terms of searching for information about gout online and requesting an appointment with a specialist. In addition, some participants mentioned having a personal plan to deal with future gout flares, including knowing when to take colchicine, which appeared to establish confidence in managing their disease. "I mean the bottom line is I'm the patient and know my body so ultimately it becomes my responsibility." (male participant) "then in my you know research online, I did a little bit more, I discovered a few more things and what the, what the causes were." (male participant)
Funding	Study was supported by an operating grant from the Canadian Initiative for Outcomes in Rheumatology Care and a team grant titled "PRECISION: Preventing Complications from Inflammatory Skin, Joint and Bowel Conditions" (THC number 135235) from the Canadian Institutes of Health Research.
Limitations and applicability of evidence	Minor limitations doe to concern over the role of the researcher.

Study	Humphrey 2016[16]
Aim	To explore the experience of treating gout among primary care clinicians and understand the perceived barriers to effective therapy.
Population	Fourteen health professionals who had regular interactions with patients with gout: six general practitioners (GPs), four nurses, and one pharmacist.
Setting	Primary care practices, New Zealand
Study design	Qualitative, semi-structured interviews
Methods and analysis	Participants were recruited by the interviewer, a medical student (six general practitioners (GPs), four nurses, and one pharmacist). Interviews were conducted and themes were derived inductively from the data.12 Validation interviews using the same questions were held with one GP and two practice nurses recruited from general practices from another Primary Health Organisation (PHO) in South

Study	Humphrey 2016[16]
	Auckland (total number of participants = 14). Clinicians who had regular interactions with patients with gout participated. A single interviewer conducted semi-structured, one-on-one interviews with all study participants using questions compiled by one of the researchers. Health professionals were asked to discuss potential barriers to effective gout treatment, patients posing particular problems, memorable gout patients, and ways changes in their practice in the community and nationally could improve the quality of gout management. Further questions were asked if clarification was required. Interviews were conducted in a private setting convenient to each participant and interview duration varied from 20–60 min. To form an idea of organisation-wide perceived barriers to optimal gout treatment, clinicians were included who affect gout management through prescribing urate lowering therapy (ULT) or who provide allied healthcare or support such as practice nurses and pharmacists. Two GPs also had a management role in their organisations. Weekly meetings were held to clarify and define emergent themes. Group meetings were then used to validate themes in discussions with clinicians from the PHO, members of the Māori Gout Action Group, and at Continuing Medical Education meetings with PHO GPs, some of whom had taken part in interviews. Initial guideline and starting point for the interviews: • What are the barriers to effective gout treatment? The themes and questions to be focused in this qualitative study may change over time. The interview may be completely open to allow ideas to originate from the patient, focus group or healthcare worker. In the event of a lack of spontaneous rapport the following questions may be used to facilitate the patient or group in volunteering information. • What experience do you have of treating gout or seeing patients with gout? (Please give examples of memorable or typical patients you have seen.) • Which patients pose particular problems? • What do you feel are the barriers to effective gout therapy? • What factors in your practise need to be changed in order to improve the success of gout treatment. • What changes could be made at a community level to reduce the burden of gout? • What could be done at a national level to improve gout treatment/reduce the burden of gout arthritis?
Findings	**Lacking knowledge/ being misinformed**
	The perception of acute gout as being triggered by diet was felt to negatively affect effective gout treatment. Combinations of comorbidities and treatment side effects meant that gout therapy for individuals was complex. This created uncertainty as to the best management of acute and chronic gout. Participant 2 (Pharmacist): Well, it’s about the complexity of the condition, the co-existing morbidities, so like for example renal function, and the fact that allopurinol as a preventer, and I know it’s not the only preventer, but needs to be managed carefully.
	Lack of time and resources

Study	**Humphrey 2016**[16]
	Some clinicians perceived that their practice's focus was on shorter waiting times, with limited access to follow-up appointments with the same doctor. Participant (GP): ''Practices who offer drop-in systems can have large volumes of patients in their waiting room, and if there are limited numbers of staff, doctors in particular, working, then there's some time pressure on doctors to see patients relatively quickly'' Interviewees felt there were insufficient resources to treat patients with gout and that the problem needed more central government funding. Lack of time, the systemic barrier most commonly referred to, was perceived as a barrier to delivering effective healthcare because it limited the time available to talk to patients, explore their willingness to adopt behavioural change, and provide gout education. Participant (GP): ''It's another thing, too, the time issue. Cause if you're really, really, busy, you don't spend time to talk to the patient, you don't have time, if we're busy.'' Participant (GP): ''Of course, also it's the health professionals, you know, I blame also ourselves that we don't spend enough time to educate people about gout.''
	Desire of nurses to educate patients Nurses spoke about the importance of relationships in educating patients and understanding barriers They described a desire to help in managing gout but felt that it was not part of their job description or an expectation of their role. Participant (Nurse): ''We actually don't do much with the patient, we just take blood pressure and weigh, and then they go to the doctors…while they're here, we do talk to them about the foods and taking medications regularly and alcohol limits and all that. But not really into it, one-to-one, you know? And yeah, so if we do something like that, more education on it, one-to-one, then we'll feel that we do something about it.'' One nurse interviewed had been involved in gout management and felt able to improve patient engagement and gout management through education, in research studies, and as part of practice development.
	Cultural and language barriers Clinicians felt that talking about food and alcohol was necessary to prevent gout attacks but was also a cultural issue that was difficult to confront. If they were not from the same culture participants at times were reticent about bringing up the subject of food and alcohol. Perceptions of the patients and their apparent lack of concern for having gout were felt to be culturally based issues. Language differences formed a barrier to communicating the mechanisms of gout attacks and its treatment and made it difficult to persuade patients to adhere to recommended behaviours and ULT. This challenge was compounded by limited time to explain and educate. Participant Pharmacist): ''You can never perceive the level of comprehension. It's very hard, you know, people will go to them 'do you understand?' and they'll go [nods head] and mean 'no'.''
Funding	Counties Manukau District Health Board.
Limitations and applicability of evidence	Minor limitations due to the role of the researcher.

Study	**Jeyaruban, 2016[17Jeyaruban#1193]**
Aim	To explore management of gout from the perspective of GPs, while identifying the barriers and possible strategies for improvement.
Population	14 GPs Age: 20-29 (1), 30-39 (5), 40-49 (5), 50-59 (2), 60-69 (1) GP registrar: 3, independent GP (consultant): 11 Number of patients with gout seen per month: 1-5 (7), 6-10 (4), >11 (3)
Setting	Four general practices, Australia
Study design	Qualitative- semi-structured interviews
Methods and analysis	Fourteen semi-structured interviews were conducted in person by the primary investigator. Interviews lasted 30-45 minutes. The interview was piloted on two final year medical students, and later two graduates to assess face validity and minor changes to wording were made based on feedback. The 14 interviews were performed in a standardised manner. The information was audiotaped and transcribed in full after removal of any identifying information. Later, the data were coded on a line-by-line basis using paper and highlighted and analysed using thematic analysis and an abductive approach to describe and explain key concepts that arose from the data. Analysis was then performed between different categories and overarching themes were identified. An axial coding was used to regroup the themes. The conclusions were then validated with data from literature with quantitative data. Data saturation was reached in analysis of themes that were derived from the interviews.
Findings	**Knowledge of guidelines-** most were aware of the guidelines for gout, but many were not aware.
	Barriers to effective management The most common barrier for treatment was reported to be failure to adhere to lifestyle changes. Lack of education about gout was another common theme. ''I think their compliance and the understanding of the risk are the biggest barriers'' ''However much you explain they don't understand the nature of the illness so I think literacy might be a barrier''
	Strategies to improve gout management Written information such as flyers and GP management plans to improve patient's understanding. Providing sample packs of medication to patients as they would return when the medication runs out in a couple of days- this would be a way to resolve the barrier of lack of consultation time. Education about the complications of gout could help patients having side effects with medication. ''Maybe a uniform guideline for everyone that everyone says the same thing to the patient.'' ''I write GP management plan for a few of them that have other problems too…I tend to write management plan if they are working with me…''
Funding	Supported by James Cook University Honours Fund.

Study	Jeyaruban, 2016[17Jeyaruban#1193]
Limitations and applicability of evidence	Minor limitations due to the role of the researcher not being addressed.

Study	Latif, 2019[26]
Aim	To explore patient perception of the role of a nurse-led complex package of care in facilitating engagement with urate-lowering therapies (ULTs) in the management of gout.
Population	N=30 (26M/4F). Age: 65.17 (11.51) years (mean), 36-85 years (range). Participants were recruited from an RCT investigating a nurse-led package of care for gout. Ethnicity: white (n=28), Chinese (n=1) and East-African Asian (n=1) backgrounds
Setting	Hospital/ (22) telephone (8) interview
Study design	Qualitative- semi-structured interviews using elements of grounded-theory methodology including open and axial coding, constant comparison, and theoretical sampling
Methods and analysis	Two hundred and fifty-five participants randomised to the nurse-led care arm of the RCT were mailed a questionnaire about gout and its current treatment after the end of the study. The first 100 participants who were contacted with the survey were also approached to participate in an interview study. Of these, 52 people showed an interest in participating in the interview study, and 30 people (58%) were sampled to reflect differences across gender, age, ethnicity disease duration and type of ULT (i.e. allopurinol, febuxostat or benzbromarone) and were purposively recruited. A semi-structured interview guide was designed by the researchers. The agreed-upon questions focused on patients’ perceptions of management of gout before, during and after the nurse-led intervention and covered areas such as their beliefs about the causes and consequences of gout, their symptoms (frequency and severity), the impact of their condition on their daily life and psychological and emotional wellbeing, medical management of their condition, their perception of ULT, previous contact with healthcare professionals and advice and information they had received, their treatment history and preferences, and their level of adherence to healthcare professional advice about treatment. The interview schedule was piloted with a few participants and no revisions were required. Interviews lasted twenty to ninety minutes. Twenty-two participants opted to be interviewed in the City Hospital Nottingham, in a private room located in Academic Rheumatology and the remaining eight were interviewed by telephone. Interviews were audio recorded and transcribed verbatim by an independent transcription company. Member checking was done throughout the interviews. The data were analysed in parallel with the data-collection process, and initial results informed subsequent sampling and data collection. Analysis began with open coding to identify concepts and generate codes. Conceptual codes were grouped into major categories. Analysis proceeded with axial coding exploring relationships between major categories. The constant comparison Method was used, allowing the data to be compared and contrasted within and between interviews, concepts, and major categories. Memos were also written to capture impressions of the data and to record emerging concepts and categories. NVivo version 11 software was used to facilitate coding of all transcripts and a subset was blind-coded.

Study	Latif, 2019[26]
Findings	**Improved knowledge and understanding of gout** Participants while reflecting on their experiences, frequently stated that primary-care practitioners had provided little information about the role of ULT in the management of gout. Post-intervention, most participants indicated that increased knowledge of the causes and long-term effects of gout fostered their engagement with ULT. They explained that they primarily sought to engage with ULT to help lower urate levels, eliminate the crystals and thus prevent further flares. While participants understood the role of pharmacologic interventions in the long-term management of gout, many were unaware of the importance of simultaneously making lifestyle adjustments: they preferred to rely on medication alone. However, many indicated that the provision of dietary information addressed misperceptions about the role of diet in the management of gout. Participants were also worried about the effect of progressive urate crystal deposition on their joints and the risk of irreversible joint damage. For most, knowledge of the long-term consequences of gout together with a desire to prevent further flares became a driver for engagement with treatment. ‘’feel good that I understand what was happening and what caused it [gout] and why they’ve done it whereas other people I know that are just under the doctor, they have no real clue’’
	Increased confidence from having information Some participants had previously been prescribed fixed, low-dose ULT by primary-care practitioners which had failed to prevent flares. These participants were reluctant to re-engage with ULT until the nurse told them that the dosage needed to be optimised to prevent further flares. When they discovered that this could be determined by monitoring SU levels and up-titrating ULT against a specific target level, below the saturation point for crystal formation, they were persuaded to re-engage with ULT. ‘’But mostly it’s the talks [with the nurse] that were helpful because dealing with people who specifically have this condition as an expertise, it’s good to be able to do that, whilst the GP, he had a knowledge of it but it wasn’t sufficient to get the situation under control.’’ ‘’Fine, it was absolutely great, she [nurse] explained what would happen, the targets [optimum uric acid level] that we were aiming to get.’’ ‘’learned the right level of uric acid into the blood, yes, had to be below a certain limit, always take the pills, don’t forget and I can remember the side-effects, negative ones.’’
	Regular monitoring After initiating ULT, participants believed that periodic contact with the nurse provided them with the impetus to persist with their medication. Those with previous experience of up-titration under a primary-care practitioner explained that they had not received information about the process, found it slow and were demotivated when they experienced flares as they had expected the treatment to prevent flares at a much earlier stage. Participants valued the long-term monitoring and review of their condition and treatment– frequently suggesting that ongoing dialogue with a healthcare professional, especially while establishing a new regime, encouraged them to persevere with ULT. Most suggested that the availability of information on current and target SU levels provided the

Study	Latif, 2019[26]
	psychological motivation to continue with ULT while determining the optimum dose during an up-titration process. Participants were impressed by the consistent and timely access they had to a supportive healthcare professional, and the speed at which the target SU and optimum ULT dose was achieved. Both meant they suffered minimal inconvenience. ‘’The doctors, with all due respect to them, I’m a number in a vast amount of numbers for them. They give you 10 minutes and, you know, I’m not knocking the doctors at all, but you can’t get the right dose [ULT dose] in 10 minutes.’’
	Involved patients in decision-making about treatment Patients were able to explore the risks and benefits of the treatment options available and make an informed decision about treatment in discussion with their healthcare professional. Most explained that they shared their preferences, goals and values, and the healthcare professional communicated information about the condition and treatment options. Some participants had researched treatment options and dietary restrictions, and bought this knowledge to discussions, as well as the relevant past experiences of family/friends. Patients with other medical conditions raised concerns about contraindications of ULT and interactions with other prescriptions. They were reassured when nurses provided information about potential side effects and prescribed the best suited ULT, feeling that their patient-specific risk factors were being addressed. ‘’It’s actually talking and being able to talk to the nurses involved in the study and getting encouragement from them, the fact that we’re working together, it’s not just me on my own, seeing the GP’’.
Funding	The Nottingham Gout treatment trial was funded by Arthritis Research UK (Grant number: 19703 to MD). One of the authors was funded by Arthritis Research UK (Grant number: 21297 to AA).
Limitations and applicability of evidence	Minor limitations due to applicability of study (aim was to investigate a nurse-led intervention in gout care). Population was predominantly white and of an older age living in a single region.

Study	Liddle, 2015[27] Richardson, 2016[41] Richardson, 2015[42]
Aim	The aim was to explore reasons for the low prescription rate for urate lowering therapy (ULT) and the low adherence to treatment through an exploration of patient experience and understanding of ULT treatment for gout.
Population	43 UK patients with gout (29 men; 14 women; age range 32–87 years) were recruited from general practices, rheumatology clinics, gout support groups and through online advertising. Age at interview (n): 30-49 (7), 50-69 (23, 70-89 (13) Time since diagnosis (years): 1-5 (10), 6-10 (6), 11-15 (9), ≥16 (18) Ethnicity (n): White British: 40, Asian British: 3
Setting	Participants’ homes or workplaces United Kingdom

Study	**Liddle, 2015[27] Richardson, 2016[41] Richardson, 2015[42]**
Study design	Qualitative- narrative and semi-structured interviews
Methods and analysis	An experienced qualitative researcher conducted face-to-face semi-structured interviews with 43 participants in their homes or workplaces. Interviews lasted between 25 min and two hours. Using a narrative approach, the interviews focused on the oral history of each person's experience of gout to identify their concerns, meanings, and priorities. The interviewer used additional questions to prompt reflection on areas of interest identified through the literature review and/ or advisory group. Using this approach meant that unanticipated areas could be explored as they arose, thus identifying salient issues for people with gout. Following informed consent, interviews were audio or video recorded depending on participant preference, transcribed, and checked. All transcripts were coded under broad categories, using NVivo 10 to assist with data management. A second researcher checked these to identify any additional codes. Analytic themes relating to specific topics, including long-term treatment – the focus of this paper – were then developed further, through discussion with main authors. Liddle 2015 and Richardson 2016 use the same population but perform different analyses. Richardson 2015 is a subset of female patients.
Findings	**Liddle 2015: issues relating to the diagnostic process**
	Triggers and delays within the diagnostic interval Patients talked about several delays and problems they encountered during the period before a diagnosis was made, including misdiagnosis and difficulty getting an appointment when symptoms were most severe. Some patients with gout attacks in joints other than the first MTP joint, such as the knee, had their symptoms attributed to other causes such as sports injuries. Gender was another factor that appeared to cause delays for some women. ''I decided eventually to go to the GP. And the GP looked at my foot and the first GP that I saw […] said, 'If you weren't a woman, I would say this is gout'.'' ''I went to the GP and explained all the symptoms […] she said, 'Well I don't think you've got gout' […]and she said, 'Well it's very unlikely because- female, and your age, and you're not particularly overweight, or anything, but we'll test anyway'.''
	Accepting or doubting the diagnosis Patients who remained unconvinced about the accuracy of the diagnosis either questioned the severity of their symptoms, the method of diagnosis, or had not reconciled the diagnosis with their ideas about the causes and characteristics of people likely to be affected. Others felt that their diagnosis of gout was more the result of a process of elimination than it was a process of identification (or confirmation) of the condition, leading them to suspect that doctors were 'not sure' about what was causing their symptoms. Dislike of gout label- negative associations
	Desire for greater information at the point of diagnosis Not all patients were aware that gout was a chronic condition that required long-term management. While some patients were not surprised by the diagnosis, others were shocked, angry, or confused because they believed their

Study	Liddle, 2015[27] Richardson, 2016[41] Richardson, 2015[42]
	lifestyles were very different to those they associated with gout. The contradiction was reinforced by some health professionals placing an emphasis on lifestyle changes.
	Actions on receiving the diagnosis Being diagnosed with gout was an immediate prompt for further action by some patients. For example, they spent time searching the internet for information about the condition, joined internet forums or discussion groups for people with gout, or asked their GP for referral to a specialist. One key unanticipated finding that has not previously been reported in the literature was that, after doing research on the internet following diagnosis, two patients had bought equipment to monitor their own SUA levels. I've got one of those little kits that you use. So, I wanted to make sure that […] wanted to understand my own disease and manage my own disease, so I've been doing that ever since. […] So, the first thing I did was, I calibrated my monitor with the blood test. […] that seemed like an accurate representation of what the bloods were telling me. […] And I've actually, at some points, titrated my own dose of Allopurinol. (Adam, 41yrs) Another common pattern was that patients began to change their diets in response to information they read on the internet, regardless of whether or not their GP had recommended such changes. ''I've looked up online information relating to gout and the causes of it. And I think for as many articles that are written there's a different identifier and you know if I were to- I just get the impression that if I were to follow all the advice that's in all the articles I've read, I wouldn't eat or drink anything ever again because there just seems to be such a wide array of possible causes.''
	Richardson 2016: issues relating to the use of medication
	Knowledge and understanding of gout and its treatment Patients' perceptions and understanding of the nature of gout influenced their attitude towards medication. If they did not see it as serious or long-term they were less likely to take ULT. Patients' understanding of the nature of gout could change over time, and with experience and increased knowledge. Increased knowledge of the long-term effects of gout can move a patient towards a higher likelihood of taking ULT: "The doctor said if you don't take any medication it will get worse and it can affect your joints, I mean permanent damage. So I had no choice, I have to take the medication."
	Desire for information and monitoring Most participants knew little about gout before diagnosis and recalled little written information from their GP. Information is a key factor in patients' decisions to start and continue taking ULT. Patients wanted information on causes of gout, including the role (if any) of diet, relationship between urate levels and gout attacks, and the implications of taking medicine for the rest of their lives. In particular, the impact of long-term medication was sometimes seen as being underestimated by the health care practitioner, "When my attacks became more frequent, I went back to the GP to ask for a referral back to the rheumatologist to discuss, you know, 'Is this the time to start allopurinol?' And my GP initially refused to refer me, he said we didn't need to - 'I'll just put you straight on allopurinol'. And I remember, sort of having a conversation, 'Well, actually, you know, I'd like to discuss….'

Study	Liddle, 2015[27] Richardson, 2016[41] Richardson, 2015[42]
	"I think when you've had a diagnosis, it would be really helpful to sit down quite quickly with a doctor […] to actually talk through what your options are…" "… so I think you need that sort of an approach to try and help the person understand and get it under control. So it's like a joint effort over a period of time, rather than just a one-off visit after you've identified the problem." The desire for an ongoing dialogue with a health care professional, especially while establishing a new regime, is also reflected in patients' desire for long-term monitoring and review of the condition and treatment.
	Richardson 2015: Female specific issues (female patients n=14/43) age range 32 to 82 **Onset and diagnosis** The GP looked at my foot […] and said, "If you weren't a woman, I would say this is gout." So I went to the GP and explained all the symptoms and she said, "Well I don't think you've got gout but I'd better test you for it because your symptoms are sort of connected with that." And she said, 'Well it's very unlikely because-female, and your age, and you're not particularly overweight, or anything, but we'll test anyway." Both of the above patients actually went to the doctor with symptoms, but for others the stereotype of it being a man's disease may prevent them from even getting that far. ''Erm, I suspect, I suspect people might be surprised. As I said earlier, I think it may very well be that some women go undiagnosed because it's not spoken of as something-as a condition that women can be diagnosed with.'' ''I'm not sure how much GPs know about it, to be honest. And I'm not trying to belittle them. It's just that it's not one of those red flag things that, "You have to read this." And then I'm also not erm a very representative example of someone who has gout that they have to worry about. I'm not a 70-year-old Indian man or an 80-year-old English man, for that matter. I'm, I'm young and, and a female doesn't really come that often to them so I don't really think they know much about it. They don't, I think.
	Understanding of and finding information about gout Women in the study reported knowing little about gout before being diagnosed: ''I'd be interested to know if there were people a lot younger than I was. Perhaps if it is connected to the menopause or to age, or age related for women, or perhaps because of the oestrogen or something like that. Had you heard of that [gout more common after menopause] before I just mentioned it? I had vaguely, but I'd forgotten, yeah. But it's never something that's particularly prominent when you read articles or anything. For younger women, stereotypes of age and gender provide a particular context in which they attempt to understand their own experience of gout. When the stereotypes of age and gender interact, things become challenging, particularly for young women. For men, the issue is often that their age and gender are aligned with the stereotypical characteristics, whereas for women, the opposite applies. Women may have other issues as a result of gout that are unique in terms of their gender. For example, one of our participants who wanted to conceive found it difficult to find accurate information regarding gout and pregnancy,even including medication safety. For her, gout was delaying what she saw as the next stage in her life. In contrast, for one patient it is simply about not recognising herself in the information that is available and the impact that has on her identity as a woman:

Study	**Liddle, 2015[27] Richardson, 2016[41] Richardson, 2015[42]**
	‘’So I erm and then I suppose it’s not-I would assume, there’s not that many women out there because you can’t find a lot of information on women with gout. And what impact it can have. Apart from the general information then.’’ Some of the participants found online forums useful, for their role in sharing experiences with other women: ‘’But from a woman’s point of view, get on the forum and try and get in touch with people, especially women who’ve got, because they are going to be more understanding. Because especially from my point of view the men that I’ve come across with it, have abused their bodies, and know then themselves they’ve got gout through doing what they’ve done, so I think-but from - normally from a woman’s point of view, you know you - you don’t drink as heavily as men and that and because it’s more that we’ve always thought it was connected to drink, but I just think it’s beneficial for women to be in touch with women who’ve erm-who’ve developed it-definitely.’’ The focus on men and, what the women perceived as self-inflicted factors, and the overall scarcity of relevant information for these women diagnosed with gout created severe challenges to their identity, epitomised by one patient’s comment that she felt like a “freak of nature”.
Funding	National Institute for Health Research School for Primary Care Research (NIHR SPCR) Grant reference number 136
Limitations and applicability of evidence	Minor limitations due to role of the researcher

Study	**Martini, 2012[29]**
Aim	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.
Population	n= 60 people with gout (54M/6F) Age: 23-93 years (range), 61 years (mean) Ethnicity: 10 Pacific Islander, 17 Maori 56 patients had been prescribed allopurinol. Of the 39 who knew their dose, 11 were taking 100mg daily, 4 were taking 200 mg daily, 19 were taking 300mg daily and 5 were taking 600 mg daily in two divided doses. Two patients were taking probenecid (1or 2mg daily). Inclusion criteria: patients were included if they had been prescribed allopurinol and/ or colchicine and were able to communicate in English.
Setting	Pharmacy, New Zealand
Study design	Qualitative, semi-structured interviews
Methods and analysis	Patients were identified by pharmacists at 13 community pharmacies in urban regions of Auckland and Waikato that were likely to have a high number of Maori and Pacific Islander customers. Six pharmacy students took the interviews. Interview questions were developed after discussions with a rheumatologist, gout nurse specialist and an academic and clinical

Study	Martini, 2012[29]
	pharmacist. Interview questions explored participants' knowledge of gout and the medications prescribed for the condition, how gout affected their lives and whether they were aware of support groups or found other ways of managing the disease. Consistency and appropriateness of interview techniques were ensured through a training session with qualitative researchers. The interview was piloted on 7 volunteers without gout to standardise the approach of the 6 interviewers. Participants were interviewed for up to 30 minutes in a private area of the pharmacy. Interviews were audiotaped with the participants' approval. Audio and written interview data were transcribed and uploaded onto NVivo 8 software. Data were reviewed by all 6 pharmacy student researchers to extract themes. A general inductive thematic approach was used where researchers each reviewed the responses and grouped them into common ideas or patterns and then collectively agreed on development of themes and subthemes.
Findings	**Knowledge of triggers and risk factors** Only 4 (7%) participants thought it might be genetic, despite 28 participants having a family history of gout. 4 (7%) had ''no idea'' what causes gout. 51 (85%) know that certain foods and drinks associated with ''high living'' , particularly seafood and alcohol could trigger attacks. 5 (8%) did not believe diet had any impact on gout. Two participants <35 years thought gout did not affect young people.
	Knowledge of medications used for gout 42% of participants had some knowledge of how ULTs work. Of these, 12% admitted to non-compliance. Some patients were able to identify which medications were for gout or how they worked from blister packs. Only 33% of participants knew which medications to use both acutely and prophylactically. One believed ''allopurinol is a pain medication'' and used it only when they had an attack. Another was not sure whether to take naproxen daily or for acute pain attacks only.
	Gout complications 73% were unaware of complications and comorbidities associated with untreated or poorly managed gout
	Sources of gout information Most participants received information from their family physician- believed this provided them with the most detail but often did not fully understand: ''the doctor said rich foods [can trigger gout] but not too sure which ones'' ''gout is a buildup of salts so salty foods cause gout'' Two participants suggested that HCP should always check that information was understood as they often felt ''too shy'' to clarify or ask questions, and they ''just accept what the doctor gives''. The second most common source of information was family and friends. While this was beneficial in terms of dietary advice and medication compliance, it also contributed to the development of 'myths' . Most participants only visited a pharmacy to pick up medications or purchase over the counter medications, but some expected their pharmacist to be more involved in education about medication management. Some participants did receive information, but this was

Study	Martini, 2012[29]
	primarily from one pharmacy. Participants mentioned that ''the directions [on their medications] were sometimes unclear'', and one participant was confused about which medications were to be taken each day when prescribed allopurinol, omeprazole and an NSAID together.
	Knowledge of services and support groups Five participants knew of services and support groups for gout. Most were unaware that Arthritis NewZealand offered support for people with gout. Two participants were members of support groups and 11 considered joining. The remaining participants did not want to join as they felt they had enough support from family, did not believe they required any, or that their gout was not severe enough.
Funding	No funding stated
Limitations and applicability of evidence	Moderate due to possible selection bias, unclear role of researchers, lack of quotes. Applicability: Maori/ Pacific Islander population

Study	Rebello, 2016[40]
Aim	To explore patients' knowledge on the use of gout medicines, and in particular their awareness of the maximum dose of colchicine, the dangers of colchicine overdose, and their opinions on restricting colchicine dispensing. The study also investigates where patients receive gout information.
Population	People with gout attending a rheumatology clinic, New Zealand Of the 30 interviewees, 24 (80%) M and 6 (20%) F, ranging in age from 28 to76 years. Ethnicity: Samoan (n = 8; 27%), Māori (n = 7; 23%) and NZ European (n = 7; 23%). 28/30 were taking colchicine. The time of gout diagnosis ranged from 2 weeks to one participant having established disease of more than 50 years. Sixteen (64%) participants reported having a first-degree relative with gout. Twenty-five (83%) participants had pre-existing co- morbidities, 17 (68%) with multiple co-morbidities. The most common co-morbidities were hypertension, cardiovascular disease and/or diabetes.
Setting	Rheumatology clinic in an area with a high prevalence of gout, New Zealand
Study design	Qualitative, semi-structured interviews
Methods and analysis	A semi-structured interview was developed jointly by the authors. The questionnaire was based on previous literature and anecdotal accounts in clinical practice and allowed exploration of participants' experience in dealing with acute gout attacks, their knowledge and level of medication use (particularly colchicine) in managing chronic gout and the types or sources of medicines information they

Study	Rebello, 2016[40]
	received. Questions specifically related to information: How do you get your information about your gout (GP, friends, family, Internet?) - How often do you see your health professional?- Is there any more information you would like regarding colchicine itself in the management of your gout? There are several patient support groups available for gout patients- Are you interested in joining any of these groups?- Do you think the Gout Clinic has been helpful in managing your gout? Consistency of questioning style and appropriateness was ensured through a training session with external researchers, and the process was piloted with senior academics at the University of Auckland and lay people. After participants had read the Participant Information Sheet and agreed to participate, they signed a consent form and permission was sought for the interview to be tape recorded. At least two researchers were present during participant interviews (one as questioner and one as observer/ note taker). A debriefing with co-researchers took place after each interview to ensure consistency of the interview process. Interview recordings were transcribed verbatim by the two researchers, and through discussion with four other final year Pharmacy students the data were imported into NVivo version 10 for coding and analysis. A coding frame based on participant responses to the interviews and other key themes and concepts that subsequently emerged from the data was developed. All members of the study team contributed to developing the coding frame; a draft was discussed within the research team and refined, and further modifications were made after applying codes to the first two transcripts. The research team discussed the coding process as it progressed and to ensure inter-coder reliability a consensus was reached where there were uncertainties about how to code particular data items. A thematic approach was used to analyse the data.
Findings	**Colchicine knowledge, effectiveness and adherence** The majority of the participants viewed colchicine as a 'painkiller' for use only during an acute flare. However, a few knew that low dose colchicine was effective in preventing or reducing gout attacks or reducing uric acid levels, and understood that colchicine was to be taken until allopurinol was established.
	Medicines information Most of the participants received most of their information about gout and gout medicines from their GP, while a few downloaded digital references or printed material themselves. Only a couple of participants mentioned their pharmacist as an information resource. The medicines information received was mostly about dietary triggers, causes of gout, indications for colchicine and its side effects and the complications or consequences of leaving gout untreated. Most participants asked the researchers for extra information about gout because they found the information they had previously received was contradictory and difficult to understand. Participants with English as a second language usually found it difficult to comprehend medical jargon spoken by physicians. ''It's very hard for us [Pacific Island] people to understand the terminologies…but it's good…if they can…print it out… and give us information especially in our own language so our elders can understand…' [P11]. '…less words more pictures…I know a picture…it tells me a lot. But little extra information; not too much; highlight; bullet point maybe…' [P8].

Study	**Rebello, 2016[40]**
	'…they said what not to eat on the book...on the sheet said I can eat it… so it was confusing…Feel annoyed like I had no idea' [P3].
Funding	No funding stated
Limitations and applicability of evidence	Applicability: 28/30 patients were taking colchicine

Study	**Seow, 2020[46]**
Aim	To explore the perceptions regarding living with gout of patients with gout in Singapore
Population	People with gout N=15 Gender: all male Ethnicity: 12 Chinese, two Malay, and one Filipino The inclusion criteria were: adults who (a) were 21 years old and above, (b) had been diagnosed with gout for 6 months or more using the American College of Rheumatology/European League Against Rheumatism Gout Classification Criteria, and (c) were able to speak and read in English and/or Mandarin Chinese. The exclusion criteria included patients who (a) had been diagnosed with mental disorders, (b) had cognitive impairment, and/or (c) had hearing and/or speech impairments.
Setting	Rheumatology clinic of a public tertiary hospital, Singapore
Study design	Qualitative – semi-structured interviews
Methods and analysis	Individual face-to-face semi-structured interview was chosen as the method for data collection, using an interview guide that was developed based on the researcher's prior knowledge, literature review, piloted and revised before commencing the actual study. The interview guide was reviewed by two researchers from the rheumatology department who had the clinical experience to ensure sufficient coverage and appropriateness of the questions. Four broad topics were covered by the guide: (a) general experiences (e.g., How did you feel when you first heard that you have gout? Please share with me your experience living with gout. How has gout impacted your life? How do you currently feel about living with gout?), (b) coping (e.g., How do you cope with your condition? What are the positive and negative supports that you have received?), (c) treatment and adherence (e.g., Please share with me how you feel about the treatment prescribed for you by your consultants. Do you follow the treatment plan prescribed for you? If not, what are the reasons?), and (d) health care needs (e.g., In what areas do you think health care professionals can improve in the management of your condition?). Questions were posed in no specific order and were added or dropped, depending on the direction of the interview.

Study	Seow, 2020[46]
	During the study, potential participants were selected and referred to the main researcher based on the inclusion and exclusion criteria provided. All interviews were conducted by the main researcher in either English or Mandarin Chinese according to the participant's preference. The duration of each interview ranged from 12 to 42 min. Thematic analysis was used to analyse the data collected in this study. The transcribed data were first analysed by the main researcher, who familiarized herself with the data through transcribing the audio-recorded interviews, repeatedly reading the transcribed data, and generating preliminary ideas. Two bilingual researchers in the study team then reviewed the translated transcripts against the original recordings to correct any mistakes and to ensure accuracy. Any data that had similar characteristics and connotations were extracted and collated. After coding, subthemes were generated by categorizing relevant codes together. Following which, these subthemes were evaluated and refined to form themes.
Themes with findings	**Interactions with Doctors** **Negotiating treatment plans.** Instead of the usual paternalistic relationship, some participants in this study were noticed to be autonomous in their treatment plans. These participants had treatment plans that were negotiated and determined on a monitoring basis of the treatment outcomes. **Receiving informational support from doctors.** During the interviews, some participants narrated about how informational support was given through the monitoring of their disease progress and the provision of medications and dietary advices. ''She (the doctor) used to explain to me (about) reading purine rich food, which I did not understand. So, she gave me a lot of advice on what can be eaten and what to eat lesser (of).''
	Coping with gout using internal and external resources Receiving supports from family and friends. Support from family and friends was another approach participants adopted to cope with their gout. ''Because my friend (is) also a sufferer for many years and he told me that you should go and see the rheumatologist instead of just getting a drug from a GP.''
Limitations and applicability of evidence	Very minor limitations

Study	Spencer, 2012[53]
Aim	To explore patient and provider illness perceptions and barriers to effective management of gout in general practice.
Population	20 participants with gout: 15M/5F. Age 35-81years (mean age 61, SD 10.2). Mean duration of disease was 12 years (SD 11.1, range 2-42 years)

Study	Spencer, 2012[53]
	18 health care professionals (6 GPs, 15 general physicians and 7 practice nurses.) Inclusion: age 30-100 years, had suffered from clinical gout within the previous year (irrespective of any ULT) and had an SUA level >360µmol/l (i.e., sub optimally treated)
Setting	Patients: home/ hospital, HCP: their place of work/ Nottingham City Hospital
Study design	Qualitative, semi-structured interviews
Methods and analysis	Two semi-structured interview schedules were designed to ensure that critical topics were covered in both the patient and HCP interviews. Patient topics included: patient beliefs about causes and consequences of gout prior to attendance at the gout clinic; their symptoms (frequency and severity); impact on daily life; emotional and psychological impact; what helped or hindered attacks; management of pain; contact with health professionals; advice/ information received; treatment history and preference; future expectations about treatment and outcome; and adherence / non-adherence to health professional advice. Health professional topics included: experiences of dealing with gout patients ;knowledge and training in relation to gout; current clinical practice; attitudes to the development of an intervention to improve best practice; and perceived barriers to the effective management and treatment of gout. A grounded theory influenced approach was used to ensure a systematic process was followed in developing knowledge and theory. The process of constantly comparing data continued until 'theoretical saturation' was reached and no new categories or themes were uncovered. Due to the large amounts of verbatim text generated, a computer package that assisted with qualitative data analysis was utilised. Once an interview was completed, the tape recording was uploaded onto a PC and transcribed with the help of a transcription kit and transferred to Nvivo 8. Analysis of the data started in parallel with the data collection, and initial results informed subsequent sampling and data collection as themes and issues emerged. Memos were written about emerging categories, to summarise a point, to critique information and to relate emergent theories to existing literature. The authors met regularly to discuss coding and interpretation of data.
Findings - patient	**Lack of knowledge and understanding about cause and consequence of gout** Lack of knowledge and understanding about cause and consequence of gout and the importance of making adequate lifestyle changes and adherence to lifelong ULT. Lack of awareness of pathogenesis of gout. Focus on acute attacks. Lack of knowledge of possible long-term effect of progressive urate crystal deposition and the risk of irreversible joint damage/ osteoarthritis. Participants felt that this aspect had not been explained. Unaware of preventative medication. ''I mean, I just thought I had arthritis and had to put up with the pain in my joints that have developed over the last seven years. I didn't realise that, if you could get the uric acid levels down in your blood, you could try and prevent gout attacks from happening.'' ''Over the last thirty years I have been dealing with gout in a number of ways, I initially just dealt with it with pain killers and just carried on working'' ''I took the Allopurinol for some time…and didn't have any attacks, so I thought I had cracked it. I thought it had gone so I took myself off the Allopurinol and I thought I would be fine''
	Viewed as an alternative rheumatic disease All 5 women preferred to view and treat gout in this way due to social stigma. Some were unaware that it was a form of arthritis. ''I didn't think that women suffered with gout''

Study	Spencer, 2012[53]
	Hesitance in seeking help Due to belief that it was self- inflicted, considered part of ageing, stigma
Findings- HCP	**Gout not managed as a long-term disease but as an acute condition** Many GPs and most hospital physicians were reluctant to offer ULT until patients had suffered recurrent frequent gout attacks for some considerable time. Most mainly offered NSAIDs for acute attacks and presumed patients would prefer this to lifelong medication. Several GPs highlighted how patient adherence to ULT left them little option other than to repeatedly prescribe NSAIDs. ULT not considered until frequent and severe attacks. ‘’Even in my own mind I don’t treat gout as a chronic disease, I just tend to deal with the acute event so I am just as guilty in not always offering preventative options or giving that information, because perhaps a fifty year old may not have another attack for 10 years’’.
	Lack of education and information given to patients HCPs assumed patients had better understanding than they did. Many patients were given little information about gout, its prognosis, or available treatments. Very few surgeons were aware of available patient literature or gout websites and most HCPs used verbal information alone to inform their patients about gout. Several GPs commented that they did not always give enough information to patients about possible long-term consequences of gout or explain that gout is a life-long condition. ‘’I think with gout because of time pressures I think education and health promotion about the condition are missed at diagnosis and just the acute attack is delt with. Plus, I suppose there are a lot of assumptions going on, because gout is such a well- known condition/ diagnosis that the patients looks like he/ she understands when you say its gout’’
	Lack of understanding and knowledge of gout Most GPs/ physicians had a reasonable knowledge of gout, some practice nurses were not very knowledgeable about gout or its management. Nurses only encountered gout as a comorbidity in patients who accessed nurse-led chronic disease management clinics. In the absence of knowledge, most HCPs mirrored general population perspectives (self-inflicted, due to unhealthy lifestyles). ‘’I think I would usually just make that decision from my clinical experience and would tailor that to my patient’s need. I don’t tend to use clinical guideline for gout I wasn’t aware that any existed’’ ‘’Even I as a GP do associate gout with the old fashion traditional view that links the condition with the ‘well to do’ port drinking’’ ‘’I think that there is a lack of knowledge by both patients and health professionals. I just thought you just had gout flare-ups and then it just went away, so there is definitely a need for education and better training’’
	Lack of training and education in best practice for the treatment and management of gout At undergraduate and postgraduate level therefore many HCPs use self-directed learning as needed.
Funding	Arthritis Research UK (award ref. 18827)
Limitations and applicability of evidence	Minor limitations

Study	**Te Karu, 2013**[56]
Aim	To explore the perceptions, understanding and treatment of gout among Maori
Population	Those who identified as Maori and had a history of gout were eligible to participate. Urban participants were invited from the Improving Adherence using Combination Therapy (IMPACT) cardiovascular polypill trial undertaken in Auckland. Rural participants were recruited via a gout clinic in a rural town where the principal researcher worked as a clinical pharmacist. N=12 (8M/4F)
Setting	Participants homes (most interviews), clinic (3 participants), New Zealand
Study design	Qualitative- interviews
Methods and analysis	The principal researcher undertook semi-structured interviews with open ended questions. Participants were able to respond in English and Maori. As part of the process, whakawhanaungatanga (a discussion of connection of persons through genealogy and/ or a Maori specific process). The principal researcher transcribed the interviews. Wherever possible, participants were sent transcripts to check for completeness and representativeness. Thematic analysis of transcripts was undertaken by two of the researchers independently, who then met to discuss their findings and agree on themes. On occasion a third researcher was also engaged. Interviews continued until saturation of themes was achieved.
Findings	**Insufficient information from providers** ‘’I don’t think they gave you enough. It kind of wasn’t even the basics. There were no follow-ups or anything and I was going regularly. There must have been time in there. I didn’t know about uric acid levels or what I should aim for. In my mind, I never had it explained.’’
Funding	Funding not stated
Limitations and applicability of evidence	Minor limitations due to unclear recruitment of patients and role of researcher. Concerns over applicability (Maori population)

Study	**Vaccher, 2016**[58]
Aim	To explore the understanding of gout and its management by patients and general practitioners (GP), and to identify barriers to optimal gout care.
Population	15 GPs (9 women and 6 men) 22 patients (3 women and 19 men) Age: <40 n=2, 40-49 n=5, 50-59 n=4, 60-69 n=7, >70 n=4 Ethnicity: Australian European: 9, Italian: 3, Fijian: 2, Other: 8

Study	**Vaccher, 2016**[58]
	BMI: 18.5-25 n=3, 25-30 n=12, >30 n=7 Patient-reported co-morbidities: hypertension: 5, diabetes: 3, renal: 5, respiratory: 5, cardiac: 8, other: 12
Setting	Australia
Study design	Qualitative- semi-structured interviews
Methods and analysis	Recruitment. Using a snowball recruitment strategy, GP known to the research team were invited to participate. Each GP interviewed was asked to identify 1–3 patients with gout and invite them to participate. Additional patients were contacted by a member of the research team. Interviews. Consenting GP and patients were interviewed by 1 researcher either in person or by telephone. Interviews were focused on exploring participants' experiences with gout, medications prescribed, lifestyle interventions, and education received, and were designed to evoke discussion. Semi structured interview guides for both patients and prescribers were provided (not available in paper). Participants were reimbursed for their time. Each interview was recorded and transcribed verbatim. Analysis. A process of inductive thematic analysis was used. Each transcript was read independently by 2 reviewers and separate themes were identified for GP and patient transcripts. After analysing half of the transcripts, the reviewers met to discuss emergent themes and developed a framework for analysis of the remaining transcripts. Once analysis was complete, the reviewers met again to compare themes. Interviews were stopped when thematic saturation had occurred; that is, when no new themes were identified compared with those in preceding interviews. General discussion topics for the interviews included: General Practitioners Obstacles to gout management Associations with other diseases/risk factors Acute attack management Chronic/ long-term management Allopurinol usage Education Need for more resources/services/guidelines Referrals: rheumatologist, dietitian, etc. Patients with Gout Management of acute attacks Long-term gout management Knowledge of gout and medications Personal triggers

Study	Vaccher, 2016[58]
	Medication risks, adherence, and complementary therapies Research undertaken and the need for more education Broader effect of gout: work/social life/stigma
Findings	**Current approach to gout (GPs)** All GPs stated that they gave their patients some verbal education about gout, and about half the doctors reported that they gave their patients written material. However, some doctors suggested that patients were not given enough information. For example, 1 doctor stated, “I should give them handouts probably, so they’ve got more education”. To further assist patients, most GP said that they were happy to refer complex cases to a rheumatologist, and some doctors recommended that patients see a dietitian.
	Barriers to care (GPs) Fewer than half the GP interviewed were aware of management guidelines for gout. “I’m sure they exist… I haven’t actually personally, ah, looked at anything that’s called gout guidelines” Knowledge of risk factors. While most doctors noted that “[there was] always the issue of alcohol and diet” as risk factors for gout, other risk factors such as genetic associations, renal function, or concomitant use of medications such as diuretics were rarely identified. Education. Many GPs felt that they did not receive sufficient education on gout management, which led to some GPs expressing a lack of confidence in treating patients. One doctor explained, “There’s definitely more that I can learn to make me more confident”. Further, some GP believed that more community awareness of gout was needed. One doctor said, “I don’t think there is any awareness in the community, or significant awareness of gout”. About half of the doctors suggested that more GP resources, such as flow charts, and patient educational material, including “a website” or “some groovy YouTube video” could be helpful. Patient factors. Some GP mentioned that patient factors such as comorbidities could complicate gout diagnoses and treatment. The majority of GP noted that low medication adherence was a major barrier to successful treatment: “They’re not always compliant because you have to convince them that this [allopurinol] is prevention”. Several GPs stated that cultural and language barriers complicated patient education and resulted in different understandings about gout. For instance: “I’ve got a fair number of Pacific Islanders and Maori folk who consider, you know, gout’s just part of the normal picture of life”.
	Understanding and Management of Gout by Patients The majority of patients with chronic gout reported that they were taking daily allopurinol, with about half stating that their dosage had been modified over time, including patients altering their own dosages. When directly asked, fewer than half the patients stated that their UA concentrations had been tested in the previous year. Several patients explained that they had tried complementary therapies Level of care. All patients stated that they had sought GP advice for gout. About half of the patients had been referred to a rheumatologist, with visit frequency varying widely, from “I’ve only been to the rheumatologist’s once” to multiple appointments each year. A few patients mentioned that they had accessed other health professionals, such as a dietitian. Complementary practitioners were also consulted, as 1 patient commented, “We went to a naturopath and she made up the herbal medicines”.

Study	Vaccher, 2016[58]
	Barriers to Optimal Gout Management in Patients Understanding of gout. Most patients had a basic knowledge of gout, for instance: “It’s uric acid in the blood”. A few patients were unsure whether or not they actually had gout. One patient stated, “It’s a just constant sort of a pain, it’s as if it was more arthritic than goutish”. Most patients were aware that diet and alcohol intake could increase the risk of a gout attack. Comments such as “you’ve got to stop drinking red wine [and] beer” were common. Despite this, only a small number of patients cited other associations, such as “it’s an old man’s disease” or “it was a hereditary issue”. **Understanding of gout management.** Overall, knowledge of gout medications was poor. Fewer than half of the patients taking allopurinol were aware of its mechanism of action/ Very few patients understood the function of colchicine, despite its common usage. Fewer than half of the patients interviewed could identify the earliest manifestations of an acute attack, limiting the opportunity for prevention, for example with colchicine. **Medication-related barriers.** No patients were aware of allopurinol hypersensitivity syndrome. Several patients said they wished they had been more aware of medication options, for instance: “It probably would have been nice to have been told about it [allopurinol] a bit earlier”. **Education about gout and its management.** Fewer than half of the patients recalled receiving written or verbal information about gout from their GP. Examples of educational material received included “brochures”, “a card about gout”, and “[the GP] told [them] what not to drink, or not to eat”. The majority of patients explained that they had researched gout themselves, including reading their medication product information, purchasing books, and browsing the Internet. A common response was: “When they said I had it [gout], I went and Googled it”. Many patients expressed an interest in learning more about gout or having more informative resources, for instance: “If there’s some reading to do or, I’d like to read it, yeah”. Often, patients had particular questions they wanted answered, such as: “I wonder what, ah, what triggers it in some people and not in others”.
Funding	Supported by the Lexy Davies Trust, St. Vincent’s Hospital, Darlinghurst, New South Wales, Australia and National Health and Medical Research Council Programme Grants (568612 & 1054146).
Limitations and applicability of evidence	moderate limitations due to recruitment method, unclear role of researcher and data analysis not fully reported

Study	Van Onna, 2015[59]
Aim	To explore the health literacy of patients dealing with gout and to understand perceptions that might account for non-adherence to urate lowering therapy.
Population	Patients with gout attending primary or secondary care. N=15 (14M/1F)

Study	**Van Onna, 2015**[59]
	Age: 63 (12), range: 47-83 years Mean disease duration 11 years (range 3months to 26 years; SD 7 years) 6 patients had tophaceous disease All had ≥1 cardiovascular risk factors Current treatment: 7 were using colchicine or NSAIDs plus ULT, 3 were using only colchicine or NSAIDs, 5 were using only ULT 4 patients were taking >20 units of alcohol per week
Setting	The Netherlands
Study design	Qualitative- semi-structured interviews
Methods and analysis	An interview guide was developed to secure data comparability. A pilot interview was conducted to ensure that the questions were clear and addressed all important topics. Each interview was audio-taped and fully transcribed afterwards. Topics addressed: * General questions: age, general medical history, work status. * Gout-related medical history: year of first gout attack, presence of tophi (physician verified), number of gout flares over the past 12 months. * Knowledge about gout and awareness about the importance of correct medication intake to prevent both acute and chronic consequences of gout. * Knowledge about prescribed medication for gout (anti-inflammatory drugs and/or ULT), perceived side effects. * Perceptions about effectiveness of gout treatment and perceived advantages and disadvantages * Patients' action and coping plans related to medication adherence, extent of self-efficacy. * Patients' opinions and preferences for educational interventions to address lifestyle and pharmacological measures in order to optimize the outcome of patients with gout. All transcripts were read, annotated, and analysed by two independent readers. A coding system based on the grounded theory approach was developed by making a taxonomy of the data and following the structure of the interview. The readers met regularly to discuss coding and interpretation of the data. In case of disagreement, consensus was reached between the two readers after re-reading the specific passage of the transcript. Illustrative quotes made by patients were collected.
Findings *All quotes translated from Dutch	**General knowledge about gout and treatment of gout** Four patients could give an adequate description about the pathophysiology of gout. These four patients mentioned that crystals cause gout and indicated that high levels of uric acid are associated with crystals or inflammation, which may eventually result in the formation of tophi ("Gout means that you have too much uric acid, the kidneys cannot get rid of it. As a consequence, the uric acid or purines accumulate in the joints. Then you get crystals in the joints, often the ankle or the big toe. Then you get inflammation and eventually formation of tophi."). Five additional patients mentioned the word "crystals", but without further specification. One patient thought that gout is caused by "gout sugars"; another patient mentioned an imbalance between acid and alkaline in the body as a cause of gout. Eight patients mentioned the words "inflammation" and/or "arthritis". With regard to exacerbating factors of disease, patients indicated that alcohol (12 patients), (red) meat (8 patients) or sea food (4 patients) increase the risk of a gout flare. Four patients, all used ULT,

Study	Van Onna, 2015[59]
	knew the difference in mode of action between NSAIDs/colchicine and ULT (quote 2). Primary care patients had in general a lower level of knowledge about gout, except for one patient that used ULT in combination with colchicine as needed. Patients recruited from primary care were more often not aware of the possible long-term consequences of gout, such as tophi and/or joint destruction. Twelve patients considered gout as a chronic condition.
	Opinions about educational programmes about gout Half of the patients expressed that they would have wanted to know more about the aetiology of gout, treatment goals, long-term consequences and lifestyle modification at the time of diagnosis: “I wish someone told me about the consequences of gout. A few years ago, well, this is what happened: when I had no pain at that moment, I drank a lot of beer and experienced an attack a few days later. Nowadays, I have to deal with the consequences of such a lifestyle.” “How does the medication for gout work? And combinations? And it is not clear enough that gout causes wounds with crystals and tophi.” The patients who only used NSAIDs or colchicine intermittently, because they have no indication for long-term ULT, more often expressed to have no specific interest in information about gout. Several patients admitted that they had searched the Internet for information, but the obtained information was often incorrect or ambiguous. “Yes, I searched the Internet, and was buggered around. I ordered something, you should only take a few drops a day, well, it had an awful taste. I have immediately disposed it in the trash can.”
	Gout medication treatment adherence Both patients with and without sufficient knowledge about the pathophysiology and consequences of gout admitted non-adherence. Twelve patients indicated that treatment of gout only encompassed treatment of the acute attack and were unaware of long-term treatment goals to avoid structural joint damage. Almost all patients indicated that the main reason for medication adherence was a reduction in the number of gout flares and less pain. For two patients their lack of adherence was due to physicians giving conflicting messages about medication.
Funding	No funding stated
Limitations and applicability of evidence	Minor limitations due to the role of the researcher

Appendix E –GRADE-CERQual tables

Table 5: Summary of evidence: information needs

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Review finding 1: Patient knowledge of causes of gout					
8	7 Semi-structured interviews; 1 focus group	Causes of gout were poorly understood and many alternative causes were suggested, including alternative pathophysiologies, injury and ageing.	Limitations	Minor limitations[a]	MODERATE/ HIGH
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	
Review finding 2: Patient knowledge of dietary advice					
7	6 Semi-structured interviews; 1 focus group	Many patients requested dietary advice, commonly wanting to know what foods and drinks were ‘safe’ and what were to be avoided.	Limitations	Minor limitations[b]	MODERATE/ HIGH
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	
Review finding 3: Long-term impact of gout/ monitoring.					
8	7 Semi-structured interviews; 1 focus group	Gout is often treated as an acute condition and the long-term consequences were not frequently understood or discussed.	Limitations	Minor limitations[c]	HIGH
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
				adequacy	
Review finding 4: Lack of information specifically for females					
2	Semi-structured interviews	Delays in diagnosis due to gender, poor provision of female specific information.	Limitations	Minor limitations[d]	HIGH
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	
Review finding 5: Online sources of information					
5	Semi-structured interviews	Patients commonly searched the internet for information following diagnosis. Information online was often found to be incorrect, contradictory, or ambiguous.	Limitations	Minor limitations[e]	MODERATE/ HIGH
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	
Review finding 6: Information preferences					
7	Semi-structured interviews	Patients wanted more time, especially at diagnosis, more oral and written information and to be involved in the decision-making process	Limitations	Minor limitations[f]	MODERATE/ HIGH
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	

(a) Five studies with minor issues; unclear relationship between the researchers and the participants (Chandratre 2016, Harrold 2010, Jeyaruban 2016, Liddle 2015, Spencer 2012); two studies with moderate concerns about recruitment and the process of the analysis (Martini, 2012,Vaccher 2016) one study with moderate concerns about the role of the researcher (Deprouw 2019).

(b) Five studies from 4 populations with minor or very minor issues; unclear relationship between the researchers and the participants (Chandratre 2016, Latif, 2019 Liddle 2015, Richardson 2016, Seow 2020); two studies with moderate concerns about recruitment and the process of the analysis ((Martini, 2012,Vaccher 2016), one study with moderate concerns about the role of the researcher (Deprouw 2019).

(c) All studies had minor or very minor concerns relating to the role of the researcher (Chandratre 2016, Howren 2018, Liddle 2015= Richardson 2016, Martini 2012, Rebello 2016, Spencer 2012, Van Onna 2015), one study with moderate concerns about the role of the researcher (Deprouw 2019).

(d) The studies had minor or very minor concerns relating to the role of the researcher (Liddle 2015, Richardson 2016, Spencer 2012)

(e) All studies had minor or very minor concerns relating to the role of the researcher (Howren 2018, Liddle 2015, Van Onna), with the exception of one study (Vaccher 2016) with moderate concerns about recruitment and the process of the analysis and one study with moderate concerns about the role of the researcher (Deprouw 2019).

(f) All studies had minor or very minor concerns relating to the role of the researcher (Harrold, Latif, Liddle 2015= Richardson 2016, Rebello, Seow, Van Onna 2015, with the exception of one study (Vaccher 2016) with moderate concerns about recruitment and the process of the analysis.

Table 5: Summary of evidence: support needs

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Review finding 1: Role of GP					
4	Semi-structured interviews	Need for improved and continuing medical education. GPs felt they didn't have enough time or appropriate material to provide to patients. There were language/cultural barriers and a lack of awareness of guidelines. Most information was provided verbally; lack of resources	Limitations	Minor limitations[a]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	
Review finding 2: Role of nurses					
3	Semi-structured interviews	Nurses felt that with more training they would be better placed to educate and monitor patients.	Limitations	Minor limitations[b]	HIGH
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Finding	Criteria	Rating	Overall assessment of confidence
			Adequacy	No concerns about adequacy	
Review finding 3: Role of pharmacists					
2	Semi-structured interviews	Pharmacists had a good understanding of medication related issues and of dietary information. Able to 'bridge the gap' between patient and GP due to having more time. Opportunity to offer info at each prescription.	Limitations	Minor limitations[c]	MODERATE
			Coherence	No concerns about coherence	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	
Review finding 4: Referral to specialists					
5 (4 populations)	Semi-structured interviews	A variety of views on specialist referral were found, both from patients, family/friends, and their GPs.	Limitations	Minor limitations[d]	LOW
			Coherence	Moderate concerns about coherence[e]	
			Relevance	No concerns about applicability	
			Adequacy	No concerns about adequacy	

(a) Two studies had minor or very minor concerns relating to the role of the researcher (Spencer 2012, Te Karu 2013); two studies had moderate concerns about recruitment and the process of the analysis (Martini 2012, Vaccher 2016),

(b) Most studies had minor or very minor concerns relating to the role of the researcher (Humphrey 2016, Latif 2019), one study with moderate concerns about the role of the researcher (Deprouw 2019)

(c) Both studies had moderate concerns about recruitment and the process of the analysis (Counsell 2018, Martini 2012)

(d) Most studies had minor or very minor concerns relating to the role of the researcher (Harrold 2010, Liddle 2015, Richardson 2016, Seow 2020) one study with moderate concerns about the role of the researcher (Deprouw 2019)

(e) There was a variation in experiences with some patients requesting referral at first diagnosis, while others were unaware of specialist input.

Appendix F – Excluded studies

Clinical studies

Table 6: Studies excluded from the qualitative review

	Reason for exclusion
Aati, 2014[1]	No relevant outcomes
Curiel, 2012[4]	Incorrect study design: systematic review of drugs for people with gout and CKD
Davatchi, 2008[5]	Incorrect study design: Epidemiological study; quantitative interviews with the general population to assess prevalence of different musculoskeletal complaints
Day, 2017[6]	Incorrect study design: RCT protocol
Dowell, 2017[8]	Does not match review question (secondary analysis of a paper looking at gout consultations)
Fernon, 2016[9]	Does not match review question (patients' views on design of an e-tool for gout management)
Fields, 2017[11]	Incorrect study design: not qualitative- evaluating MDT educational programme (quantitative data only)
Fields, 2018[10]	Incorrect study design: review paper
Gow, 2011[12]	Not available
Hmar, 2015[14]	No relevant outcomes
Jimenez-Linan, 2017[18]	Incorrect study design: survey of online patient information resources; accuracy assessed by rheumatology fellows
Jordan, 2019[19]	Incorrect study design: Linguistic analysis of search histories of people searching for gout; no qualitative data analysis (themes)
Katz, 1975[20]	No relevant outcomes
Kelly, 2020[21]	Incorrect population (included other forms of arthritis; very limited themes specific to gout)
Kiadaliri, 2019[22]	Incorrect study design: Matched cohort study assessing relationship between educational inequalities and mortality in people with gout
Kool, 2016[23]	Incorrect study design: Delphi conducted among health professionals and systematic review to identify potential items of a gout specific ICF core set
Krasnoryadtseva, 2020[24]	Incorrect study design: RCT comparing education interventions including personal versus generic medical images
Krasnoryadtseva, 2020[25]	Incorrect study design: the general public completed a quantitative questionnaire about an information leaflet on gout.
Moghimi, 2015[30]	Incorrect study design: Epidemiological study; quantitative interviews with the general population to assess prevalence of different musculoskeletal complaints
Morris, 2016[31]	Incorrect study design (analysis of consultations- not interviews)
Oh, 2011[33]	Incorrect study design: Patient interviews and literature review to evaluate a web-based self-management program; states that interview questions were open and close ended but all results are in percentages.
Oh, 2013[34]	Not English language
Petrie, 2018[35]	Incorrect study design and population: quantitative questionnaires used to assess effect of renaming gout of illness perception among general public.
Punzi, 2020[36]	Incorrect study design (survey- quantitative data only)

	Reason for exclusion
Rai, 2018[37]	Incorrect study design: systematic review which does not directly answer question and has no quality assessment.
Rakic, 2017[38]	Incorrect study population: interviews about synthetic biology with people with gout and diabetes and unclear what proportion had gout
Ramsubeik, 2018[39]	Incorrect study design: Systematic review of RCTs and observational studies of educational and behavioural interventions
Rogers, 2019[43]	Incorrect study design: RCT comparing effect of different study invitation materials on trial participation
Rolland, 2017[44]	Incorrect study design: abstract only
Schroter, 2019[45]	Incorrect study design: RCT comparing effect of different competing interest statements on doctors' perceptions of education articles
Singh, 2014[48]	No relevant outcomes
Singh, 2014[47]	No relevant outcomes
Singh, 2014[49]	No relevant outcomes
Singh, 2019[50]	Incorrect study design: literature review
Singh, 2020[51]	Incorrect study design: internet survey- form with a list of responses to areas for improvement
Spaetgens, 2016[52]	No relevant outcomes
Spencer, 2012[53]	Incorrect study design: systematic review which is not relevant to outcomes of interest.
Stewart, 2016[54]	Incorrect study design: Systematic review of RCTs and observational studies of the first metatarsophalangeal joint
Stewart, 2020[55]	No relevant outcomes
Teoh, 2019[57]	Incorrect study design: flare diary entries were analysed; no qualitative data
Zhang, 2007[60]	Incorrect study design: Quantitative questionnaires used to assess risk factors for recurrent gout attacks.

Table 7: Studies identified but not included in the qualitative review due to saturation being reached

Study	Reason
Lindsay, 2011[28]	No relevant themes apart from a single quote adding to the theme of I for long-term impact of gout. The theme had already reached saturation point (where 8 studies were already included) so this study was excluded