

**Supplementary data.** Liddle et al. Mapping patients' experiences from initial symptoms to gout diagnosis: a qualitative exploration

## **Appendix 1: Topic guide**

### **Overall experience**

Story about gout

### **Discovery**

Finding out; Feelings; Other people's reactions; Previous knowledge; What was important at that time?

### **Living with gout**

What is it like to live with gout e.g. effects on day-to-day life/typical day with a flare; Managing at home e.g. stairs, toilet, shoes; Pain and management; Work/chores (and finances); Leisure; Social life; Relationships (including physical aspects); Frequency of flares/attacks; strategies/important aspects of management; Impact of other conditions

### **Treatment**

Medication; Side-effects; Impact of other conditions on treatment; Experiences with doctors; Taking medication; Other remedies – over the counter/alternative/complementary; Expectations about treatments; Thoughts about effectiveness of treatments; Hospital admission/referral with gout?

### **Support**

Sources of support; Support from GP/health professionals; Support during an attack; Groups/forums; Religion/spirituality; Impact on other people e.g. partner

### **Other people's reactions**

Telling other people; Reactions; Interactions with health professionals; Views about care from health professionals; Interactions with other people with gout; Stereotypes; Embarrassment; Stigma

### **Information**

Feelings about information provision; Sources of information e.g. internet, support groups, word of mouth; Useful information; Additional information needs

### **Individual characteristics and gout**

Gender; Age; Living arrangements; Other conditions; Length of time since diagnosis

### **The future and advice to others**

Feelings about gout and the future; Thoughts about what would improve the experience of living with gout; Messages/advice for others with gout; Messages/advice for health professionals

## Appendix 2: Main themes from analysis of qualitative interview data

The analysis resulted in six main themes related to diagnosis:

1. patients' interpretations of symptoms
2. decisions about seeking medical attention
3. triggers and delays within the diagnostic interval
4. accepting or doubting the diagnosis
5. thoughts and feelings on receiving the diagnosis
6. actions on receiving the diagnosis

Quotations are used to represent the range of responses expressed by participants and illustrate the findings. All names used are pseudonyms.

### 1. Patients' interpretations of symptoms

Patients described how, once they experienced symptoms, they began to analyse these to try to identify the cause and determine what action to take. While some patients recognised their symptoms as fitting with their pre-existing knowledge of gout, or as comparable with the symptoms of other people they knew with gout, being puzzled about the cause of the pain was a common experience. Resulting attempts to identify the cause were based on patients' general health knowledge and past experiences of pain or their medical history (e.g. operations). Box 1 summarises the wide variety of possible causes that people considered. The intensity of pain was sometimes particularly worrying because patients thought it could be caused by a life-threatening illness.

#### Box 1: Possible explanations considered by patients for their initial symptoms

Infection
Insect bite/sting
In-growing toe-nail
Chilblains
Working too hard/being on feet for long periods of time
Other forms of arthritis
Side effect from taking statins
Shoes
Cramp
Stubbed/broken toe
Other unnoticed injury
Previous operations/damage to joints

The location of pain within and/or around a joint was a factor that appeared to cause particular confusion. The location, combined with the severity of the pain, led patients to believe that the pain should be a result of physical trauma, and this conflicted with their knowledge that they had not injured themselves, and could not see any obvious signs of physical trauma.

### 2. Decisions about seeking medical attention

Once patients had appraised the nature of their symptoms, and identified or ruled out possible causes, they then made a decision about seeking medical attention. Box 2 illustrates some of the varying approaches patients took when deciding if, or when, to consult a medical professional. Responses ranged from making an appointment to see the GP as soon as possible – often motivated by pain intensity – to waiting for several months or years before seeking advice. The intensity of the pain encouraged some to consider visiting an Accident and Emergency (A&E) department.

## **Box 2: Patient decisions about seeking medical advice**

*“I woke up one morning, got a real big pain in my big toe, and I thought that I'd broken my toe and slept funny in the night or something of that nature. [...] I could hardly walk, had a real pain, as though it was - a bit like a fracture almost. So I made an appointment at the doctor” (John, 50yrs)*

*“I first got a swelling in my big toe, and I hobbled around for about a week and then my wife persuaded me to go to the doctor [...] I thought I had kicked it or something like that, I was working and it got worse so I took my slipper to work, put my foot in the slipper and carried on, and I thought the bruise would go.” (William, 78yrs)*

*“I woke up in the night with a very, very painful big toe. I straightaway realised that it was gout, 'cause my father also had gout [...] and that lasted for about 24 hours and then totally resolved itself. And then I had another attack, a similar attack, about a year later, and that lasted for 48 hours. Same – same area, on my big toe. And then I had a third attack, that started very similarly [...] I thought like it would resolve, like the other two, and it didn't, and it got very disabling. I was still working, but I was really struggling to walk and so I went to the doctor's and they diagnosed gout straightaway.” (Graham, 55yrs)*

In some cases, long delays in seeking medical advice were due to patients self-diagnosing and/or self-treating one or more attacks. Despite being in extreme pain, some patients displayed a more general reluctance to seek medical attention. Steve's account demonstrates that financial pressures also played a role:

*“I'd worked with it for 3 weeks, walking on the side of my foot [...] it's probably the worst pain I've had, in my life [...] I was a piece worker so what I made I got paid for, if I didn't make it, I didn't get paid, so and, you know, we were, young family then, so... [...] eventually I just had to give in and go to the Doctors and get signed off for a week or two [...] and you'd go back before you were right, but poverty dictates doesn't it sometimes, so you go back.” (Steve, 64yrs)*

Delays in consulting a GP were also reported by those who were abroad on holiday at the time of their first attack. Patients either visited their GP shortly after they returned to the UK (by which time their symptoms had resolved or lessened), or waited until they experienced a subsequent attack.

### **3. Triggers and delays within the diagnostic interval**

The 'diagnostic interval' describes the period of time between the first appointment with a health care professional and the formal diagnosis being made.[35] This varied

widely, from those who were diagnosed in their first appointment or a few weeks later, to those who were not diagnosed until a later appointment several months or years later. Patients talked about a number of delays and problems they encountered during the period before a diagnosis was made. Henry was initially misdiagnosed, while Linda reported problems trying to get appointments during the periods when her symptoms were most severe:

*“I went to the A&E [...] I saw a doctor there and he thought I’d been bitten on the foot, which was interesting, and they gave me some drawing paste to put over the actual area, it was the usual place, on the big toe, swollen there, and he said, ‘If it doesn’t improve come back and we’ll have a look at it’. [...] Obviously it didn’t improve [...] I’d had an x-ray as well on the first occasion and that didn’t really throw up anything [...] The doctor didn’t identify what it was [...] In fact in fairness, I don’t think he really knew what it was, it was just really a shot in the dark, so my medical advice then was not geared towards gout, it was something completely different.”* (Henry, 63yrs)

*“I think it started about two or three years ago. I started getting pains in my feet and inflammation. Every time – by the time I could get an appointment with the GP, because it was quite painful, all the inflammation had gone. So he never really saw it when it was at its worst. [...] The inflammation had gone down and so it didn’t look that bad, you know. I don’t think they realised quite how bad it was. [...] He really didn’t have any answers, which was the frustrating thing, really.”* (Linda, 46yrs)

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. Joanne was not diagnosed straight away despite the fact that her GP recognised her symptoms as consistent with gout:

*“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’.”* (Joanne, 56yrs)

#### **4. 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.

For Georgina, being female and in her 40s were both factors that led her to doubt the diagnosis:

*“I often doubt, I think ‘oh have they got it wrong?’ you know, because I don’t speak to anybody who’s got it, especially my age, you’re talking like really – much older men, like my Nanna knows people who’ve got it, but [...] they’re not women.”* (Georgina, 41yrs)

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’ what was causing their symptoms. This suspicion was reinforced in those who had had multiple tests (which included checking for suspected fractures or septic arthritis) before the diagnosis.

## 5. Thoughts and feelings on receiving the diagnosis

A desire for greater information provision at the point of diagnosis was a strong theme in the interviews. Finding out how to ease the pain was a priority, but patients also wanted to know:

- How gout would affect their everyday lives
- What they could do to manage the condition and prevent another attack
- What the treatment options were
- Why they had gout
- Whether lifestyle changes could be an effective alternative to drugs

Not all patients were aware that gout was a chronic condition that required long-term management (See Richardson et al., under review). Adam was aware of the chronic nature of gout, but felt that his doctor was dismissive of the impact that being diagnosed with a long-term condition might have on him:

*"It does take a period of adjustment [...] rather than, 'I've got something in the background which flares up occasionally' [...] the prospect of, 'I've got to take this for the rest', you know, 'the rest of my life,' is... it was difficult to adjust to. And I said that to my GP and he said, 'Oh, just...' matter-of-factly said, 'Oh, lots of people take tablets for the rest of their life.' So, I actually got a bit angry at that response."* (Adam, 41yrs)

While some patients were not surprised by the diagnosis, others were shocked, angry, or confused because they believed their lifestyles were very different to those they associated with gout. The contradiction was reinforced by some health professionals placing an emphasis on lifestyle changes.

Patients' own preconceptions, and/or their concerns that other people might view gout as a 'rich man's disease' caused by too much port or red meat, led some to feel embarrassed or uncomfortable at the thought that other people would think they drank too much alcohol or had an unhealthy diet. Resistance to the label of 'gout' featured strongly in some interviews:

*"It's got a bit of stigma to it and I don't know why because it's just an illness like anything else, but it has. [...] I try to hide the fact that I've got it. I will try to walk normally, I might be in excruciating pain, but because I regard myself as being fairly fit, when I've got it I tend to feel embarrassed that people might be looking at me and think, 'oh what's the matter with him?' That's not the problem, it's when they say, 'what's the matter with you' and you say, 'I've got gout', you know, there's stigma to it."* (Henry, 63yrs)

Judith chose to explain her symptoms as 'arthritis':

*"I think probably in the beginning, I didn't actually tell anyone. I just said, 'Oh, I had a pain. I had trouble with my big toe.' [...] I think because of that sort of possibly kind of embarrassment. It's easier to say that you've got arthritis or something, rather than saying that you've got gout. [...] Probably because people might assume that you drink and eat lots of red meat and you're overweight and things like that, and you're not."* (Judith, 61yrs)

For Georgina, the caution expressed by her GP before diagnosis, followed by comments made by a practice nurse, reinforced her feeling that it was abnormal to be a woman with 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' [...] I think she did seem a little - well more surprised than me really initially. [...] I had to ask our nurse three times, 'Did you say gout?' [...] She said 'I'm as baffled as you' [...] Yeah I was kind of thinking [...] that 'god, I'm a bit of a freak really' [...] 'am I half man or something?' You know, testosterone overload or something? [...] When you think the medical profession then are a little bit gobsmacked..."* (Georgina, 41yrs)

## **6. 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, patients had bought equipment to monitor their own SUA levels. For Adam, this was an important way of understanding and feeling in control of his condition:

*"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 their GP had recommended such changes. Nye's comments illustrate how challenging it could be for patients to make decisions about diet based on information from the internet:

*"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 that 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."* (Nye, 69yrs)