doi:10.3233/978-1-61499-666-8-28

# A User-Centred Approach to Designing an eTool for Gout Management

Anna FERNON<sup>a</sup>, Amy NGUYEN<sup>a,b</sup>, Melissa BAYSARI<sup>c</sup> and Richard DAY<sup>a,b</sup> <sup>a</sup> University of New South Wales, Australia <sup>b</sup> St Vincent's Hospital, Darlinghurst <sup>c</sup> Centre for Health Systems & Safety Research, Macquarie University

Abstract. Introduction: Gout is a chronic inflammatory arthritis with increasing prevalence in Australia and rates of non-adherence to therapy higher than for any other chronic disease. Electronic health interventions can increase adherence to treatment for many chronic diseases. This study set out to involve end-user patients in the design of a gout self-management eTool. Methods: Four semistructured focus group sessions were held in July and August 2015 with 13 patients with gout (age range 39-79 years). Focus groups involved group discussions of potential eTool features and critiquing disease self-management websites and applications. Focus group sessions were audio-taped, transcribed and analysed by two independent researchers to identify useful eTool features and patient perspectives of using technology to manage their health. Findings: Participants were open to using a supportive gout self-management eTool and identified a number of potentially helpful features, including educational material, serum uric acid monitoring and medication reminder alerts. Discussion: Focus groups with patients with gout revealed a number of features that should be included in a gout self-management eTool. These results will inform the design and implementation of an eTool for patients with gout and may be broadly applicable to teams designing eTools for other chronic diseases.

Keywords. Gout, electronic health, eTool, app, user-centred design

#### Introduction

Gout is a chronic inflammatory arthritis with increasing prevalence in Australia[1]. Gout is caused by the deposition of monosodium urate crystals in joints and other tissues in the presence of persistent hyperuricaemia. It is characterised by acute inflammatory attacks causing severe pain, impaired function and ultimately, with recurrent acute attacks, joint erosion and other organ damage[2].

#### Managing Gout

Guidelines for the diagnosis and management of gout are readily available[3]. It is known that gout can be essentially cured with adherence to an appropriate urate lowering therapy protocol[2]. However, urate lowering therapy is often not taken in accordance with evidence-based guidelines and rates of non-adherence to chronic gout medications are higher than for any other chronic disease[4-6]. Self-management strategies have been shown to be effective in increasing adherence to gout therapy and providing curative gout treatment[5, 7, 8].

## Utilising Electronic Health for Gout Self-Management

A range of novel technology-based interventions are being developed as a socially and economically viable way to increase patient self-management and adherence to treatment[9]. Mobile applications (apps) have been shown to be effective in improving diet, education, access to care, medication use, physical activity and weight in the management of arthritis and pain[10, 11]. As gout is a chronic arthritis characterised by episodes of pain, it seems likely that an electronic tool (eTool), such as an app or website, may be effective in augmenting gout management. However, in designing such a tool, it is pertinent that patients and physicians are involved in mobile health app development to ensure that the developed tools are useful and user friendly[12, 13].

## **Research Questions**

Do patients with gout believe they would benefit from the use of a self-management eTool? What do patients with gout think this eTool should look like?

## 1. Methods

#### 1.1. Focus Group Development

Focus group questions were developed with input from a rheumatologist, health services researchers and a medical student. Questions related to how participants managed gout, how they used technology to manage their overall health and their preferences on design concepts and potential features. A pilot focus group was conducted with volunteers who did not have gout to ensure that the questions were easily understandable and encouraged a natural flow of conversation.

#### 1.2. Recruitment

One hundred and twenty six patients with gout known to us by their GP or rheumatologist were invited to participate. Participants were excluded from the study if they were cognitively impaired or were not fluent in spoken English.

# 1.3. Participants

Thirteen patients with gout participated in the focus groups. This included 11 men and two women. The mean age of participants was 60 years, the median age was 63 years and the age range was 39-79 years. Ten participants reported owning a smartphone, 10 reported using a computer to access the Internet multiple times a day and one reported rarely using computers. The highest level of education completed ranged from primary school (n=2) to postgraduate study (n=2).

## 1.4. Procedure

Four semi-structured focus group sessions (with 3-4 participants each) were held in July and August 2015. A one-page questionnaire was used to collect basic demographic

information. Each focus group session was moderated by a medical student with the support of a senior researcher. The focus group sessions involved a group discussion, an educational presentation about gout by the moderator, and an opportunity for each participant to use iPads to view six existing gout management apps and one beta web-app called Healthy.me developed by the Centre for Health Informatics, Macquarie University. The sessions ranged from 90 minutes to two hours in duration.

## 1.5. Analysis

The focus group sessions were audio-taped, transcribed and de-identified. The transcripts were analysed by two independent researchers who coded text segments for potential themes concerning how patients self-manage their gout, use of technology, and what features they perceived as useful in an eTool. The two researchers met to discuss themes, came to an agreement on any discrepancies in theme extraction, and created a framework of themes[13, 14]. Potential features that were idiosyncratic to a small number of participants were excluded during data analysis. As the coding framework developed, transcripts were re-analysed in light of emerging themes.

## 1.6. Ethics

Ethics approval for this research study was gained from UNSW Human Research Ethics Advisory Panel, reference number 2014-7-10.

# 2. Findings

Focus group participants were open to the idea of using a gout self-management eTool. Participants generally held the attitude, "I don't use any apps for health stuff at the moment but I'm very open to doing, to doing that if they can help.

# 2.1. eTool Features

Participants discussed potential eTool features that they believed would be helpful, shown in Table 1.

# 2.2. Scope and Role of the eTool

All participants agreed that an eTool to assist management of all co-morbidities would be more useful than an eTool specifically for gout self-management and that having separate eTools for each comorbidity could lead to disuse. One participant said, "If you had one for gout, one for this, one for all the conditions, right, I'd be up to seven or eight applications... I wouldn't use them." (P5) Participants reported they would use an eTool as a portable health record to facilitate giving an accurate medical history. For example, a participant said, "What I would find useful would be an app...to have access to your history to show to a doctor if it's a new doctor or you have to see somewhere." (P6)

Feature	Supporting Quote	Additional Information	Supporting Quote
Education	"This would have been great when I was having my first attack because I really didn't know anything about it." – P7	Include lifestyle advice	"One of the biggest things with me, with my condition, was my weight and one of the things to help me was to try to reduce a lot of weight promoting weight lossI think is a big thing." – P2
		Use of images	"You want some images. Understand a lot of people prefer to see the image." – P3
Serum urate monitoring	"If I have a continuous graph of my levels and I know that I can see that here I had a gout attack then I'd make sure I do something about that level." – P6	Results interpreted for patients	"It's good to input all that information but then how do you assess it, how's it then formatted or table- ised to then show you where you're at, what you've got to get to sort of thing?" – P2
Medication reminder alerts	"It would be nice if there was a little, 'Would you like a reminder? What time would you like your reminder?' And then, and then you go, 'Oh, ok,' and then it automatically links up to your notifications of some sort, and it goes, 'Hey, don't forget to take your tablets.' And you go, 'Ah, thanks mate.'" – P1	A persistent notification may be more useful	"An alarm alone would not help but a persistent notification should be available, should be generated if you haven't, let's say, acted upon the alarm." – P6
Record acute gout attacks	"That would be good for a person having an initial gout attack because they don't know how it affects them so they can write it all down and take it to their doctor to work out the medication." – P5		
Contact details of health providers	"When you go to hospital, as far as I know, they say who's your heart doctor, who's your this doctor, who's your that doctor. Geez, what's his name again? I only saw him last week. Because my memory is shit so that kind of thing would be handy, yes, for me anyway." $-P12$		
Gout research updates	"If there's an app that, I don't know, once a month or once every three months or something, that brings out possible new measures to deal with gout, either medically or exercise or diet or whatever, that would be useful."		

Table 1. Useful eTool features for patients with gout

Key: P = Participant

-P7

## 2.3. Barriers to eTool Uptake

Many participants in our focus groups lacked awareness of eTools for gout and eTools in general. Statements to the effect of, "I didn't even know they exist," and, "I wouldn't think of it," were expressed by most participants. Most participants were also unfamiliar with technology, with a participant stating, "I just don't feel comfortable using technology." (P10) Some participants felt this was a common problem for older people, saying, "You're lucky there's only one person here who really knows, in the older generation, who really knows about computers... I think there's only about one in ten, because a lot of my friends, they're not interested in computers either." (P9)

## 3. Discussion

Involving end-users in the eTool design process has been widely called for in the literature[12, 13]. This study collected end-user opinions to enable the user-centred design of a future gout self-management eTool. Our results reveal that overall patients with gout feel they would benefit from the development and use of such a tool. The direction towards integrated electronic health records, such as the MyHealth record, is supported by these results. Participants in this study are in part calling for something akin to the MyHealth record in recommending that an eTool should incorporate features to support self-management of multiple co-morbidities. Although not raised as a concern in our study, patients may have security concerns relating to the use of the MyHealth record[15] and this will be further explored when developing our eTool. Many of the features that participants felt would be useful to their gout self-management have been shown to be effective in apps for managing rheumatic diseases other than gout[11]. The main barriers to using such an eTool are lack of awareness that such tools are available and a lack of familiarity with requisite technology.

## 3.1. Limitations

The response rate was low, with only 13 patients participating of the 126 invited. Although the number of participants was small, theme saturation was achieved following 4 focus groups. That is, participants recommended the inclusion of the same features. Some patients reported a lack of interest in using technology as a reason for declining to participate which may have contributed to a selection bias where focus group participants may have been more interested in eTools than the wider gout patient population. This phenomenon will be explored further in future research.

## 3.2. Future Directions

The results of this study will inform the design of an eTool for patients with gout but may also be broadly applicable to research in designing eTools for other chronic diseases. Based on end-user recommendations, the eTool we develop should be compatible across multiple platforms and ideally would communicate with existing electronic health infrastructure, such as the MyHealth record. Usability testing will be undertaken as an objective way of evaluating the design and addressing any potential user-related issues before wider dissemination of the eTool. A large randomised controlled trial examining the effectiveness of the eTool is also planned.

#### References

- P.C. Robinson, W.J. Taylor, T.R. Merriman, Systematic review of the prevalence of gout and hyperuricaemia in Australia. *Internal Medicine Journal* 42(9) (2012), 997-1007.
- [2] F. Perez-Ruiz, Treating to target: a strategy to cure gout. Rheumatology 48(suppl 2) (2009), ii9-ii14.
- [3] D. Khanna, J.C. Fitzgerald, P.P Khanna, S. Bae, M.K. Singh, T. Neogi, et al., American College of Rheumatology guidelines for management of gout. Part 1: Systematic nonpharmacologic and pharmacologic therapeutic approaches to hyperuricaemia. *Arthritis Care & Research* 64(10) (2012), 1431-46.
- [4] L.R. Harrold, S.E. Andrade, B. Briesacher, M.A. Raebel, H. Fouayzi, R.A. Yood et al., The Dynamics of Chronic Gout Treatment: Medication Gaps and Return to Therapy. *The American Journal of Medicine* 123(1) (2010), 54-9.
- [5] F. Rees, W. Jenkins, M. Doherty, Patients with gout adhere to curative treatment if informed appropriately: proof-of-concept observational study. *Annals of the Rheumatic Disease* 72(6) (2013), 826-30.
- [6] L. Silva, E. Miguel, D. Peiteado, A. Villalba, M. Mola, J. Pinto, et al., Compliance in gout patients. Acta reumatologica portuguesa 35(5) (2009), 466-74.
- [7] N. Martini, L. Bryant, L. Te Karu, L. Aho, R. Chan, J. Miao, et al., Living with gout in New Zealand: an exploratory study into people's knowledge about the disease and its treatment. *Journal of Clinical Rheumatology* 18(2) (2012), 125-9.
- [8] J. Barlow, C. Wright, J. Sheasby, A. Turner, J. Hainsworth, Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling* 48(2) (2002), 177-8.
- [9] M.D. Iversen, M.E. Connors, M.R. Menapace, A.J. Samson, E. Tessitore, Technology applications to improve health outcomes and self-management in patients with arthritis. *International Journal of Clinical Rheumatology* 9(5) (2014), 487-504.
- [10] R. de la Vega, J. Miró, mHealth: a strategic field without a solid scientific soul. A systematic review of pain-related apps. *PloS one* 9(7) (2014), e101312.
- [11] A.R. Pereira Azevedo, H.M. Lopes de Sousa, J.A. Faria Monteiro, A.R.N. Pereira Lima, Future perspectives of Smartphone applications for rheumatic diseases self-management. *Rheumatology International* 35(3) (2015), 419-31.
- [12] M. Arnhold, M. Quade, W. Kirch, Mobile applications for diabetes: a systematic review and expertbased usability evaluation considering the special requirements of diabetic patients age 50 years or older. *Journal of Medical Internet Research [Internet]* 16(4) (2014), e104
- [13] T. McCurdie, S. Taneva, M. Casselman, M. Yeung, C. McDaniel, W. Ho, et al., mHealth consumer apps: the case for user-centered design. *Biomedical Instrumentation & Technology* 46(s2) (2012), 49-56
- [14] K. Moen, A-L. Middlethon, Qualitative Research Methods, Research in Medical and Biological Sciences: From Planning and Preparation to Grant Application and Publication (2015) 321
- [15] E.C. Lehnbom, A.J. McLachlan, E.B. Jo-anne, *Health Informatics: Building a Healthcare Future Through Trusted Information. A qualitative study of Australians' opinions about personally controlled electronic health records, IOS Press, HIC, 2012.*