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

Anna FERNONa, Amy NGUYENab, Melissa BAYSARIc and Richard DAYa,b
aUniversity of New South Wales, Australia
bSt Vincent’s Hospital, Darlinghurst
cCentre 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 semi-structured 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
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)
Table 1. Useful eTool features for patients with gout

<table>
<thead>
<tr>
<th>Feature</th>
<th>Supporting Quote</th>
<th>Additional Information</th>
<th>Supporting Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>“This would have been great when I was having my first attack because I really didn’t know anything about it.” – P7</td>
<td>Include lifestyle advice</td>
<td>“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...I think is a big thing.” – P2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Use of images</td>
<td>“You want some images. Understand a lot of people prefer to see the image.” – P3</td>
</tr>
<tr>
<td>Serum urate monitoring</td>
<td>“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</td>
<td>Results interpreted for patients</td>
<td>“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</td>
</tr>
<tr>
<td>Medication reminder alerts</td>
<td>“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</td>
<td>A persistent notification may be more useful</td>
<td>“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</td>
</tr>
<tr>
<td>Record acute gout attacks</td>
<td>“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</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact details of health providers</td>
<td>“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</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gout research updates</td>
<td>“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.” – P7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Key: P = Participant
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


CSC was excited to participate at HIC in the following:

**Tuesday 26 July**

*Industry Stream – System Implementation*

11:50am: "The EMR as a platform for clinical transformation" - Dr Vinod Patel University of Warwick and Barts Health NHS Trust (UK) and Delia Dent, CSC

**Wednesday 27 July**

*Posters session - Academic/Scientific papers*

1:20pm: "Consumer first! Redesigning the dual diagnosis journey" - Dr Joanne Curry Western Sydney University, CSC

Learn more in our magazine, **The Journey to Digital Health**

CSC was proud to support the Health Informatics Society of Australia and their annual event, Health Informatics Conference. HIC 2016 is the premier digital health, health informatics and e-health conference and exhibition in Australia. The HIC conference program brings together a wonderful line up of international, national and local presenters sharing insights and case studies.
DIGITAL HEALTH INNOVATION FOR CONSUMERS, CLINICIANS, CONNECTIVITY AND COMMUNITY
This book series was started in 1990 to promote research conducted under the auspices of the EC programmes’ Advanced Informatics in Medicine (AIM) and Biomedical and Health Research (BHR) bioengineering branch. A driving aspect of international health informatics is that telecommunication technology, rehabilitative technology, intelligent home technology and many other components are moving together and form one integrated world of information and communication media. The series has been accepted by MEDLINE/PubMed, SciVerse Scopus, EMCare, Book Citation Index – Science and Thomson Reuters’ Conference Proceedings Citation Index.

Series Editors:
Dr. O. Bodenreider, Dr. J.P. Christensen, Prof. G. de Moor, Dr. U. Fors, Prof. A. Hasman, Prof. E.J.S. Hovenga, Prof. L. Hunter, Dr. I. Iakovidis, Dr. Z. Kolitsi, Mr. O. Le Dour, Dr. A. Lymberis, Prof. J. Mantas, Prof. M.A. Musen, Prof. P.F. Niederer, Prof. A. Pedotti, Prof. O. Rienhoff, Prof. F.H. Roger France, Dr. N. Rossing, Prof. N. Saranummi, Dr. E.R. Siegel, Prof. T. Solomonides and Dr. P. Wilson

Volume 227

Recently published in this series

Vol. 226  J. Mantas, A. Hasman, P. Gallos, A. Kolokathi and M.S. Househ (Eds.), Unifying the Applications and Foundations of Biomedical and Health Informatics
Vol. 225  W. Sermeus, P.M. Procter and P. Weber (Eds.), Nursing Informatics 2016 – eHealth for All: Every Level Collaboration – From Project to Realization
Vol. 222. E. Ammenwerth and M. Rigby (Eds.), Evidence-Based Health Informatics – Promoting Safety and Efficiency Through Scientific Methods and Ethical Policy

ISSN 0926-9630 (print)
ISSN 1879-8365 (online)
Digital Health Innovation for Consumers, Clinicians, Connectivity and Community

Selected Papers from the 24th Australian National Health Informatics Conference (HIC 2016)

Edited by

Andrew Georgiou
Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, Sydney, Australia

Louise K. Schaper
Health Informatics Society of Australia, Melbourne, Australia

and

Sue Whetton
School of Health Sciences, Faculty of Health, University of Tasmania, Launceston, Australia

IOS Press
Amsterdam • Berlin • Washington, DC
Preface

There’s never been a more exciting time to be involved with health informatics. In the last few decades, health informaticians have established the knowledge base and practical expertise to facilitate the development of ever-more capable technical systems, increasing connectivity, expanding access and greater mobility of e-health and information management systems. We have seen the evolution from simple computer based records to systems that allow intra-organisational, national, even international communication and information exchange. We have also seen progress in e-health and most recently m-health, facilitating access to information and advice almost anytime, anywhere. The health informatics community is now building on this strong foundation, taking a central role in the digital transformation of the healthcare sector. The Australian National Health Informatics Conference (HIC), Australia’s premier health informatics event, is a key avenue for facilitating this transformation. This Conference, organised by the Health Informatics Society of Australia (HISA), with the support of the Australasian College of Health Informatics (ACHI), provides the ideal professional and social environment for clinicians, researchers, health IT professionals, industry and consumers to integrate, educate and share their knowledge to drive innovative thinking, to enhance services and allow greater consumer involvement. This is emphasised in the primary theme of the 2016 Conference: Digital Health Innovation for Consumers, Clinicians, Connectivity, Community.

The papers in this volume reflect this theme, highlighting the cutting edge research evidence, technology updates and innovations that are seeing the digital transformation of the healthcare sector. The papers are indicative of the wide spectrum of work encompassing major theoretical concepts, examples of key applications of new technologies and important new developments in the field of health informatics. They emphasise the central role that health informatics and e-health play in connecting information systems, being smart with data, and enhancing both practitioner and consumer experience in healthcare interactions. Welcome to the innovation boom.

This year’s program maintains the high standard of papers for which the conference is well-known. All papers were blind-peer reviewed by three experts in the field of health informatics. These reviewers are widely considered to be prominent academics and industry specialists. The contribution of the Australasian College of Health Informatics, particularly the voluntary participation of Fellows, in supporting this review process is gratefully acknowledged. Similar contributions made by many senior and experienced members of the Health Informatics Society of Australia is also acknowledged. Forty papers underwent the initial review and feedback process. Resubmitted papers were then validated by the Scientific Program Committee to ensure that reviewers’ recommendations were appropriately addressed or rebutted. In total 20 papers were selected for inclusion in this volume. Congratulations to all the authors.

Andrew Georgiou
Louise K. Schaper
Sue Whetton
Acknowledgements

The Editors wish to thank the following people for their efforts in reviewing the papers submitted for HIC 2016.

A/Prof Andrew Georgiou, Macquarie University
Dr Sue Whetton, University of Tasmania
Dr Michael Bainbridge, ASE Health
Dr Melissa Baysari, Macquarie University
Vicki Bennett, Vicki Bennett Consulting
Dr Jen Bichel-Findlay, University of Technology, Sydney
Heidi Bjering, University of Western Sydney
Neville Board, Australian Commission on Safety and Quality in Health Care
Dr Andy Bond, National E-Health Transition Authority
Dr Douglas Boyle, University of Melbourne
Ian Bull, ACT Health
Dr Kerryn Butler-Henderson, University of Tasmania
Dr Joanne Callen, Macquarie University
Paul Clarke, JamPac
A/Prof Elizabeth Cummings, University of Tasmania
Maria Dahm, Australian Institute of Health Innovation
Dr Karen Day, University of Auckland
Cathy Doran, Health Informatics Consultant
Dr Juanita Fernando, Monash University
Joanne Foster, Queensland University of Technology
Janette Gogler
A/Prof Heather Grain, E-Health Education
Dr Kathleen Gray, University of Melbourne
Dr David Hansen, The Australian E-Health Research Centre, CSIRO
Christian Hay, GS1 Switzerland
Leanne Holmes, Holmes Health Information
Dr Evelyn Hovenga, Global eHealth Collaborative
Dr Inga Hunter, Massey University
Jitendra Jonnagaddala, University of New South Wales
Prof Yogi Kanagasingam, The Australian E-Health Research Centre, CSIRO
Dr Kenneth Lee, University of Tasmania
Dr Michael Legg, Michael Legg & Associates
Dr Hugo Leroux, The Australian E-Health Research Centre, CSIRO
Dr Hugh Leslie, Ocean Informatics
Lawrence Lim, Griffith University
Amy Mayer, National Allied Health Classification Committee
Simon McBride, The Australian E-Health Research Centre, CSIRO
Dr Vincent McCauley, IHE Australia
Prof Jon Patrick, Health Language Analytics
Dr Lua Perimal-Lewis, Flinders University
Dr Mirela Prgomet, Macquarie University
Dr Magdalena Raban, Macquarie University
Derek Ritz, EcGroup
Dr Basema Saddik, King Saud Bin AbdulAziz University for Health Sciences
Dr Antony Sara, South Eastern Sydney Local Health District
Dr Philip Scott, University of Portsmouth
Prof Jeffrey Soar, University of Southern Queensland
Prof Paula Swatman, University of Tasmania
Alan Taylor, eDevelopment Solutions
Dr Chandana Unnithan, Victoria University
Dr Deborah van Gaans, University of South Australia
A/Prof Klaus Veil, eHealth & HL7 Training Partners
Dr Deborah Verran, Sydney Local Health District
James Walters
Prof Jim Warren, University of Auckland
A/Prof Trish Williams, Edith Cowan University
# Contents

Preface v  
*Andrew Georgiou, Louise K. Schaper and Sue Whetton*

Acknowledgements vii

Development of an Electronic Notification System for Influenza-Like Illness Sentinel Surveillance 1  
*Mehnaz Adnan, Donald Peterkin and Graham Mackereth*

Avoiding Failure for Australia’s Digital Health Record: The Findings from a Rural E-Health Participatory Research Project 8  
*H. Almond, E. Cummings and P. Turner*

Leveraging the EHR to Facilitate Efficient Surgical Audit: A Case Study from a Ophthalmic Private Practice 14  
*Ben Connell and Trevor Ward*

Feasibility of Technology Enabled Speech Disorder Screening 21  
*Andreas Duenser, Lauren Ward, Alessandro Stefani, Daniel Smith, Jill Freyne, Angela Morgan and Barbara Dodd*

A User-Centred Approach to Designing an eTool for Gout Management 28  
*Anna Fernon, Amy Nguyen, Melissa Baysari and Richard Day*

Development of an At-Risk Assessment Approach to Dietary Data Quality in a Food-Based Clinical Trial 34  
*Vivienne Guan, Yasmine Probst, Elizabeth Neale, Allison Martin and Linda Tapsell*

Two Studies on Twitter Networks and Tweet Content in Relation to Amyotrophic Lateral Sclerosis (ALS): Conversation, Information, and ‘Diary of a Daily Life’ 41  
*Bronwyn Hemsley and Stuart Palmer*

Promoting UV Exposure Awareness with Persuasive, Wearable Technologies 48  
*M. Sazzad Hussain, Liam Cripwell, Shlomo Berkovsky and Jill Freyne*

Hello Harlie: Enabling Speech Monitoring Through Chat-Bot Conversations 55  
*David Ireland, Christina Atay, Jacki Liddle, Dana Bradford, Helen Lee, Olivia Rushin, Thomas Mullins, Dan Angus, Janet Wiles, Simon McBride and Adam Vogel*

Classification of Movement of People with Parkinsons Disease Using Wearable Inertial Movement Units and Machine Learning 61  
*David Ireland, Ziwei Wang, Robyn Lamont and Jacki Liddle*

Predicting Unpanned Return to Hospital for Chronic Disease Patients 67  
*Sankalp Khanna, Norm Good and Justin Boyle*
Capturing Accurate and Useful Information on Medication-Related Telenursing Triage Calls
   R. Lake, L. Li, M. Baysari, M. Byrne, M. Robinson and J.I. Westbrook 74

Little Things Matter: A Time and Motion Study of Pharmacists’ Activities in a Paediatric Hospital
   Elin C. Lehnborn, Ling Li, Mirela Prgomet, Wing Y. Lam and Johanna I. Westbrook 80

Healthdirect’s After Hours GP Helpline – A Survey of Patient Satisfaction with the Service and Compliance with Advice
   Ling Li, Andrew Georgiou, Juan Xiong, Mary Byrne, Maureen Robinson and Johanna I. Westbrook 87

Analysing Health Professionals’ Learning Interactions in an Online Social Network: A Longitudinal Study
   Xin Li, Karin Verspoor, Kathleen Gray and Stephen Barnett 93

An Implementation of Clinical Data Repository with openEHR Approach: From Data Modeling to Architecture
   Lingtong Min, Juanjian Liu, Xudong Lu, Huilong Duan and Qingzhi Qiao 100

Finding and Exploring Health Information with a Slider-Based User Interface
   Patrick Cheong-Iao Pang, Karin Verspoor, Jon Pearce and Shanton Chang 106

An Ensemble Approach for Record Matching in Data Linkage
   Simon K. Poon, Josiah Poon, Mary K. Lam, Qinglan Yin, Daniel M.-Y. Sze, Justin C.Y. Wu, Vincent C.T. Mok, Jessica Y.L. Ching, Kam-Leung Chan, William H.N. Cheung and Alexander Y. Lau 113

Access and Use: Improving Digital Multimedia Consumer Health Information
   Alex Thomas 120

Integrating the Radiology Information System with Computerised Provider Order Entry: The Impact on Repeat Medical Imaging Investigations
   Elia Vecellio and Andrew Georgiou 126

Subject Index 133

Author Index 135