2016:41:1 Developing Research into the Usability of a Digital Self-Management Website for People with Osteoarthritis: A UK Patient and Public Involvement Study

**ABSTRACT**

**Background/Aims:** This study engaged people with osteoarthritis (OA) in the design and development of research into the usefulness of digital self-management approaches in OA. We aimed to (1) explore current attitudes of people with OA towards using e-health to self-manage joint pain in the future, and (2) identify facilitators and barriers for people with OA to engage with self-management techniques using e-health. Findings were used to help inform and design a subsequent mixed methods study.

**Methods:** A qualitative approach was used. Ten participants with self- reported symptomatic knee and/or hip joint pain were recruited from a national OA patient and public user group. They accessed and practised using the myjointpain.org website for two weeks, with no prior training, to self-manage their joint pain. One semi-structured telephone interview was used to explore their experiences. Data were transcribed and thematic analysis used to identify key themes.

**Findings:** Three key themes emerged; attitudes towards use, facilitators in use, and barriers in use. Participants reported that they believed (i) e-health has the potential to act as a go-to source of information and to deliver and support individualised self-management strategies and (ii) could act as a early disease support tool. Facilitators were identified that encouraged and supported use including personalised and interactive aspects of e-health education alongside prompting and perceived trustworthiness of the website. Excess information was identified as a barrier in use.

**Conclusion:** Current attitudes towards using e-health to self-manage joint pain reflect promising potential for exciting new OA interventions and research. Personalised and interactive aspects, trustworthiness of the tool, and prompting may promote engagement with e-health initiatives, Excess information may discourage use. Further research to consider e-health was recognised as relevant and potentially useful.

**Keywords:** osteoarthritis, self-management,e-health, facilitators, barriers

**INTRODUCTION**

There is compelling evidence that osteoarthritis (OA) is a global disease with substantial and increasing personal and economic impact. OA is the most common form of joint disease. The disease affects approximately 8 million people in the United Kingdom (ARUK et al., 2014) and with an increasingly ageing population (Office for National Statistics, 2012), the incidence and prevalence is set to increase. Consequently, the development of clinical and cost effective interventions to support people self-managing their OA is timely and important.

OA intervention includes both non-pharmacological (e.g. exercise and manual therapy, weight loss, acupuncture, aids and devices) and pharmacological (e.g. oral analgesics, topical treatments, NSAIDS and highly selective COX-2 inhibitors, intra-articular injections) treatment (NICE, 2008). Direct NHS costs for in-patient OA treatment have increased by 80% from the year 2000 to 2010/11 where current OA surgery and drug costs account for > £895 million, indirect costs span > £3.2 billion, and related services contribute an addition £258 million (Chen et al, 2012).

It is therefore timely that NICE recommend that all patients with OA have access to education and support for individualised self-management programmes (NICE 2014). Both verbal and written education is advocated throughout an individual’s management plan. Personalised self-management approaches and programmes are identified as key components in the non-surgical management of knee osteoarthritis (McAlindon et al, 2014). Digital E-health approaches where health services and information is delivered or enhanced through the internet and related technologies (Eysenbach, 2001), are becoming more prevalent. The internet has been used successfully to promote supported self management in OA (Pietrzak et al., 2013) and can augment patient satisfaction with OA care (Sciamanna et al., 2005). One such e-health initiative to enable individuals with OA effectively self-manage their condition is the ‘myjointpain.org’ website. Myjointpain,org was developed by Arthritis Australia, patients, and OA expert clinicansto support and engage patients with OA and help them develop self-management skills. Myjointpain.org features a range of online tools and in-depth information. The website screens users for hip, knee or hand osteoarthritis, creates self-management plans tailored to the individual, and can build an osteoarthritis action plan that allows the user to create goals, weight management & exercise strategies, track progress and locate local healthcare professionals that can offer face-to-face support. The myjointpain website aims to complement consultation with doctors or qualified health care providers rather than replace it. There is some evidence that this digital approach for an OA self-management website is effective in an Australian population (Umapathy et al., 2015). Significant improvements for users compared to non-users in self-management (absolute change score 15% vs 2%, P=.001) and weight reduction (absolute change scores 3% vs –6%, P=.03) measured on the Osteoarthritis Quality Indicator, were recorded following 12 months use.

We were keen to explore if there was potential for such an approach to be useful for a UK OA population and wanted to engage patient and public involvement (PPI)representatives in reviewing the e-learning package to see if they felt that this could be a useful approach to study further within the UK. PPI refers to engagement *with* or *by* members of the public rather than *to, about,* or *for* them (National Institute for Health Research, 2014). Although PPI has existed in the UK since 1974 (Hogg, 2007), it is only in the past decade that PPI has become integral in developing applied research (Steward al., 2011). We worked alongside a group of UK research partners recruited from the patient and public Involvement group from the Arthritis Research UK Centre of Excellence for Sport Exercise and OA. As an early exploration of a new self-management website, engaging PPI groups in the initial consultation and review was deemed appropriate and pragmatic. It was anticipated that the PPI groups’ comments would help inform future associated research applications and aimed to determine (i) current attitudes of a PPI cohort towards using e-health to self-manage joint pain in the future, and (ii) the perceived facilitators and barriers for people self-managing their OA using e-health.

**METHOD**

Arthritis Research UK Centre of Excellence for Sport, Exercise and OA PPI representatives were invited to take part in this study in July 2014, via a patient and public involvement/engagement facilitator at Nottingham University Hospitals NHS Trust. They were included in the study if they reported that they experienced hip and or knee joint pain, and had access to the internet. There were no exclusion criteria. Twelve PPI members were invited to participate via a PPI facilitator in Research and Innovation, at Nottingham City Hospital. As this study was deemed as a PPI exploratory consultation and engagement study, clinical research ethics approval was not required . However, the study was designed along the framework of good clinical research governance. An information sheet outlining the purpose of the study, and an accompanying consent form was posted by the PPI facilitator to all members expressing interest in becoming involved. Ten of the twelve members responded to the study request and provided written consent to be contacted by the study team. An initial telephone call to each member outlined the brief of the study. PPI members were then invited to set up a user account on myjointpain.org and to explore the website’s content over a two week period. One follow-up telephone call was arranged to discuss the member’s experiences of the website, at least one week after trialling its use.

*Data Collection*

An interview guide was used to prompt the interviewer. PPI participants were asked about their current attitudes towards using e-health to self-manage their joint pain in the future, what they perceived would facilitate their use, and what they thought acted as a barrier in their use of the self-management programme. Probes included exploring how they found the registration, navigation, and presentation of the website. Each interview was recorded using a Dictaphone and transcribed verbatim.

*Data Analysis*

Thematic analysis was used to analyse the data (Braun et al., 2006), encompassing a six step approach. Transcripts were (1) read and re-read, with (2) interesting features of the data set coded. These (3) codes were categorised into potential themes and subthemes before being (4) reviewed and refined. (5) Themes were defined and named before (6) producing a final report. Themes were independently verified to ensure reliability of results.

**FINDINGS**

**Participant demographics**

Ten PPI representatives agreed to take part. The PPI members consulted had a mean age of 56.7 years (range 42 – 74). Most were female (n = 7, 70% and all were British White (n=10, 100%). Education levels ranged from no education to Master’s degree. Ninety percent (90%) of PPI members (n=9) reported experiencing joint pain in at least one of their knees, and 40% (n=4) reported joint pain in at least one hip.

Thematic analysis identified seven subthemes surrounding the attitudes, facilitators and barriers for people with OA to engage in e-health self-management.

*Insert table 1 here*

**(1) What are the current attitudes towards using e-health to self-manage joint pain in the future?**

Positive attitudes towards using e-health to self-manage joint pain

Every PPI member was open to consider using e-health approaches in self-management of their OA. They were a motivated participant group who were keen to apply new methods of self-management in dealing with their joint pain.

*“I think [using e-health on an ongoing basis] would be excellent”* and that they would “*do everything that [they] can”* for their joints (PPI4 6;34)

E-health self-management programmes were identified as having the potential to reduce pressure on current NHS services, “*To help people with e-health I think it would be a massive massive boost. I think it’d be really good for the NHS and the surgeries. I would – I would certainly use it. I’d definitely use it”. (PPI5 5;25)*

This e-health initiative has the potential to encourage self-management, acting as a motivational tool; *“I think that’s the impressive bit. I think it’s a motivational tool for some people and I don’t think it’s asking too much”* (PPI7 4;16)*.*

Early disease support

In particular, it was found that e-health could be a good starting point for those newly diagnosed with OA, acting as a source *“that can help people understand the condition better” (*PPI5 5;47).

PPI members described “feeling lost” upon diagnosis, with little information on their condition. One PPI member believed myjointpain.org had the potential to be a *‘one-stop website’ (PPI7 2;39)*, providing information to newly diagnosed patients via the internet.

Another participant echoed this, describing her experience when newly-diagnosed; *“Like I say, when I was diagnosed, my GP said ‘Come back in 20 years’, and just put the phone down. That was it. So that was – that left me stumped and I had to find out my own information on being diagnosed with osteoarthritis. So if I’d known about [the website] a year ago, that would have been brilliant.”* (PPI6 2;8).

The importance of understanding what could be done to help oneself at the start of the disease was something that was deemed important. It was an area that was not thought to have been managed well in the past. One participant was given the impression that there was nothing that she could do until her OA deteriorated, having been told “*to go away and come back when I got worse”* (PPI3 8;4).

**(2) What are the facilitators in people self-managing their OA using e-health?**

Four themes emerged upon discussing facilitators; personalised action plan, prompting, interactive aspects, and trustworthiness of the website.

Personalised Action Plan.

Some PPI members identified their self-management action plan as a facilitator for the website; *“Well it’s my management plan – that’s what makes this stand out”* (PPI7 3;30). In particular, personalised goals tracking a user’s progression was identified as an “*attractive”* (PPI2 2;9) element of the website. Whilst another participant elaborated, *“Oh my God, so I can actually, you know, see my progress and rather than someone saying ‘right here’s your plan, I hope it’s successful”(PPI1 5;6)*. In particular, the individualised aspect of the website and plan was motivating. The website was seen as useful and was seen to *“promise that [the self-management plan] is going to be useful on a personal basis”(PPI2 1;31) .* The fact that the website had perceived personal relevance was also important *“And that was the big thing I saw about it, that er, you know, the whole thing seemed to say ‘this is for you’ and that motivates me. I want it to be for me. I don’t want it to be for the NHS, whoever or whatever the NHS is” (PPI1 4;39)*

Prompting

PPI members emphasised the importance of the website prompting them to continue their self-management programme. One participant admitted that they “*do get a bit lazy and a prompt would be brilliant” (PP19 3;12).* Whilst another spoke about the realities of everyday life and endorsed the use of an automatic weekly email to prompt her to track her progress; *“An automatic email that goes out at the end of every week and says ‘have you been on the website?’, ‘Have you updated your plan – your updated action plan?’. I think that would be a great thing to, erm, prompt people because, you know, people work like I do and being a mum and that you might not – you forget about things like this”*. (PP15 3;48)

Trustworthiness

Every PPI member reported that they trusted the content of the website. There appeared to be a number of elements that facilitated this feeling of trust. The perceived honesty of the information on the website was acknowledged, *“Well if it wasn’t going to be able to answer your question, it didn’t kind of try and answer it and, er, wriggle around a bit.. We can’t answer that one. And well, look that makes you trust it then ‘cause you go ‘Ok that’s – that’s fair. If you don’t know the answer to that, that’s good”(PPI1 2;20)* . and it was important that the originator of the website Arthritis Australia was deemed to be credible ; *“I mean one assumes that, erm, Arthritis Australia is an authoritative source”* . One PPI member reported that she would cease use of the programme if “*the site put up some wrong information”* (PPI5 6;8)

Interactive aspects

The website contains both informative (e.g. disease and drug information) and interactive (e.g. individualised action plans, videos, quizzes, case studies). Every PPI member found the interactive aspects of the website engaging. The hip and knee operation animation videos was seen as “*a great thing to put in” (PP15 2;49).*

And it was evident that participants enjoyed the mix of approaches *“So, you know, you’ve got a picture of where you feel the pain rather than just write the word ‘hip’ or ‘knee’ or whatever. I think people quite like that slightly interactive – well I know I do” (PPI4 7;13)*

The interactive components were popular; *“I’d be open to it. Especially something that is visual rather than text based. Erm and something which is also interactive so I can, like, log how many knee lifts I’m doing or something like that.”* (PPI3 6;32).

**(3) What are the barriers in people self-managing their OA using e-health?**

Excess information

The predominant barrier that PPI members reported in self-managing their OA using e-health was excess information within the website. While the fact sheets were reported as *“very good”* (PPI4 6;20) and *“informative”* (PPI5 5;40), some members felt that there was too much information; *“It was very text based. Very very very text based. There was a lot of information.”* (PPI3 6;43). “*I actually thought [the website] was quite good but there is an awful lot of information on there” (PPI4 1;28).*

Suggestions were made to overcome this including reducing the quantity of text with *“bite size chunks” (PPI3 5;41),* using *“very simple language*. *Short sentences” (PPI3 5;41),* and providing additional links for those who want further information; *“I think maybe there should be – maybe there should be different levels that people can look at. You know, if you want to know this information, maybe there can be a link to it*” (PPI4 8;12)

**DISCUSSION**

This group study indicated that using e-health to self-manage joint pain has potential as a new intervention for those with OA and identified a number of factors for further exploration in future research. PPI members suggested that the personalised action plan, prompting for use, interactive aspects, and their trustworthiness of the content of the website, facilitated use. In contrast, excess information acted as a barrier for use.

***Promising potential for a digital self-management program for people with OA***

As the aging population increases, further pressure is being placed on the NHS. Self-management strategies can be effective for patients with OA (Thorstensson et al., 2015) however limited face-to-face clinical time in an OA context places further emphasis on the need for accessible self-management resources to be made available (Barlow et al., 2002). Consequently identifying alternate cost-effective self-management strategies is important (Kroon et al., 2014). As the Internet grows increasingly accessible, it is becoming an important source for health-related information, providing a new medium for self-management programs. There is already a base of research indicating that digital interventions are efficient and can play an important role in engaging people to develop self-management techniques for their OA joint pain. A Cochrane review has already identified improved clinical outcomes as a result of digital interventions for those with long term conditions (Murray et al., 2005) and such interventions have been proven to reduce the use of healthcare resources (Ory et al., 2013). As Myjointpain.org is a relatively novel digital intervention program, it was important to first gain insight from PPI members to shape our research and determine whether future research was feasible.

***Facilitators to engaging people with digital self-management approaches***

The ways in which information is imparted to people with newly diagnosed OA is important as informed patients are better equipped to self-manage joint pain. Our preliminary exploratory work alongside PPI research partners suggests that this e-health approach has the potential to act as a go-to source of information and individualised self-management strategies for people with OA. Our results indicate that continued emphasis should be placed on personalised and interactive aspects of the website, as opposed to more generic guidelines. Personalised plans appear to promote engagement in using e-health websites. This is in line with Morrison et al, (2012) findings that tailoring self-management e-health intervention can positively impact a program’s effectiveness. Huang and Chang’s (2014) work also supports our findings confirming that the interactive aspects in e-health programs promote engagement with content.

Prompting was another key issue that was reported by our participants as crucial in maintaining engagement with an e-health website. Our PPI group suggested that this can be done via e-mail or mobile notification, for example, providing a cost-efficient manner in which to encourage users to engage in self-management. This is in line with previous findings that demonstrate that the use of email and telephone prompting techniques can significantly impact self-monitoring effectiveness (Greaney et al., 2012). Automated email and/or telephone notification alerts may also support the cost-effectiveness of such a scheme and could be considered for further development of e-health platforms in this area.

***Barriers***

Too much information and medical ‘jargon’ were identified as a barrier to engaging with this health website. . Keeping language short, simple, and accessible will help and engage lay members from a variety of backgrounds, including them in the design process will also assist in ensuring that the information is accessible. Links to additional information were also suggested by our participants. This would allow text to be kept to a minimum while offering further information to those who seek it.

***Limitations to the study***

This project was intended to engage with PPI participants to help inform the early development and design of future research work.  People who volunteer to join studies as PPI are not always typical or representative of the target population. This was the case in our study, as exemplified by the 70% female and 100% British White PPI representation. Future work to develop strategies to support and engage PPI representatives from a more diverse background and harder to reach groups is required.

**CONCLUSION**

This group study indicates promising potential for a United Kingdom led e-health initiative to address self-management of OA. Personalised and interactive aspects, trustworthiness of the tool, and prompting may promote engagement with e-health initiatives, Excess information may discourage use. Positive feedback and attitudes from this group of PPI research partners suggest that future research into the use of myjointpain.org is warranted to identify how the website could best serve a UK population in managing their hip and/or knee joint pain

The authors report no conflicts of interest

**Key Points:**

* Current attitudes towards using e-health to self-manage joint pain reflect promising potential for exciting new OA interventions
* PPI partners idntified that how information is imparted to newly diagnosed patients with OA is important to to be considered. E-health may have the potential to act as a go-to source of information & individualised self-management strategies.
* Emphasis should be placed on personalised and interactive aspects of the website to promote engagement.
* Prompting is crucial in maintaining engagement. (e.g. via e-mail and mobile app notifications)
* Excess information can act as a barrier in use. Consideration of fog index is important in overcoming this barrier, keeping language simple.

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TABLES

Table 1: Key themes, and subthemes identified

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| --- | --- | --- | --- |
| **KEY THEMES** | *ATTITUDES* | *FACILITATORS* | *BARRIERS* |
| **SUBTHEMES** | Positive attitudes towards using e-health to self-manage joint pain | Personalised action plan | Excess information |
| Early disease support | Prompting |
| Interactive aspects |
| Trustworthiness |