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Intention of Use of the Patient-centric Research Engagement Portal (PREP)

Completed Research Paper

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Abstract

Patients are keen to participate in health research in this era of participatory health, but they cannot easily obtain information about research; meanwhile, researchers are facing challenges when recruiting participants for their research because their messages cannot reach patients efficiently. To mitigate both issues, we explore the use of a patient-centric research engagement portal (PREP), which is a unified system to disseminate information about research studies and to collect registrations for the participation of research projects. In this paper, we particularly investigate the intention of use of PREPs by conducting focus groups and semi-structured interviews. As a part of our analysis, we propose a model to describe the patient-related and the owner-related factors that affect the intention of use. Finally, we conclude with several design implications for information systems to recruit and engage with research participants.

Keywords: Health Research, Participant Recruitment, Research Portal, Patient Register

Introduction

In the era of participatory health and the advocacy of patient activation, patients are encouraged to actively participate in the healthcare process and self-manage their own conditions (Coughlin et al. 2018). Patients are motivated to participate in research projects related to their conditions as a part of their self-management. Nevertheless, recruiting them for clinical research and delivering research-related information to them are challenging problems for health researchers. With the prevalence of the Internet, it is now possible to seek potential participants and disseminate the information about research projects on the web. In fact, researchers have a history to use online tools for promoting their research, for example, social media and research websites. However, there is little knowledge to integrate these technologies and to ensure they are useful to both users and researchers.

As a technological solution for the aforementioned issues, we developed a web-based *patient-centric research engagement portal* (PREP). Although there are already many uses of patient portals in the medical sector, ours focuses on improving research engagement: in one way it serves as a patient-oriented research portal which distributes the development and the latest research outcomes to users; in another way it incorporates the functions of a patient register that collects information of human participants for various research projects. The main purpose of this portal is to facilitate information sharing and personal data collection at the same time. With the help from the peak body of musculoskeletal (MSK) patients in Australia, we have co-designed the system with their patients and

built a pilot version of PREP. It was used as an artefact for studying the theoretical and the design aspects of the systems to recruit and engage research participants, which is an under-researched area in the current literature.

Figure 1 presents an overview of the PREP. Figure 1(a) shows the research portal interface of the system. The research portal features health research projects related to the conditions and allows users to find and explore these projects with different criteria (e.g. project status, location and keywords). The website also displays completed projects and the latest research from other partnered organisations. In this way, researchers are able to post updates and findings of their research on this website even they have finished recruiting participants. This respects participants' efforts because they can monitor the progress of the research, and also facilitates higher transparency of research. When there are updates about certain projects, email notifications will be sent for reminding users to re-visit the system. Figure 1(b) demonstrates the patient registration page. Patients can register their medical and contact details with the system. When users identify the research projects that they are interested in, they can express their interests directly on the website, then their information will be passed on to the relevant researchers. In addition, users may choose the provide consent to automatically include themselves as potential participants for new studies related to their conditions.

Figure 1 consists of two screenshots of the National MSK Research Register interface. Screenshot (a) shows the 'Browse Projects' page, which includes a search bar with filters for keywords, location, and project status. Below the search bar, there are three featured research projects: 'Greater Trochanteric Pain Syndrome Shoe Insert Study', 'A Pilot Study of a Psychologically Informed Physiotherapy for People Awaiting Knee Replacement Surgery', and 'Patient Power: Feasibility of a Notepad-Based Intervention to Encourage Patients to Ask Questions About Their Care'. Each project listing includes a brief description, location, project status, and level of involvement. Screenshot (b) shows the 'Personal Information' registration page, which includes fields for title, first name, last name, gender, year of birth, email address, and password. There are also checkboxes for 'Participant' and 'Study participation'.

Figure 1. The User Interface of Our PREP for (a) Disseminating Research Information; and (b) Patient Registration for Studies

As a new use of technologies, users' intention of use is crucial to the success of a PREP system. Additionally, understanding and addressing the needs of patients through the design of information systems are the key to efficient participatory healthcare. A proper design respecting the perspectives of patients can lead to the success of PREP implementations. This motivates us to conduct the current study, which specifically investigates the intention of use and the factors that affect the use of PREPs, so that we can generalise the knowledge of implementing such systems. As such, the following two research questions have guided our work:

- *RQ1*: What are the perspectives of patients in relation to the intention to use of a PREP?
- *RQ2*: How can a PREP be designed to improve patients' intention to use?

In terms of research design, this project mainly used the Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al. 2003) and the conceptualisation of research portals (Becker, Heide, et al. 2012) to inform data collection and analysis. We conducted focus groups and semi-structured interviews to explore the drivers and issues with PREPs, and these theoretical frameworks were used to guide the discussions of focus groups and interviews. 17 patients were consulted after a one-month user trial. Their responses were transcribed and analysed using a qualitative methodology.

The findings include both theoretical and design perspectives. Our theoretical contribution includes a model towards a multi-faceted understanding of the intention of use of PREP systems. The proposed model is comprised of patient-related (such as knowledge needs, health literacy, the motivation of helping research, trust, experience and location) as well as system-related factors (such as content, information quality, usability and privacy). Then, we outline several design implications addressing

these factors based on the feedback from our participants. Our work aims to provide a preliminary model towards better support for future research and implementations of this type of unified systems.

This paper is structured as follows. In the next section, we present the related work and the construction of our theoretical model. Then, we introduce our research approach, followed by the results of the study and the discussion of our contributions.

Literature Review

This section presents the related work about patient portals, research portals and patient registers. Then, we explain the theoretical background of our study.

Patient Portals

Patient portals are patient-centric tools to allow convenient access to all or parts of their medical records (Rigby et al. 2018), as well as their health information such as medication lists, test results, bills and appointments (Halder et al. 2019). Additionally, research suggests that patient portals can act as a system for improving communications between patients and healthcare providers (Al-Ramahi and Noteboom 2018), sharing patients' experience of taking medications (Hong et al. 2016), and enhancing patient engagement (Halder et al. 2019). However, limited research has investigated how patient portals can be used for engaging patients in research projects. A recent example uses a web portal to allow patients to propose research questions that matter to them, and researchers can source funding and translate these questions into real research projects on the same portal (Zuccato et al. 2019). Nevertheless, this approach may not suit patients who wish to participate in a solid project to learn knowledge about their conditions (Pang et al. 2018), and researchers with existing projects who want to seek patient participation cannot benefit from this model as well. Therefore, we aim to explore the use of a patient-centric portal for engagement of established health research.

Research Portals

As patient portals are less research-oriented, we have also reviewed the literature about research portals. Research portals are traditionally used for disseminating research information and advancing scientific research (Becker, Knackstedt, et al. 2012). Additionally, researchers adopt research portals for purposes such as identifying resources, locating experts, preparing regulatory approvals and managing research findings (Harris et al. 2011; Rodafinos et al. 2018). Research portals can simplify the effort of collaboration and data management across research teams, therefore increase the overall research productivity (Cheng et al. 2011) and help to create communities of researchers (Becker et al. 2011). Research portals are also described as the e-portfolio for individual researchers for presenting research outcomes to a wider audience (Peña-López 2007). Our literature review shows that research portals are one of the solutions for knowledge and information sharing among researchers and organisations. However, there is little to learn from for using similar tools with patients, who are often not experts and situated outside healthcare and academic organisations. These are blanks that we would like to address in our work. As such, our portal is positioned to update patients with the latest research, which is similar to research portals, but the difference is that the audience of ours is patients.

Patient Registers

On the other hand, our system acts as a patient register which allows patients to enrol themselves in medical studies. Patient registers are databases which organise the personal information, the medical histories and the contact details of patients, so that researchers can use such information to evaluate specified outcomes for a population defined by a disease, condition, or exposure for predetermined scientific, clinical or policy purposes (Gliklich et al. 2014). Some registers store patient information by extracting from medical records or discharge reports, and such automatic opt-in is controversial due to ethical issues and legal implications (Haynes et al. 2007). Other consumer-oriented registers allow people to record their information and this "consent for contact" approaches are found cost-effective for the research community (Bryant et al. 2016). Therefore, the enrolment and privacy models could be potential barriers to keep patients from using a PREP and worth investigation.

While patient registers are proven helpful in recruiting participants (Fazzino et al. 2015; Sully et al. 2013), other challenges are reported in designing and building such systems. It is reported that patients and participants are difficult to receive news and updates about scientific research from researchers, and therefore there is a need to improve the communication between patients and researchers (McKevitt et al. 2015). Registers as KMSs are aid of decision-making at the centre of clinician-patient discussions and quality improvements (Keller et al. 2009), but the resistance from stakeholders, lack of motivations and low perceived usefulness are key barriers for the adoption of such systems (Keller 2017). Bryant et al. (2016) suggest that a moderate ratio of registrants starts the process but do not complete in one session, which prompts the needs of an iterative registration process and regular reminders. As a new integration, we do not know whether PREPs inherit such issues. This demonstrates a research gap for understanding an effective design for patient registers, specifically the intention of use and barriers, as we set out in the current research.

Theoretical Development

We base on the three pieces of work to investigate the intention of use, namely UTAUT (Venkatesh et al. 2003), the extended model by Becker et al. (2012) for research portal adoption, and the rich description of research engagement (Pang et al. 2018). UTAUT poses four key constructs to predict the intention of using technology, namely performance expectancy, effort expectancy, social influence and facilitating conditions. Additionally, gender, age, experience and voluntariness of use are the moderators of the impact of the four key constructs of the usage (Brown et al. 2010; Venkatesh et al. 2003). It has been argued that UTAUT lacks constructs to help researchers to understand the adoption of a particular technology in a concrete situational context, although it offers measurements to factor in the different aspects of the intentional use of technologies (Brown et al. 2010). In this case, we supplement UTAUT with the model from Becker et al. that focuses particularly on the adoption of research portals, as well as the work from Pang et al. which investigates the potential of recruiting health research participants with technologies (e.g. patient registers). Not every element in these models and theories are included in our theoretical development for brevity. Next, we present the constructs related to our study and explain the necessity of their presence in our model.

Knowledge needs and learning opportunities are the first group of factors in our construct. Research portals as KMSs aim to address the gap between the knowledge of users and the systems by allowing users to learn more knowledge in a specific domain (Becker, Heide, et al. 2012). Similarly, patients increasingly believe the needs of self-managing care and maintaining their own health (also known as patient activation) (Lee et al. 2014). However, patients are found not having enough information sources and they hope to learn about the latest development in medicine and science by participating in research with research portals (Pang et al. 2018). As such, the needs of learning and acquiring knowledge are important factors to validate in the current study.

Health literacy, which refers to the ability to seek, find, understand, and appraise health information and apply the knowledge gained to addressing or solving a health problem (Norman and Skinner 2006), is a factor affecting technology use in digital health (Huhta et al. 2018). Lay-users often find online health information difficult to read and understand (Lam and Lam 2012), which affects the use and the experience of health websites (Pang et al. 2015). As health literacy also refers to how users assess the quality of information (Bodie and Dutta 2008), it is similar to the *information quality* construct suggested by Becker et al. (2012), which shows an impact on the intention of use of research portals. In fact, information quality is a user's assessment of whether an information system can provide valid information and therefore it has been seen as an enabler of adoption (Cenfetelli and Schwarz 2010). However, from the patient perspective, whether a piece of information matching their health literacy affects their judgements about the validity of information, and therefore it should be interpreted as a part of information quality in this context.

Experience is a significant factor in technology adoption. In UTAUT, the experience in the early stages of the use of technologies has an influence on the behavioural intention of technology adaptation (Venkatesh et al. 2003). In the context of research portals, the literature suggests that experience can positively affect the performance expectancy and the effort expectancy (Becker, Heide, et al. 2012). On the other hand, user experience is induced through their interactions with an

artefact or a system, and its *usability* contributes to such an experience (Sande et al. 2017). In the context of health information behaviour, the lack of appropriate design for accessing information can affect the usability of a system, its user experience and user satisfaction (Pang et al. 2015). For these reasons, we include both experience (as a user factor) and usability (as a system factor) as parts of our model.

Trust is another long-standing issue with the adoption of health information systems. Trust enables patients and health consumers to take control of their health and assists them to make informed decisions (Daraz et al. 2019). The Health Information Privacy Concern model suggests that trust is a key driver for individual's privacy concerns which may affect the adoption of health technologies (Kenny and Connolly 2016). In the era of misinformation being spread over the web and social media, it is critical to understand the trust factor and how it moderates the use of research portals and the participation of health research.

Finally, we choose to exclude some elements from previous literature in our theoretical model. *Situational characteristics of research community* (such as *peer influence* and *shared norms*) and *situational characteristics of environment* (such as *incentives*) are some factors in the model proposed by Becker et al. (2012). However, this is not applicable in our patient-oriented system because such factors are only related to researchers. On the other hand, research has found that certain health conditions have demographical biases in favour of certain gender and age groups (Arthritis and Osteoporosis Victoria 2013). These biases imply that the general population may not represent the users of our patient-oriented system targeting for some specific conditions. Thus, although *gender* and *age* have moderation effects in the original version of UTAUT (Venkatesh et al. 2003), it is not suitable to include such constructs in the context of our research.

Research Design

In this section, we elaborate our research design for examining the intention of use of PREPs based on our theoretical model. Then, we present our system and briefly introduce its features, followed by the methodology and the explanation of the data analysis process.

Design-oriented Research

We adopt the design-oriented research approach (Zimmerman et al. 2007) to understand how and why people use a PREP for finding and participating in health research. The design-oriented research approach consists of multiple stages. Firstly, researchers begin with defining the research problem and understanding the problem with the users. Then, a solution is designed for the problem and an artefact is built according to the design principles identified in this process. Finally, the artefact will be evaluated with the users, where design improvements and knowledge are generated. The key goal of this approach is to generalise new knowledge and to contribute to academia (Fallman 2007). With this approach, design is a mean through which we seek to produce new knowledge by involving design activities in the research process (Fallman 2007). Artefacts, as prototypes, are designed and created to provide concrete embodiments of theory and technical opportunities (Zimmerman et al. 2007). As such, design-oriented research can produce knowledge that normally could not be generated by other theoretical analysis or traditional empirical approaches, because it systematically enquires into a real-world context using an artefact. The contributions of the research should be novel integrations of theory, technology, user needs, and context, instead of refinements of existing products in literature or commercial markets (Zimmerman et al. 2007).

Research Methodology

Our PREP system was tested among a group of MSK patients who had a month to use and trial the system. The final participants for the current study were sourced from this user group. Email invitations were sent out to the pilot test users for seeking their involvement, and they could choose to participate either focus groups or phone interviews. Focus groups were the preferred, however, if participants could not attend the focus groups, semi-structured interviews were arranged over the phone. Recruitment continued until data saturation was reached. Focus group guides and interview

questions were constructed using the theoretical model we developed. Focus group and interview facilitators prompted the participants to discuss the usability, information quality, registration, privacy and trust aspects of the system. This research was approved by the Human Research Ethics Committee of the University of Melbourne (Approval ID: 1647787.1).

We employed a qualitative approach to analyse data, which can derive deep understanding and experience of patients when interacting with the system. All focus groups and interviews were recorded and transcribed for data analysis. Transcripts were processed using the thematic analysis approach (Braun and Clarke 2006; Guest et al. 2012), which was comprised of reading the data, mapping key ideas into codes with the open coding process, and then summarising codes into themes iteratively (Creswell 2014). Two researchers independently analysed and coded the data to assure consistency, accuracy, and quality. Coding conflicts were discussed and resolved in this process.

Participants

We successfully recruited a total of 17 participants in our study, including 5 from a focus group and 12 from phone interviews. 15 of our participants were female and 2 were male. Their average age was 62 (SD=12, range 44-83). The most common condition was rheumatoid arthritis. A quarter of our participants had osteoarthritis, and a quarter had osteoporosis. Three of our participants had musculoskeletal comorbidities.

Results

We present the major themes emerged from our data in each of the sub-section below, accompanied by some representative quotes and participant identifiers.

Knowledge Needs and Learning Opportunities

Participants were keen to use the PREP as a tool to learn more knowledge about their conditions and to bridge their knowledge gaps. For patients with chronic problems, they needed to know how to manage their ongoing conditions and adjust their lifestyles. Therefore, it was a long-term process for them to learn and a portal like ours could be helpful in this case.

- *“If it becomes more severe it becomes so much more important to learn to manage the condition. It becomes a part of your identity, in some ways.” (Focus Group Participant 5)*
- *“I think I would because it's relevant to what's in my life. You know. I am trying to keep good health. I am trying to find things that maybe a bit more helpful at different stages [sic], so therefore if something like this is there to assist me then yeah I'd probably use it a lot more... The main thing would be just trying to access more knowledge and with the knowledge then put it into practice. And to help myself.” (Participant 7)*
- *“Oh, to go for the research itself? Well, if you want to find out about what things are doing in there, you have to register these things. It's no different than... To me, it's no different than applying for either a house loan or something. You apply your details and that because you want to be approved of something, and that's what it is, you look at it and you think, oh, that would be interesting, I wonder what that's all about.” (Participant 4)*

Matching between Health Literacy and Information Quality

The participants suggested that they had a limited level of health literacy and may not understand the information written from a researcher's perspective. This point was often neglected by other websites which provided information with many terminologies and obtuse writing. Additionally, the information provided by the PREP should be understandable and match the literacy level of the users, and academics should work with patients and consumers to ensure the information quality (e.g. readability and transparency) is up to their expectation.

- *“I think its explanations that you can understand. If it's very researchy. You know a lot of times you go to a research website and you look at it and go, ‘no I don't understand it’... if you are*

someone who hasn't had any experience with it, it could be quite [sic], it would put you off, because you can't understand it. I think so long it's in a language that's easy for consumers to understand and follow." (Participant 10)

- *"I work in cancer research and we've got similar ones to it [the website]. But it's basically from the researcher's point of view. But there needs to be more. More transparency for consumers to be able to engage and find something... I found it quite, on numerous occasions and you just run into a brick wall. You can't find anything really, and they need to embrace something like this where people can find access to information quickly.*" (Participant 5)
- *"We need to avoid acronyms, so I know you and I are very clear around what MSK means, but some people mightn't know what MSK means, so it's really something that you need to be careful with, because it just happens, we just do it without thinking, and acronyms are just a real no-no when you're working with consumers or you're trying to work with consumers."* (Participant 9)
- *"Making sure that the language is simple enough for people to understand. Which overall, I thought was really good because some of the pages were quite wordy like there were a lot of words on some of the pages."* (Participant 6)

Experience and Usability

The experience of using the system was another factor to drive the intention of use. As the system was perceived having high usability (e.g. ease-of-use and helpful) in terms of finding relevant and needed information, our participants continued to navigate and discover more information, as a result demonstrating a higher engagement with the system.

- *"Once you are registered and you are in the website, that it was really easy to look at your interests to see the different projects. Because I think I thought I would have to put my name down to register for the different projects for each one. But the fact that you just go into that page, seemed to be really straightforward, really good."* (Participant 8)
- *"Well, I found it very good also, generally speaking. Also, not difficult at all to get into and to navigate, and was very interested to look at the research projects that were up there. So, I think it's a, yeah, a good tool."* (Focus Group Participant 4)
- *"I thought it was fairly easy to see the menus. [sic] I quite liked the different colours to highlight the different things you were entering, whether you were looking for certain diagnosis or location. I found that was nice, colourful and easy to click on. Yeah that was really helpful."* (Participant 2)

Trust

Trust was reported as a major consideration when using the PREP which stores patient information. When an information system stored users' information, they were reluctant to use if commercial elements were identified in the system, which implied that their information might have a risk to be used for profit at a later time.

- *"In terms of trustworthiness, I guess there's, for me, there's always a little bit, or perhaps a lot, less trust in the commercial institute, a profit making entity. Because they're, in terms of sharing more information or getting involved, because their bottom line's always going to be making money. So, are they going to use your information, whether it be you're selling you're data, obviously there are privacy agreements and all [sic] privacy policies."* (Focus Group Participant 5)

On the other hand, the system's look and feel had a direct impact on users' trust, when the design appeared like a professional or a medical website. In addition, logos of reputable organisations (such as the university logos used in our version) could help to increase their trust as reported by many participants.

- *"When you search the page I think it looks really professional and it looks quite medical, so it's quite academic and medical, so I think from the point of view of the consumer, I think it's sort of page that someone would come to and trust, which I think is important you know with all the range*

of websites out there. I think it comes across as trustworthy just by looking at the front page.”
(Participant 6)

- *“And I think because it is done through [a university – name anonymised] I would say it’s going to be, it will be authentic, it will be doing all the right ethical approaches to it... Because it’s under the umbrella of [a university – name anonymised] and I know that for any research to be worthwhile it has certain requirements, ethical requirements.”* (Participant 12)
- *“Because the organization I know to be reasonable, then I would’ve thought that what was there would have been reasonable. And the only research project I really looked at was the one that was at [a university – name anonymised]. So, I’m quite sure they would’ve had to have gone on before an ethics board ...”* (Participant 1)

Privacy

Privacy was another major theme emerged in the discussions with our participants. With the complicated online environment and the recent scandals of Internet companies, participants had concerns about how the data was stored, and the possibilities that the system would be hacked. They stated that these were important considerations with the system.

- *“It’s absolutely a concern, and I am sure an organisation like your does everything that you possibly can do to protect the privacy of people. And, yup that was just an example. I wouldn’t expect anybody in your organisation to be malicious but you probably can be hacked into.”*
(Participant 2)
- *“No, I think so long as you can understand what is expected of you how the information is stored and the security behind the storing of the information I think it is fine. That’s a big thing for consumers these days. How it’s stored and who is using it.”* (Participant 10)

Our participants also mentioned that logging out was an important feature in the context of patient research register. They used to log out from the system which stored sensitive information after use in order to minimise the security risk. However, log out buttons were hidden in many modern websites, which was not the desired design in the eyes of our participants.

- *“So, for a long time, I was just closing the tab. And if I go back in, I was still logged in, and I didn’t want to be. I wanted to close, log out. So, this is one of my pet peeves, these days, with websites where things are hidden... And you’ve got personal information on it someplace. So with this one, I wouldn’t be purchasing anything but I tend to just, yeah, I want to log out and then log back in.”* (Focus Group Participant 5)
- *“Because I have got this sense of, I don’t want to provide opportunities for people to actually access any information... I would prefer, and I always do as a habit, I will log out of an activity, and then log in. I’m happy to do that.”* (Focus Group Participant 2)

As pointed out by a participant, a perceived secure system could increase users’ trust in the system. It appeared that the privacy of the system and users’ trust were closely related.

- *“But, if you are in a secure situation [provided by the system] where you [can] trust the people behind, it’s not a big issue for me.”* (Focus Group Participant 1)

Helping Research

Our participants indicated that they used the PREP because they would like to help researchers to advance the field and contribute to scientific work, which in turns would benefit the patients with the same conditions. It was out of a good cause for their participation in other health-related research.

- *“I think because I am interested in helping people with these sorts of conditions. You know look, as I’m saying. I know who I am, I probably would forget that it was there. Obviously I’m somebody who does want to help where I can.”* (Participant 3)

- “I think, studies about the psychosocial aspects of it, like, coping with a chronic illness and, that sort of thing very important as well in order to, find ways to help people through their managing their conditions through their life and also to educate GPs and medical professionals and allied health professionals about, you know, the best way to help consumers.” (Participant 11)
- “The only real reason that anyone does this is cause they want to contribute to the science, really.” (Participant 8)
- “My motivation would be to contribute to any kind of research that's potentially gonna have some benefit, in the future, to help anybody else that's diagnosed with a horrible condition like this.” (Focus Group Participant 4)

Location

Our study discovered that patients looked for research projects that were closer to them. Since some MSK patients demonstrated relatively low mobility, the location of research and the travel distance mattered when they considered helping out with researchers or not. In this case, our subjects suggested that filtering by locations should be an essential feature.

- “I guess for people in the regional centres a lot of these studies tend to be in the bigger cities... And I think sometimes the studies you might be looking at places where people can access them in the regional areas. There's a big pool of people out here.” (Participant 5)
- “For example, those ones around hospital-based treatment where you've been in the Geelong Hospital, I'm in Perth, and that... And it frustrates me to be honest with you, and I think it will frustrate most people, to still have that there and to go into it and to read it and go... I would try and put together some sort of an algorithm that gets rid of the ones that are completely irrelevant to the people whatsoever...” (Participant 9)

Discussion

In this section, we discuss the factors affecting the intention of use of PREP systems, and present a model for informing the design of research portals for recruiting and engaging health research participants. In addition, we present the design implications learnt from our study, followed by the limitations of our work.

Factors Affecting the Intention of Use

In this empirical evaluation, we have identified a number of factors such as *knowledge needs*, *health literacy*, *trust*, *content*, *information quality*, *usability*, *user experience*, *privacy of the system*, *helping out research* and *patients' location*. In this sub-section, as our responses to RQ1, we elaborate on all these different aspects and compare them with different existing work.

The *knowledge needs* of patients drive the intention of use of patient-centric research portals. It has been shown that people with chronic health conditions seek online information about latest research and treatment for the hope of improvements (Pang et al. 2017; Pang and Liu 2020), and our research further demonstrates that PREPs can be one of the data sources for them to access recent development about their health conditions. There is a learning initiative in this process as our participants reiterated the expectation of learning new knowledge by taking part in research. As pointed out by the information behaviour model (Wilson 1981), when there is a knowledge gap that users need to bridge, they learn new information via the interactions with information systems. Based on this view, we consider PREP systems as an artefact to facilitate this learning process. In this learning process, *health literacy* is another contributing factor. Health literacy is defined as the abilities of understanding and using the information found (Bodie and Dutta 2008), which is the prerequisite for users to learn the knowledge presented in the system. Users have to possess sufficient literacy level to understand the information presented in order to use the system. Both of these intrinsic factors are not captured by UTAUT and we have empirically identified them in the context of PREPs.

In order to bridge the knowledge gap, the system has to provide the *content* that users need. For example, someone may want to learn about the updates of a research project, and the system should allow researchers to publicise such content. In addition, if users cannot understand the information in the system, the learning process cannot take place. As such, as part of *information quality*, the readability of the information has to match the knowledge levels and the needs of users, which is often found neglected in many modern health websites and portals (Tieu et al. 2015; Walsh et al. 2017). A mismatch in these areas decreases the user *experience* and affects the intention of use since users perceive the system not useful. Besides, basic *usability* elements of web-based systems, such as ease-of-use, intuitive menu navigation and information accessibility (see also Palmer 2002), are frequently mentioned in our study, and therefore we reckon that it has an effect on user *experience*. This study has empirically connected these knowledge-related and usability factors with the patient experience in the context of research participation and engagement.

Trust is another factor that affects the intention of use. Trust needs to be established before users register themselves in PREPs. This trust is particularly related to how researchers make use of a PREP and utilise personal information of patients, as well as whether the information will be reused for other (especially commercial) purposes. As shown in our study, when users are confident in the owner and the good causes behind the platform, they are more willing to use and engage. This is consistent with the Health Information Privacy Concern model, which suggests that a higher level of trust can reduce the level of concerns and thus improve the use (Kenny and Connolly 2016). On the other hand, the *privacy* of the system can address the needs of trust from users. As informed by our work, patients have an expectation of strong cyber-security and a high level of governance when sensitive and personal information is stored. Trust to a system can be enhanced if users can perceive or see (e.g. with a clearly written privacy policy) the measures of enforcing the privacy of the system.

Additionally, patients suggest that *helping out research* can lead to new knowledge, and this allows them to access the latest development in the medical field in return. This point can be explained in conjunction with the *privacy* and *trust* elements found earlier by the social exchange theory (Blau 1964), which indicates that users try to maximize the benefits and minimise their costs by exchanging resources with others. However, as pointed by Liang et al. (2008), the exchange cannot be operated without trust in the interactions among different actors. In our case, participants use themselves as a resource to exchange for more updates about their health problems in the process of research participation, and the PREP system can act as a platform to enable the connection between researchers and patients. However, researchers and patients are loosely related in this context, as they are not under the same organisation nor dependent with each other. It is worth to investigate more the role of a PREP, and how such systems mediate the needs of users among loose social relationships.

Finally, the locations where users live are related to the use of the system in two ways. For most of the users, they need to access the research that is located around them. On the other hand, for the people living in regional areas, because they often cannot access researchers easily, they use such platforms for accessing the latest information about research and try to connect with researchers. Our results replicate similar findings in other work (Pang et al. 2018). This provides opportunities for future work to address the needs of regional patients in the telehealth context using technologies.

In summary, no single model can cover the factors leading to the intention of use in our specialised context. Therefore, we propose a unified model with these factors based on the actors associated with these factors, as illustrated in Figure 2. We group the factors into two categories: patient-related and owner-related. Owner-related factors are elements that can be managed by the owners of PREP systems (e.g. researchers and their institutions), whereas patient-related factors represent the attributes and characteristics of patients and can be affected by owner-related factors. This model highlights that the design of PREPs needs to consider both owner and patient aspects in order to be successful.

Design Implications

Based on the proposed model, we further point out a few suggestions for designing PREP systems and preparing information about research for patients, as our answers to RQ2. In this sub-section, we provide our design advice for addressing the factors in the model from two perspectives: the knowledge aspect and the privacy aspect, respectively.

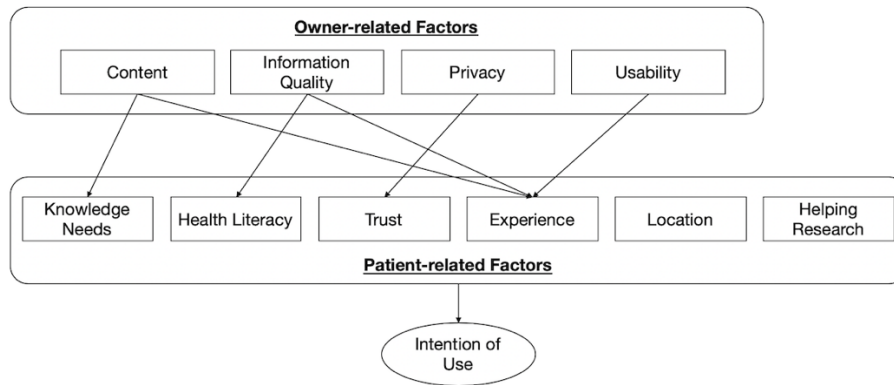


Figure 2. Our Proposed Model of the Intention of Use of PREPs

Firstly, in order to better address the knowledge and learning needs, information should be written at the level that the audience can understand. In line with other research (Pang et al. 2018; Walsh et al. 2017), patient groups and non-government organisations can assist to generate content with plain and easy-to-understand language. Reducing text-based information and including photos and testimonials from people who have participated in research in the past can help people to understand the research projects. In addition, research updates are essential for users who are keen to learn about the development and results of the studies. For those who have participated, they are interested in how the information or data they contributed is eventually used, as well as what research outcomes may have been translated into policy or practice. From this end, system owners would need to facilitate the dissemination of research updates for such users. For example, email alerts can be used to notify participants whenever there are changes happened in the projects of which they expressed interests.

Secondly, we have found that the awareness of privacy has been increasing and contribute to the intention of use, particular when PREP systems store sensitive personal information and medical history. Some design decisions can mediate users' tensions on privacy and trust, and therefore have the potential to improve the intention of use. For instance, the identity of the system ownership should be visible and conveyed properly in the design. Participants were observed to use logos of universities and organisations to differentiate the nature of the website; whereas other prior work highlights the use of "About Us" web pages in health websites to clearly describe the aims and the ownership. In fact, such identify has found relevant to the perceived information quality (Adams 2010). Moreover, users also demonstrate concerns on how their information is handled and stored. We recommend describing the details about the handling of personal information, the parties who have access, and the technical approaches (e.g. encryption) for securely storing data in the privacy policy document. This document needs to be accessible and readable by general users.

Limitations and Future Work

We acknowledge several limitations of this study. While we successfully identify the factors regarding the intention of use with the qualitative methodology, we do not examine the interactions and the moderations among these factors. Future research may use an experimental research design to evaluate these aspects. Additionally, the subjects were drawn from the patient group with similar health problems (MSK conditions) and were skewed in terms of gender and age. Future work may consider enquiring a diverse cohort of patients. Also, some aged patients may have lower health literacy and ability to interact with researchers, which prompts the need to investigate how PREPs can facilitate effective and engaging communication among different cohorts of patients and researchers.

Conclusion

On the basis of a focus group and interviews, we propose a model for the intention of use of PREPs in this paper. The innovation of such platforms is, in one way they serve as research portals to disseminate research news and updates, in another way they act as patient registers to assist with the recruitment of research participants. Our empirical study shows that owner-related factors (such as content and information quality, privacy and usability) can influence patient-related factors (such as

knowledge needs, literacy, trust, experience, location and the motivation of helping research), which subsequently create an impact on the intention of use. With proper design and planning, these platforms can be useful for both patients and researchers. Looking forward, we hope that our research can provide insights to attract patients to use such systems and to guide future implementations.

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