

Communication matters: Exploring older adults' current use of patient portals

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ABSTRACT

Objectives: Patient portals have the potential to increase patient engagement. Older patients are of particular interest as they are likely to suffer from multiple chronic conditions. Yet, questions remain about how patient portals are perceived and deemed useful by older adults. This study explored attitudes toward, perceived utility of, and requirements of a patient portal from the perspective of older adults.

Methods: We used a mixed-method approach integrating online surveys, a review of existing portals, and participatory design workshops with 17 people who were 65 years old and over.

Results: The findings demonstrate that the participants used a patient portal primarily as one of the communication channels to interact with their providers, rather than as a tool for accessing and managing personal health information. Consequently, the perception of whether or not a provider would use the patient portal was a primary factor that older adults considered in determining the adoption and use of a portal.

Conclusions: It is important to understand that older adults would perceive a patient portal as one part of a larger communication system to interact with a provider. This finding will help researchers and practitioners to advance the design and use of a patient portal to effectively incorporate it into older adults' health care and better serve the unique needs of the ageing population.

1. Introduction

Growing evidence that patient engagement improves health outcomes and reduces healthcare cost has drawn attention to the potential of patient portals [7,35]. Patient portal is a secure online system to support a wide range of patients' needs relating to personal health information management, including viewing lab results and medications, refilling prescriptions, scheduling appointments, downloading and completing forms, and reading educational materials. Thanks to the potential of portals to promote patient engagement and improve self-management, the adoption of patient portals is becoming increasingly important for quality care.

Older adults are of particular interest in improving patient engagement, as they are likely to suffer from multiple chronic conditions and consequently face an increasing amount of health information to manage as they age [13,38]. Thus, effective use of a patient portal is important for this population. However, studies have shown that older adults are less likely to use available patient portals [9,31]. Efforts have been made to enhance older adults' portal use, but mostly by elucidating barriers, such as accessibility, preference, literacy, and security concerns [8,16,23,39]. Few studies to date have reported on the current

and expected use of patient portals from the perspective of older adults themselves. A better understanding of how older adults perceive and use patient portals would help identify the unique needs of the ageing population. Therefore, the goal of this study is to investigate attitudes and perspectives toward a patient portal and its perceived utility and requirements among older adults with varying degrees of prior experiences with patient portal use.

In what follows, we first provide a literature review of older adults and patient portals. Next, we describe our data collection and analysis methods. Then, we present key findings and conclude by discussing key implications for the design of patient portals tailored to older adults.

2. Literature review

Research relating to adoption issues around patient portals has surged, likely because of the federal mandate of Meaningful Use [1]. Ruland et al. studied patient portal use and discussed various user experience issues, including tradeoffs between data security and user friendliness, that relate to adopting patient portals [29]. Wilson et al. demonstrated that Technology Acceptance Models (TAM) could predict whether patients would adopt systems such as patient portals [44]. In a

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survey of existing literature relating to the adoption of healthcare technology, Or and Karsh found that the majority of studies focused on racial, ethnic, demographic, and literacy barriers, while paying relatively less attention to experiential, contextual, social, and organizational variables that could impact adoption [25].

In the context of older adults, there is extensive research to identify barriers that prevent older adults from adopting patient portals. The most frequently identified barriers relate to the digital-divide, such as lack of access to or familiarity with technology [45]. For example, Turner et al. addressed a broader range of issues relating to accessibility from the individual end-use level, such as computer knowledge and prior technology experiences, to a systematic level, including lack of resources and infrastructure that hinders Internet access [39]. To address this problem, researchers suggested providing instructional resources, training materials, and personal assistance that could support older adults to acquire proper skills to use portals [38]. Support from family members and friends when using technology has been found to be another effective means to overcome technology barriers [34].

Health literacy is another formidable barrier in that older adults are likely to have lower health literacy, which significantly affects patients' ability to interpret the information [20,32]. For example, Liu et al. found that many patients with lower health literacy could not even read the instructions properly, let alone interpret the meaning of health information [18]. In addition, people with lower health literacy tend to be less likely to have confidence in decision-making and struggle to use comparative health information to make decisions [10]. For example, Irizarry et al. found that older adults who appreciate the potential benefits of a patient portal may still believe that they are not capable of using patient portals because they may not be able to properly interpret the information on the portal [14]. This lack of self-efficacy has been identified as one of the key factors that prevent older adults from adopting a patient portal [26].

In addition, there are some external factors that affect older adults' adoption of patient portals, one of which is patients' relationship with providers. Interestingly, this factor is known to affect the adoption of patient portals both positively and negatively. For example, studies found that support from providers increases portal use among older adults [30]. Older users believe that a portal would improve their communication with their providers [46], but they are often not offered the opportunity to use patient portal systems by their providers because providers expect that older adults would not use them [22]. On the contrary, other studies showed that older adults who are satisfied with current ways of interacting with providers refuse to use a portal [47] due to a fear that using the portal would negatively influence their relationships with providers [16]. This contradiction illustrates the complicated and still unexplored nature of older adults' relationship to patient portals.

As such, substantial efforts have been made to improve our understanding of the relationships between older adults and patient portals, which greatly advanced the fields of research and practice alike. To date, however, researchers have largely been concerned with the downside of ageing, focusing on the barriers and the assumed needs that the ageing population faces. While this approach has helped institute an agenda for enabling older people to engage in healthcare, it lacks a deeper understanding of how older adults are currently making use of patient portals. Many older people already use a patient portal by adapting it to their preferences and needs albeit the barriers. Thus, we need to go beyond the stereotypical functional limitations that are treated as defining features in older adults and learn directly from them about their needs and obstacles.

Research has recently started to explore new approaches to study how technology may be better designed for older people (e.g., [41]). Instead of simply investigating the problems older people report, researchers tried to engage them more by using a form of participatory design to better understand their needs and expectations for future technologies. Dickinson and Dewsbury recommend using a qualitative,

person-centered approach when designing technology with older adults as it increases the likelihood of a successful technology being developed [6]. Wallace et al. suggested the use of more crafted objects and prototypes designed around a particular theme to encourage reflection and "gentle ways to access complex notions and experience" [42]. A recent study that adopted a more engaging approach demonstrated that when adults in the late stage of their lives were shown how to create and share personally meaningful digital content, it helped them build connections with their peers [43]. Instead of researchers designing for older people and asking "what technology do you need?", we need to consider inviting older people themselves to reshape technology from the perspective of older adults themselves. Prior work using participatory design with older adults has been successful in understanding the unique views of older adults [5,28]. Inspired by these new approaches, this study used participatory design workshops as a primary method to engage senior citizens actively in wider discussions to explore attitudes, perceived utility, and requirements of a patient from the perspective of older adults.

3. Methods

We used a mixed-methods approach consisting of online surveys, a review of existing portals, and participatory design studies to gain a broad, triangulated understanding of older adults' current use of and perspectives on patient portals. Below, we describe each method, participants we recruited, and the techniques for analyzing the data we collected. All studies were reviewed by university-based research ethics boards.

3.1. Online survey

The first step in understanding older adults' perspective on patient portals was to get a broader sense of how older adults currently interact with personal health information online. Thus, we designed an online survey to gather data from local seniors about their experience with health information via online. We recruited survey participants via word-of-mouth and by posting classified advertisements at local senior centers, community centers, and libraries in the New Jersey metropolitan region of the United States.

To create survey questions, we first came up with three categories that would allow us to understand older adults' use of the Internet for healthcare, including general Internet/computer use, use of health information online, and demographic information. For general Internet/computer use, we created 7 questions to ask how familiar survey respondents are with the Internet (e.g., What do you use the Internet for?). For online health information, we created 9 questions to ask experiences of using health information online in general and patient portals in particular (e.g., What is the name of a website or service you used to access health information online, if any? What are the benefits/difficulties of using it?). Finally, demographic information questions include gender, age, and educational attainment. Some questions were likert scale questions, and some were open-ended. At the end of the survey, respondents were asked if they are interested in participating in a follow-up study to identify popular patient portals in the region and to recruit workshop participants. In total, 70 participants completed the survey (see Table 1).

3.2. Review of existing patient portals

From the survey responses, we chose 8 patient portals that the respondents mentioned the most frequently to investigate ways in which existing portals operate. Through an extensive literature review and survey responses, we created 7 themes that account for the usability of patient portals from the perspective of older adults (see Table 2). The primary purpose of this step was to elicit key functionality that a patient portal offers.

Table 1
Summary of survey participant demographics.

# of Participants	70
Genders	Male (36%), Female (64%)
Ages	65–69 (26%), 70–74 (40%), 75–80 (20%), 80+ (14%)
Marital status	Single (10%), Married (66%), Divorced (6%), Widowed (16%), No response (3%)
Incomes in US Dollars	Below \$30 K (7%), \$30K–50 K (10%), \$50 K–75 K (27%), Above \$75 K (36%), No Response (20%)
Highest education	High school (22%), Some college degree (36%), Some graduate degree (6%), Professional degree (36%)

The second author reviewed the portals, and that work was then validated by the first author. We identified 20 primary features that were turned into 4 categories of 20 card items to represent key functionalities or contents of the portals (see Table 4). Each item was printed on colored paper to use in card-sorting activities of a participatory design study, which is explained in the next section (see Fig. 1).

3.3. Participatory design study

To gain a deeper understanding of how older adults perceive and use patient portals, we conducted a series of participatory design workshops with 17 older adults.

3.3.1. Participant recruitment

To recruit participants, we first contacted survey respondents who expressed an interest in participating in a follow-up study and who indicated having prior experience using a patient portal. Each respondent was asked if s/he could invite three or more people from their social network aged 65 years old or over (e.g., a significant other, family members, or friends) to recruit participants for convenience sampling. Because the workshop was designed to be collaborative and creative, having a group of participants from the same social network was meant to help them feel more comfortable and express their honest opinions and feedback. Having prior experience with patient portals was not considered in recruiting invitee participants, because at least one person, the primary participant, has prior experience with a patient portal, which would allow diversity in a group in terms of perspectives on portals. In total, we recruited 4 groups of 17 participants: 2 groups consisting of 5 people, 1 group with 4 people, and 1 group with 3 people (see Table 3).

3.3.2. Procedure

A participatory design study was structured into two separate sessions: a design exploration session and a design critique session, with a two-week interval between them. Three groups met in one of the participants' homes for the study and one group met at a local senior center. All sessions were audio recorded and documented in part with video and photographs. The participants were compensated for their participation at the end of the second session.

Session 1: Design Exploration. The goal of the first session was to explore participants' perspectives, perceptions, needs, expectations, and

experiences, if any, associated with a patient portal. First, we conducted a focus group interview, where participants shared thoughts and experiences about a patient portal within a group. The questions we asked included: "What is your general perspective of a patient portal?", "Has anyone ever used a patient portal, found it useful or not useful, and why?", and "Has anyone had similar or different experiences?". The group discussion lasted for an hour, followed by a break, where tea, cake and fruit were served.

Next, each participant was given a deck of cards we created from the previous step and a packet of star stickers to do a card-sort activity [27]. Card sorting is useful to provide a tangible form to the concepts for participants to interact with and keep the conversation focused on specific aspects of interest to the researcher [33]. Participants discussed specific features or content of a patient portal using the content presented on the cards (see Fig. 1). In addition, participants were asked to stick up to three star stickers to each card to mark the importance of its content. This activity lasted for an hour, again, followed by a break, where tea, cake and fruit were served.

Finally, we ran a design sketch session where participants were given paper, colored pencils, and markers to draw what they wanted to see in a patient portal after first logging in. Participants were encouraged to share ideas, get feedback from others, and collaborate on the designs as a group. During the sketching session, the researcher took a "hands-off" approach and allowed the groups to work as independently as possible. The instructions prior to the sketching session emphasized creating an idea for an application that would be useful for them. This activity lasted for 30 min.

After the first session of all groups, we conducted a preliminary data analysis through briefly reviewing transcripts to identify key concepts and created 15 conceptual design sketches of three primary categories, *medication*, *lab results*, and *communication*, based on participant feedback and the findings from a review of portals.

Session 2: Design Critique. Two weeks after the first session, groups met again at the same location to participate in the second session. The goal of the second session was to better understand the perspectives that our target population has in the use of a patient portal, as well as eliciting information for implications for the design and use of patient portals tailored to older adults. People have been found to have difficulty envisioning intangible concepts, so providing them with sketches of ideas can make it easier to discuss their needs, perspectives, and opinions [17,21]. Thus, we used conceptual sketches as cohesive representations of ideas to inspire participants to constructively critique and reason the features and to better elaborate on their thoughts.

Participants were first shown the sketches that participants in other groups drew in the first session, and were asked to share their opinions. The questions we asked included: "Do you agree or disagree with the idea and why?" and "What do you like or dislike about the idea, reflecting on your experience?". Next, they were shown the conceptual design sketches we created and were asked about their opinions, using the same questions. Again, the participants were encouraged to share thoughts, get feedback from others, and to collaborate on the designs. This session lasted for an hour.

Table 2
Themes for evaluating existing patient portals.

Themes	Question
1. Flexibility and efficiency of use	Does the system cater to inexperienced users? [24]
2. Match between system and real world	Does the system speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms? [15,16]
3. Consistency and standards	Do users wonder whether different words, situations, or actions mean the same thing? [15,39]
4. Information quality	Does the system provide information that is easy to understand, useful, and up-to-date? [11,39]
5. Information quantity	Does the system provide adequate amounts of information for the older adults to process? [4,46]
6. Communication	Does the system support communication with the healthcare team? [2]
7. Personalization	Does the system provide ways to personalize information? [11,39]



Fig. 1. Card sorting activities during a workshop.

3.3.3. Data analysis

We conducted a robust thematic analysis of the qualitative data through a process of open coding, axial coding, and selective coding based on the Grounded Theory approach [37]. The video recordings, transcripts, participant sketches, field notes, and cards were all coded and analyzed by the research team using an inductive thematic analysis to reveal patterns across data sets. Both authors read and discussed interview transcripts and other data and developed codes to describe important concepts that emerged directly from the data. We coded independently with frequent discussion to reach consensus. We analyzed data to verify our patterns and themes and to ensure we had reached data saturation until no new themes or concepts emerged. Interrater reliability was not calculated as coding was finalized during consensus meetings.

In the open coding, we identified and coded concepts that are significant in the data as abstract representations of events and objects. Next, we categorized the related concepts created by open coding into higher conceptual phenomena themes that emerged as patterns within the data using axial coding. Then, we followed the selective coding process to integrate all concepts into a single storyline throughout building relationships across phenomena.

4. Findings

From the review of existing portals emerged 20 features or contents that portals currently provide or older adults consider needing portals to provide in 4 categories, including *medication*, *lab results*, *communication*, and other (See Table 4). Among those, the participants of a participatory design study rated the following seven features as most important in card sorting activities (by the order of ratings).

- 1 Medication > Photos, instructions, and effects and possible side effects of medication

Table 3

Summary of workshop participants.

Group	# of participants	Age	Gender	Experience with patient portal
1	4	65–69 (2), 70–74(2)	Male (2), Female (2)	Yes (3), No (1)
2	5	65–69 (3), 70–74(1), 75–79 (1)	Male (2), Female (3)	Yes (2), No (3)
3	3	65–69 (2), 70–74(1)	Male (1), Female (2)	Yes (2), No (1)
4	5	65–69 (1), 70–74(2), 75–79 (1), 80+ (1)	Male (2), Female (3)	Yes (2), No (3)
Total	17	65–69 (8), 70–74(6), 75–79 (2), 80+ (1)	Male (7), Female (10)	Yes (9), No (8)

Table 4

Functionalities of patient portals.

Category	Feature (Card Item)
Medication	List of medication Photos, instructions, and effects and possible side effects of medication Make personal note about medication Request medication refill Check prescription order status Print out medication list and details
Lab results	Lab results overview and history Detail information about lab results Treatment options and potential side effects Print out lab results
Communication	Calendar of past and upcoming appointments List of providers and their contact information Exchanges messages with providers Provider's instruction from last appointment Make an appointment Ask a provider about lab results Referral request
Other: General health information	Nutrition information Information about chronic condition management Insurance benefits

- 2 Medication > List of medication
- 3 Lab results > Detail information about lab results
- 4 Lab results > Treatment options and potential side effects
- 5 Communication > List of providers and contact information
- 6 Communication > Exchange messages with providers
- 7 Communication > Ask a provider about lab results

In what follows, we report findings from a participatory design study, organized by category, focusing on older adults' experiences, perspectives, and needs of a patient portal, as well as design ideas to

serve their needs.

4.1. Current use of patient portals

4.1.1. Medication

All participants rated the features or content relating to the medications they currently take as the most important functionality a patient portal needs to offer. We found that one of the reasons why medication information is considered critical to our participants is because medication is an important topic that they talk about when meeting with their providers. Consequently, participants considered it important to keep a list of medications they currently take so that they can ask about it during a meeting with a provider. However, none of the participants mentioned using a patient portal to access and retrieve information about their medications. Instead, a few participants said that they kept a list of medications on their smartphone so they could reference it when talking to a provider, while others said they kept their medication list on their computer and printed it out to bring to an appointment.

“I have my list of medications on a word document on my computer (so that) I can print it out, instead of wasting time writing them down every time I see a doctor... because I take a lot of prescriptions” (Participant 9)

Next, participants considered important not only a list of medication names they currently take but also detailed information on the medications, such as photos, instructions, and effects and possible side effects of different medications. Especially, possible side effects were counted of particular importance, as they considered it crucial information when a provider makes treatment decisions. Thus, many participants suggested that a portal should, if not already, provide additional information about possible side effects of the medication they take so that a patient is aware of potential side effects. Because most portals currently do not offer information about potential side effects of medications, participants often looked up online to find detailed information about medications.

“[The pharmacies] write the side effects in that printed form inside the box of the medicine, but that is really fine print. It’s easy to go on Google and read it.” (Participant 10)

When they found relevant, and especially new, information, they discussed the information they retrieved from the Internet with their providers. An experienced portal user among our participants shared her past conversations in which she asked her provider about a personalized interpretation of alternative treatment information she found online:

“[My provider is] very open to those discussions [about alternative treatments]. We’ve weighed things and gone off some things and gone on others [that I found online].” (Participant 2)

4.1.2. Lab results

Participants rated the content and features relating to the lab results, including details of lab results, treatment options, and potential side effects, a crucial functionality of a patient portal in card sorting activities. Then, the majority of participants counted lab results important not necessarily to track health changes for their own personal knowledge, but mostly to communicate these changes with other providers. For instance, several participants said they were hesitant to check their lab results on a patient portal on their own because they were not confident enough to interpret the meanings of the results by themselves, as many of them tended to misinterpret some abnormal lab results as something that would directly cause a change to the care they received (e.g., an abnormal cholesterol level might lead to changing cholesterol medication). To ensure that they understand the results while avoiding a misinterpretation, participants preferred to have their providers interpret what their results meant for them.

“I have gone on and gotten my results, but I prefer not to because I don’t know how to interpret it and it’s alarming sometimes. I prefer to just go and talk to my doctor because I have a very vivid imagination and it’s a dangerous thing, a little knowledge.” (Participant 2)

“You could misconstrue something and say oh my god, I’m dying tomorrow. I went to get blood work and [the results] came to me and I got so nervous because it just didn’t look right to me. So when I went to the doctor a couple of days later, I said oh my god, look. He said absolutely not. So sometimes it doesn’t pay to look at things online.” (Participant 8)

Most portals offer lab results as is without any further explanation or meaningful interpretation about the numbers, which significantly discouraged some participants from using the patient portal. For example, participants suggested that a lab result beyond the “normal range” would typically be marked as “abnormal” in the patient portal, though their providers would later say that the lab result was fine. The concept of a measure on a lab report outside of the normal range being automatically labeled as abnormal but later being called “normal for me” was brought up often, which interpretation was not applied to lab results. This inconsistency between what the lab results state and what a provider interprets led them to believe the lab results on the patient portal were inaccurate.

“My husband is diabetic, and very often we’ll see something that’s high [on the lab results]. Our nurse calls us with the results. She’ll say everything was fine, but [the report] will say that this was high and she said for you it’s okay. So the doctor will say that and this won’t. This is the computer.” (Participant 16)

To remedy this problem, participants suggested adding a patient portal with a feature that allows the patient to ask a provider directly about a particular lab result. A specific suggestion included a button next to each lab result that requests a call or asks a provider specific questions about that lab result immediately. These suggestions indicate that checking a lab result is, for many participants, inseparable from communicating with a provider.

“Suppose I see that my hematocrit’s low. What if I want to find out what this means? It would be nice to have a little message box to ask my doctor ‘my hematocrit is low, do I have to wait another two months ‘til I see the doctor?’” (Participant 1)

“[The button would be good] to link it to a specific thing, only because if the doctor does call you back, you might even say I don’t remember [which measure was alarming], I looked at [my lab result] and it wasn’t good” (Participant 4)

Many participants said they accessed a patient portal only to download and print out lab results to bring to appointments. Especially, participants who had to coordinate between multiple providers considered it very important and timesaving to have a copy of lab results to share with different providers. For these participants, access to a patient portal made them feel as though they prepared well for appointments and was saving time for themselves and providers by doing so.

“I can get it mailed also but normally I print it [the lab results] out from online because if you have everything then it’s better. Otherwise they call the provider then have to wait for it.” (Participant 11)

“Tomorrow I have to go to [the] oral surgeon and I’ll carry all of my medical records because they give you a form [to fill out]. So I keep all the hard copies and results like of the blood test, just printing off my laptop. I bring it to the office, just in case they need it.” (Participant 10)

There were a few participants who checked detailed lab results on the patient portal on their own or with others in their close social network. All of them had high health literacy and thus were

comfortable interacting with health information, such as having prior experience working in the medical industry, having higher education degrees, or having relatives or close friends who had medical expertise to interpret the results.

“I can sometimes see the results of the labs and have my wife look at them before the provider gets to us. Since my wife is so knowledgeable about all the gobbledygook then I hand it to her and she tells me, yeah you're okay or whatever but she understands all that” (Participant 3)

“I'm always interested in my wife's results because I understand what they mean, so I go on the patient portal to see what the results of her laboratory tests are so I know that everything is alright with her.” (Participant 14)

4.1.3. Communication

The most frequently mentioned feature during the entire participatory design sessions was *communicating with providers* for varying reasons. Consequently, features relating to communicating with providers, such as exchanging messages with providers and providers' contact information, were rated important in card sorting activities. Then, we found that participants were using a portal to exchange messages with their providers not only for logistical questions, such as making appointments, but also to ask more complicated questions about their health concerns, such as interpreting lab results or discussing treatment decisions.

“[In a message], I asked [my doctor] if it would be a good idea for me to see a specialist, and she wrote back and she said, “Yes, and the doctor you mentioned is a very good one and I think it's a good idea for you to see him.” So it saves them time. I find it a pretty good thing.” (Participant 2)

However, conventional means of communication such as telephone or face to face were still the most preferred method of communicating with a provider among most of our participants because of the immediacy of response. Especially, those who had never used a portal believed that calling the provider's office would be more convenient and successful than through the portal.

“I would want to speak with the receptionist [on the phone] and ask her because let's say she'll say Tuesday at 12:00 is no good, then I could say to her how is 1:00 and in two minutes we'll be finished with the whole thing” (Participant 16)

Other than immediacy, we identified several perspectives that our participants had on a patient portal that directly impact their decision making on whether or not to use a portal for communicating with providers. The first one is that many participants thought that a provider would not actually use the portal in a way that was meaningful to them. Several participants expressed fear that a provider would not read their messages at all. They shared their experiences when they had difficulties getting in contact with their providers via phone call and expected that similar issues would persist with a portal, too. Apparently, past negative experiences of not receiving a response or being subjected to an extended response time contributed to the participants' doubts of whether or not a provider would actually use a patient portal, which discouraged them from using a portal.

“You know they got the message doesn't mean that they're answering you.” (Participant 7)

Another prevalent perspective associated with messaging was the feeling that exchanging information via online messaging does not entail enough contextual cues. The idea of communicating through a computer and not with a person directly was not appealing to some participants because they believed that hearing a human voice enables you to pick up on non-verbal cues. In addition, because the conversation is particularly about health information, they felt that speaking to a

provider on a computer was “too far removed.”

“I don't believe in the computer. I like to hear a human voice. Especially when it comes to medical, human voice is so important. And you don't get it on the computer.” (Participant 8)

Several participants said they started using a messaging feature of a patient portal because they assumed it would be more convenient for a provider than using conventional means or a provider would want them to use it. They believed that providers would be too busy to take phone calls and that online messaging might be a timesaving alternative for providers.

“[A portal's messaging feature] is good for providers because they don't have to interrupt what they're doing. They can set aside 15 min every four hours or something [to check messages].” (Participant 3)
 “If you insist, [the provider] will call you back. But they are so busy they really want you to do it online. They are trying to get away from the calls.” (Participant 9)

Some participants said they started using an online messaging feature upon a provider's recommendation. Many of them said that their initial experience of interacting with a patient portal was very positive, such as receiving a response within a couple of hours, which resulted in not only deciding to use it for future communications but also having a positive attitude toward a patient portal in general.

“[Through a patient portal's messaging feature] I asked [my provider] about referring me to someone and she immediately wrote back later that day when she thought about it and it's pretty well done. I mean, I don't use it very often but there's a lot there.” (Participant 2)

“[The patient portal] is useful really. I had a problem and if I were to take the appointment, they will give me [an appointment] next week, but I just went online and sent her a message to please see me tomorrow and she did.” (Participant 11)

There were some participants who had negative experiences of using a patient portal to exchange messages, such as never getting a response to a message. Such experiences discouraged future use of online messaging, as well as creating strong doubts whether or not a provider uses a portal in general.

“[My wife] calls [the provider] and they said look we're very, very busy, we really suggest that you send a message - she'll get back to you quicker. So we put a message in please call me back ASAP. But they didn't call back that day so [my wife] called again and said I really need to speak to the doctor. They didn't respond. I haven't found doctors responding.” (Participant 9)

4.1.4. Summary

Medication, lab results, and communication were identified as primary purposes that our participants currently use a patient portal for or perceived a portal to be useful for. For medication, participants considered it important to keep information about their medications so they can discuss it with their providers when needed. For lab results, the level of confidence in one's ability to interpret and understand lab results determined whether or not to use a patient portal to check lab results. In addition, inconsistency between what a patient portal describes about a lab report and how a provider interprets its meaning negatively influenced our participants' perspectives on and the use of a patient portal. For communication, we found that participants' perception of how a provider would use a patient portal and their belief that a provider would want them to use a portal for communication were two key factors that determined their decision making of using a portal. The findings illustrate that the participants perceive patient portals primarily as one of their communication channels through which they interact with their providers. In other words, participants considered most features the portals offer, including those not directly

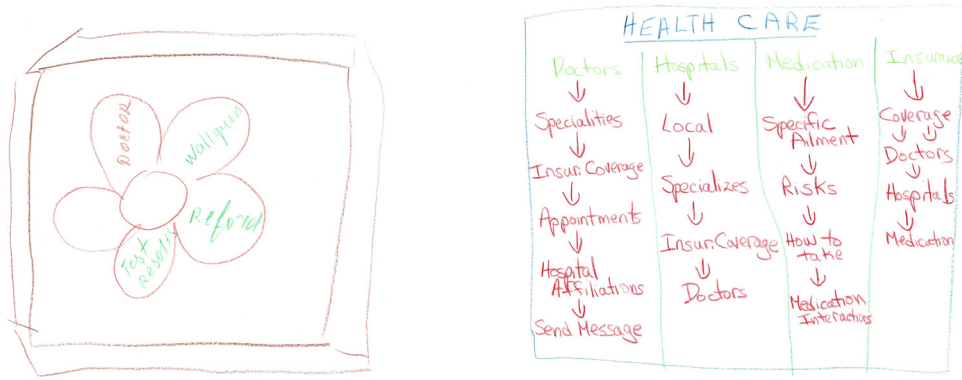


Fig. 2. Sketches of a portal's main page with key features only by Participant 17 (left) vs. with key features and associated submenus by Participant 7 (right).

associated with communicating functionality, such as medication and lab results, as a means of communication to interact with providers.

4.2. Design ideas for a patient portal

In the design exploration sessions of a participatory design study, participants expressed their needs, expectations, and requirements through sketching ideas in the first session, followed by discussing both the sketches drawn by other participants and conceptual design sketches that were created by our research team in the second session. In what follows, we report the findings from these design exploration sessions by a patient portal's categories.

4.2.1. A patient portal's main page

We first asked participants to freely draw how they would want a portal's main page to be organized. Participant 17 drew a flower shape image with each pedal representing one of the features she found most important to have on a patient portal's main page immediately after logging in, including Doctor, Referral, and Test Results (see Fig. 2 left). This sketch elicited polarized responses from participants in other groups. Some participants appreciated the simplicity of having all choices laid out as an initial menu in the drawing, expressing their concern about being overwhelmed by information overload.

"When you look at the flower one, it is not intimidating in any way. I like the fact that there's only five or six choices" (Participant 4)

"You're not getting bombarded with too many things at once." (Participant 3)

However, other participants expressed concerns about the simplicity in that such a simple design would make it unclear or difficult to access other diverse features that a portal provides. Furthermore, they objected to the simplicity, as they were opposed to the stereotypes that older adults are afraid of using technology or are incapable of interacting with complicated systems.

"That's so simplistic that I didn't know how much [functionality] you could get out of that." (Participant 2)

"[This sketch] does prove my point that people think when you get older you lose your marbles." (Participant 8)

On the other hand, Participant 7 drew a sketch that was the total opposite to Participant 17's by laying out a great number of options on a patient portal's main page (see Fig. 2 right). This participant drew the top-level menu options, including Providers, Hospitals, Medication, and Insurance, followed by several sub features within each category. Some participants appreciated it because it was organized in a pragmatic way, using clear terminology that would make it easy to access an option.

"I think this is an easy format. If you're looking for something I think it's easy to locate what you're looking for. It seems the right amount [of information]. Not too much and easy to understand and it's in

the categories that you could follow that seems to make sense." (Participant 15)

"It's very pragmatic, just more organized, I guess. My mind doesn't go like oh, what does that mean? It's so obvious to me what it means" (Participant 2)

However, other participants complained that it was too complicated. They expressed their feelings of being overwhelmed or confused because they were concerned that the number of options available to them would make it difficult to choose one particular option.

"[Fig. 3 is] very bad. If I were to see it, I would click off. I can see it's not going to be for me. It's not clear enough for me. If you overdo things it gets too complicated." (Participant 16)

These polarized responses demonstrate that the balance between simplicity and comprehensiveness is a delicate and important matter. While there is clearly a large cohort of seniors who feel excluded by technology, older adults are increasingly embracing the use of technology as tech-savvy baby boomers enter their 70s and beyond. Indeed, seniors are increasingly using the Internet and other technology, and they tend to view technology in a positive light and incorporate digital technology into their everyday lives. Many of them demand technology with full functionality that would be complex and high-end. Therefore, simplicity alone does not necessarily fulfill varied needs and expectations of older adults even within the same age groups.

4.2.2. Medication

Based on the feedback from the first sessions of the design workshop, we created 6 conceptual sketches of the medications' pages. Among those, one sketch focuses on providing informational content about medications that are personalized to the patient, including Medication instructions, Side effects, and Contact information (see Fig. 3 left) and another sketch is to enhance a user experience of communicating with providers regarding medications, including Asking questions about current medications and Requesting refills (see Fig. 3 right).

Most participants responded Sketch 1 would be more useful than Sketch 2 because it provides a more comprehensive and wide range of contents and features deemed to be useful for them compared to Sketch 2. They found it useful to have menus to contact a doctor and a pharmacist separately as then they can send relevant messages to appropriate recipients (e.g., asking questions regarding how/when to take medications to a pharmacist, while asking questions about side effects to a doctor). In addition, several participants pointed out that "side effects" would be very useful, which was one of the key features that many participants in the interviews suggested.

"[Sketch 1] is much better. It's more inclusive and has side effects." (Participant 14)

"[Side effects] is gonna be one of the things people are gonna be

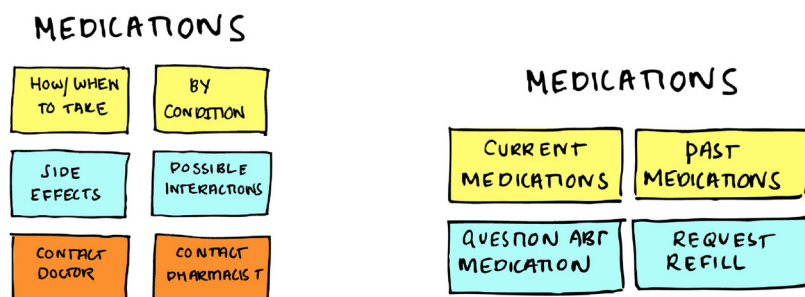


Fig. 3. Conceptual sketches of a medications main page with: a combination of informational and communicational features including instructions, side effects, and contact info (left: Sketch 1); and a combination of record-keeping and communication features including current/past medications and question/refill request (right: Sketch 2).

using fairly often. People take the medications and then they're like oh what was in the pamphlet, I threw it out. [Sketch 1] is nice" (Participant 4)

Some participants who picked Sketch 2 commended its simplicity in general and easy access to a record about current and previous medications in particular. This perspective is congruent with one of the primary purposes for which participants use a patient portal: to retrieve health records to bring to and communicate with other providers.

"It's important to know the medications you have taken in the past just so you know other complications, [in case a provider] wants to give it to you again." (Participant 8)

For the presentation of detailed medication information, participants emphasized the importance of both the quality and quantity of medication information. For quantity of information, participants wanted to access contents about medication effects and interactions. Because a provider often prescribes medications off-label without explaining what it is for unless asked, participants wanted detailed information about each medication so they can share it with others if needed. Sketch 3 was drawn reflecting on these needs, and participants found it useful both the amount and the kinds of available content (see Fig. 4).

For quantity of information, it was suggested to separate a list of medications they currently take for chronic conditions from those they took only for a brief period of time. This way, old medications they were no longer taking could be filtered out of a list of primary medications, reducing the amount of information available for medication history to a patient but making it still available for a provider to access when necessary.

"Some medication I had taken for a little time, for a week [Including that on the patient portal] is just too much." (Participant 8)

4.2.3. Lab results

Based on the feedback from the first sessions of the design workshop, we came up with 5 conceptual sketches of the lab results' pages. One is a lab results' main page that makes available key features in two categories: contents of lab results and means to communicate the results

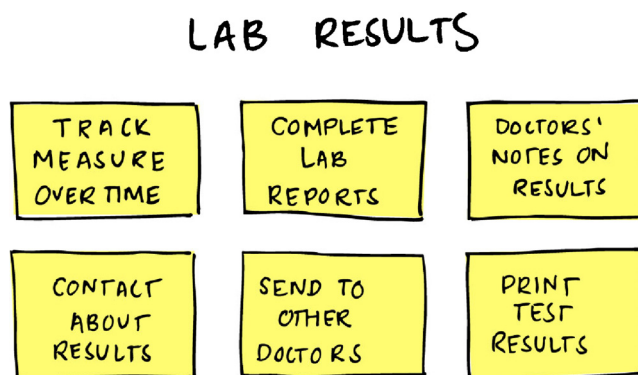


Fig. 5. Conceptual sketches of a lab results' a main page with contents and communication of lab results (Sketch 4).

with providers (see Fig. 5). Overall, participants declined the idea of viewing lab results because many of them were not confident enough to interpret the meanings of the results by themselves. Instead, they pointed out that the features that made it easier to communicate with their providers, such as "Print lab results" and "Send results to other doctors," would be very useful.

"[Sketch 4] is good. It has 'print test results' so that we can keep a file. That's very important to me." (Participant 14)

To cope with the concerns regarding the possibility of misinterpreting lab results, participants suggested a feature where a provider reviews the results and gives annotations to highlight important measures. To accommodate this, we created conceptual sketches of a results page that includes provider-reviewed results marked with a yellow background and a lab results page that has a list of specific measures with a provider's annotation to draw patients' attention (see Fig. 6). Sketches 5 and 6 received the most positive responses from participants among all the conceptual sketches. Participants appreciated the idea that the provider would review their lab results to make a meaningful interpretation for them. This feature will enable patients to easily find out which results they have to pay attention to while reducing the concerns of looking through a pile of complicated numbers and letters.

"That's good for example if you don't already understand what you should be paying attention to. It's almost like I forgot what he [a doctor] said. Then, I go back in [the patient portal] and get a refresh." (Participant 3)

4.2.4. Communication

Two key themes that came out of the first design workshop sessions regarding communication were requested *response time* (how urgent a patient needs a response) and *response channel* (through which medium a patient wants to receive a response, such as a phone call or an online message). Reflecting on these themes, we created 7 sketches with plausible solutions to these concerns. To improve a user experience of

ATORVASTATIN, 80 mg
Prescribed by Dr. Smith (cardiologist)

- > WHY DO I TAKE THIS?
- > WHAT ARE THE POSSIBLE SIDE EFFECTS?
- > HOW AND WHEN SHOULD I TAKE IT?
- > WHAT ARE THE POSSIBLE INTERACTIONS?
- > CONTACT DOCTOR OR PHARMACIST ABOUT THIS MED.

Fig. 4. Conceptual sketch of a medications subpage with detailed information about medications (Sketch 3).

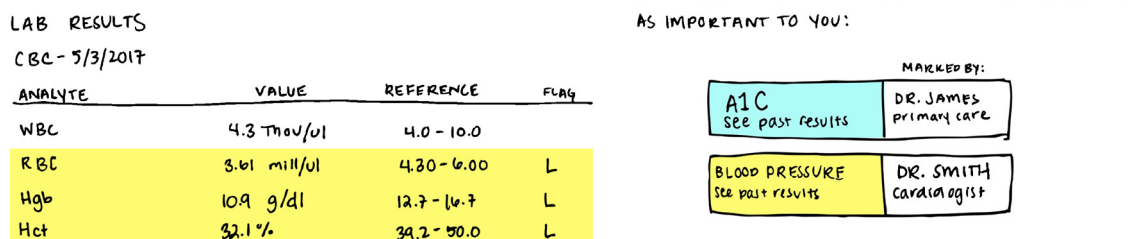


Fig. 6. Conceptual sketches of a lab results' subpage with a list of results with highlights for provider-reviews (left: Sketch 5); and provider interpretation of a particular result (right: Sketch 6).

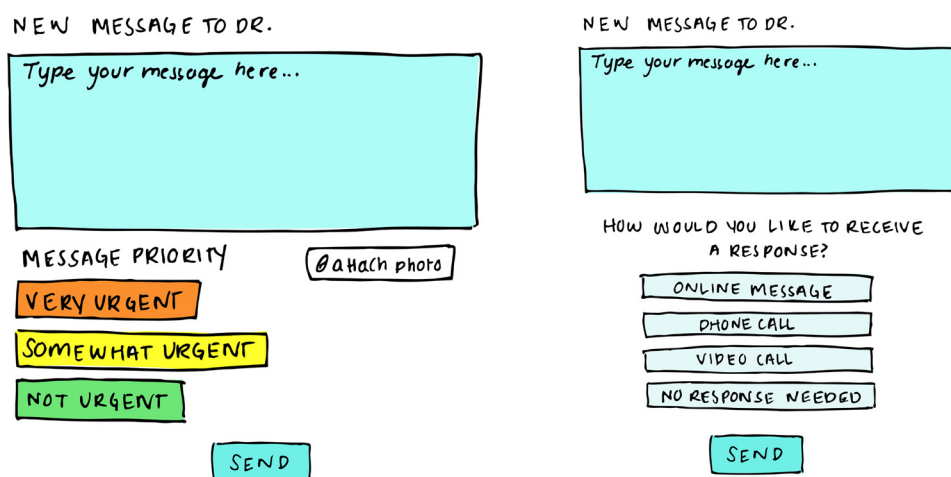


Fig. 7. Conceptual sketches of a message composition page with options: to label an urgency level of a message (left: Sketch 7); and to select different response channels (right: Sketch 8).

receiving a response on time, we created a message composition page with an option to indicate how quickly the patient would need a response (see Fig. 7 left). However, participants objected to these sketches because they were concerned about the effectiveness for two reasons. First, they said that someone other than a provider in the office, such as a secretary or nurse, would read this message before the provider and determine the level of urgency regardless of the urgency label you choose.

“The receptionist will determine “is this something that I have to interrupt a doctor [for] while he’s with another patient?” anyways.” (Participant 16)

“From the subject, [the office] will know how important and prioritize accordingly. They can make a judgment whether this needs [a response] right away or not.” (Participant 10)

Second, participants questioned if a message with the patient-determined level of urgency would really influence a provider’s response time. A patient’s perception of something being urgent might not necessarily be the same as a provider’s perception of it being urgent. Therefore, a provider would respond promptly if it were an urgent issue no matter how a patient labels its urgency and vice versa, participants thought.

“When my doctor sees [urgent] is he going to call me immediately? No.” (Participant 16)

These two concerns confirm that participants’ preconceptions about how a provider would use a portal are one of the key factors to determine their portal use.

To improve a user experience of receiving a response via a preferred channel, we created a conceptual sketch of a message composition page with an option to indicate to which channel a patient wants to receive a response (see Fig. 7 right). It was evident throughout the design

workshop sessions that our participants had a strong preference for using a phone call for communication regardless of their familiarity with technology. Thus, most participants found it helpful the idea of having a phone call as an option for the response channels. They said they would not mind using a portal to send a message, though, as long as they can receive a response in a timely manner.

5. Discussion: communication matters

Engaging patients to actively participate in their care is an effective means to improve health outcomes [11]. Patient portals have become an important pillar of patient-centered care and engagement primarily by a two-pronged approach: Providing patients with easy access to personal health data, including lab results, health histories, discharge summaries, and immunizations, to help them better understand and self-manage their conditions [40]; and improving communication with providers through direct secure messaging, online appointment scheduling, or prescription refill requests, which will lead to a positive influence on patient satisfaction, patient-provider relationships, and patient participation in making decisions about their treatment [36]. Our findings illustrate that it might not be everybody who benefits from or needs both approaches for patient engagement. Older adults may not be much interested in or need access to personal health data in greater detail, but would primarily seek to facilitate the communication aspects of a patient portal. It was evident throughout our findings that most conversations around the perception and use of a patient portal were centered on the notion of *communicating with providers* and they wanted to engage in their healthcare through effective communications with providers. Our participants described the varied ways they currently use a patient portal to manage their health information, most of which were intertwined with ways of communicating with their providers, as they consider the information on a patient portal as one part of the

communication they have with their provider. Our participants considered a patient portal as a (potentially) convenient instrument to enhance interactions with providers not only through exchanging direct messages but also sharing personal health data with various clinical stakeholders and receiving personally tailored lab results from providers. Based on the finding, we suggested concrete design implications to consider when tailoring a patient portal to the aging populations, which can be directly applicable to the current healthcare workflow.

5.1. Communication

Most participants still preferred in-person or telephone conversations when communicating with providers. Then they used the patient portal for messaging *only if* they believed their provider would prefer to use online messaging, if they were recommended to do so by a provider, or if they had positive past experiences using the patient portal. This means that perceptions of the provider's use of a patient portal (e.g., will my doctor really check my message online?) are a crucial factor that determines the decision for older adults to use a patient portal. Therefore, the patient-provider relationship, the perceived reliability of the provider, and past experiences communicating with the provider must be taken into consideration in the introduction of a patient portal to older adult patients. For example, relieving doubts about provider use of the patient portal or assuring that a provider uses the portal will be critical to increase older adults' adoption and use of a portal, as this remained a primary deterrent for many participants from using a portal for communication.

5.2. Lab results

Though several participants indicated that lab results were important to them, the fear of being alarmed by or misinterpreting abnormal reports prevented them from accessing lab results online. Therefore, they preferred having a knowledgeable person, most often the provider, review lab results for them first. When they accessed their lab results, it was solely to share them with other providers. This reflects the fact that patient engagement among the aging populations would be primarily achieved by enhancing communication and better interaction with providers.

In response to the sketches of other participants, the tension between simplicity and comprehensiveness of features became clear. As the participants continued to respond to sketches created by the researchers, this tension persisted along with other design considerations, including quantity of information, personalization, and use of information in health-related conversations.

5.3. Medications

One exception that does not directly fall under communication is medications information. Our participants found to be extremely important and consequently sought to have more information about medications than what is currently provided, such as side effects and separating a list of current medications from old ones. We assume that this might be because older people tend to take more drugs than younger people as they are more likely to suffer from more than one chronic condition [2]. However, the need to know more details about medication-related information also relates to communicating with a provider, as medication is a frequent topic of discussion with their providers. Our participants wanted to use a portal to be better prepared for a meeting with their providers (e.g., easily printing out a medications list). This informs us about strong user preferences for embedding communication channels that would allow them to interact with providers and pharmacists through the medication information features.

6. Limitations

The findings must be evaluated within the context of several limitations of the study. First, our sample of older adults was small ($N = 17$) and we used a method of convenience sampling for recruitment. One disadvantage of convenience sampling is that it runs the risk of compiling a non-representative study sample. Selection bias or unmeasured factors (e.g., relationship among people in a group, group dynamics of participatory design workshops) could have influenced the responses during the discussion sessions. These findings therefore may not generalize to the larger population of older adults. Second, the findings and discussions focused only on the three top-level categories of a patient portal (medication, lab results, and communication) and thus the assertion about communication being paramount in the design of portals for older adults may not be applicable to other categories of features or in different levels of communication such as general consultation of a disease or diagnosis. However, our findings showed that these categories are most widely used by the participants when using a patient portal, and thus we would argue that the communicational support is a predominant determinant of older adults' adoption of a patient portal.

7. Conclusion

This study used a mixed-methods approach to understand how older adults perceive and use patient portals. Our findings illustrate that the participants perceive patient portals primarily as one of their communication channels through which they interact with their providers. This conceptualization extends beyond a conventional notion of communication such as face-to-face communication or exchanging messages with providers; the participants considered most features that the portals offer, including those not directly associated with communicating functionality such as lab results and medication, as a means of communication or as facilitators to interact with providers. Consequently, we found that participants' perception of how a provider would use a patient portal and their belief that a provider would want them to use a portal for communication were two key factors that determined their decision making of using a portal. Based on these findings, we created conceptual sketches of a patient portal with key functionalities, reflecting on our participants' perception, needs, and use of a patient portal. The sketches were well received by our participants for reshaping the portal's key functionalities to serve their needs, some of which can be applied to existing patient portals immediately. We hope that these findings can help researchers and practitioners to advance patient portal design to better serve the unique needs of the aging population.

Authors' contributions

Kim and Fadem were involved in the conception of the work. Kim and Fadem designed the study. Kim provided methodological expertise. Fadem undertook the data collection. Kim and Fadem performed the analysis and interpretation. Kim and Fadem drafted the article. Kim did critical revision of the article and has given final approval of the version to be submitted.

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Conflicts of interest

There are no known conflicts of interest associated with this work and there has been no significant financial support for this work that could have influenced its outcome.

Summary points

What was already known on the topic?

- Patient portals have potential to increase patient engagement but these technologies depend on user engagement for their success
- Older patients are of particular interest as they are likely to suffer from multiple chronic conditions, but questions remain about how patient portals are perceived and deemed useful by older adults.

What this study adds to our knowledge

- Older adults perceive and use patient portals primarily as one of their communication channels through which they interact with their providers, as a tool for accessing and managing personal health information
- Their perceptions of how a provider would use a patient portal and their belief that a provider would want them to use a portal for communication were two key factors that determined their decision making of using a patient portal

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