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# Chapter



## **The equity paradox: older patients' participation in patient portal development**

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## Abstract

*Purpose:* This paper reflects on ethical concerns to patient portals design and evaluation approaches and provides a comprehensive overview of methodological considerations to advance patient participation of older patients to patient portal research and development.

*Reflection:* Barriers to the use of current patient portals experienced by older patients are concentrated on access issues and difficulties with interpretation of medical content. As patient portals' functionalities are being expanded by means of co-creation and user-testing such barriers often remain unrecognized. A main challenge of these patient participation efforts is namely to include a variety of older patients; foremost autonomous patients seem to participate. By selecting autonomous participants in co-creation or user-testing, design solutions are proposed that specifically benefit the autonomy of that patient, whereas it does not do justice to values and interests of patients who are less independent and are confronted with a wider variety of use barriers. Consequently, there is a risk of widening the gap between those who can use and benefit from patient portals and those who cannot. To prevent this from happening, we propose three main methodological aspects to consider in co-creation and user-testing activities that aim to optimize patient portal functionalities.

*Implications:* We encourage policy makers and patient portal developers to use present-day's momentum to include older patients' abilities, needs and context in the decision-making and investments in further advancing patient portals. We further stimulate future research that aims to improve methods to overcome challenges of older patients' participation regarding design and evaluation of eHealth systems.

*Keywords:* Human Factors, patient-centeredness, equity in healthcare, patient-provider information

## 1. Introduction

A pivotal role is allocated to patient portals in improving quality of care and as such the deployment of patient portals is promoted by Western governments and healthcare delivery systems [1-3]. A patient portal is an internet-based aid and foremost an application build on an Electronic Health Record (EHR) infrastructure of a specific healthcare organization, often offering patients basic functionalities. Such functionalities can be tools to schedule appointments, view laboratory results and personal medical information, request repeat medication prescriptions and send secure messages to their healthcare team [4-5]. By means of these functionalities portals aim to position patients at the center of care and promise to offer remote digital access to healthcare provision for all; thereby these portals aim to improve important components of quality in health care for the 21st century, such as patient-centeredness, efficacy and equity [3].

Older patients are a major target group of patient portals, since they typically need more healthcare services related to the high prevalence of chronic diseases amongst older people. The above mentioned functionalities of patient portals can therefore be useful to these older patients especially. For example, being able to communicate with a healthcare team from home and performing administrative health tasks digitally, instead of in the hospital, could benefit those who are less mobile. Studies reporting on various user groups of patient portals confirm these benefits [6-7]. These studies explain that users of patient portals are affected by several (chronic) medical conditions and are often 55+, or even 65+, years old [6-7]. Nevertheless, 60% of people aged 65+ are affected by one or more chronic medical condition(s). Compared to this percentage, the rate of current active users within this population remains low [6, 9]. Growing evidence does suggest that older patients are interested in using a patient portal, either themselves or with help of their caretaker, yet they currently experience barriers to this use [9].

In advancing patient portals to reach their aims to support older as well as general patient populations, patients' participation in its design is viewed as essential to accustom portals to patients' preferences: involving patients and physicians early and continuously in the iterative development process [10]. Activities for instance exists of end-users being involved in discussing new healthcare planning and delivery processes supported and redesigned by a patient portal implementation. Methods to involve end-users in co-creation of patient portals are: interdisciplinary sessions in which especially appointed client counsels interact with physicians and designers; interviews or patient focus groups; or by appointing consumer leaders as staff. End-users can also be involved in improving a patient portal's usability, i.e. by user-based tests and evaluations. Nevertheless, a major problem is that older patients are often not thoroughly involved in those activities. Patients who are able and motivated

to participate in co-creation and user-testing are contributing to the advancement of patient portals' design by expressing their needs [11]. Yet, as a consequence the needs and abilities of older patient populations, especially older disadvantaged patients, seem not to be adequately addressed in patient portal design due to an under-representation of these populations in co-creation and user-testing. This negatively influences their adoption of portals or similar eHealth products and increases the complexity for them of engaging in healthcare [12].

This paper therefore reflects on methodologies used to improve and implement patient portals from the perspective of the older patient target group. Conform [13], we performed a critical review of literature on advances in patient portal developments, its barriers for older patients and their challenges in co-creation and user-testing. This is combined with extensive experiences within the field of co-creation and user-testing with end-users regarding eHealth and patient portal use, consisting of over 10 years of research activities within this field (LP, MJ, GW) and 5 years of eHealth implementation activities in two major hospitals in The Netherlands (GW). By means of this abductive research strategy [14], we provide a comprehensive overview of methodological considerations in advancing patient portal research, development and use. We have observed a gap in emerging theory and practice, regarding the ethical concern of patient portal implementation and use for older patients: diversity aspects of older patients seem to be neglected in current advances of patient portals, thereby jeopardizing equity since this may widen the gap between those whom can benefit from portal use and those who cannot. The purpose of this paper is to offer insights and suggestions for improvement regarding this ethical concern.

## **2. Advances in patient portal developments and its barriers for older patients**

Given the increased development of patient portals, in our experience there is a trend that portals are transforming from merely a 'service to patients' into a means that are expected to fulfill a major role in integrated care for patients' self-management of their disease. This is supported by literature, explaining that instead of solely providing medical information on diagnosis, the basic functionalities of patient portals are expanded with usage functions for patients to monitor and manage symptoms and signs of their medical condition and assess the impact of their condition on their physical, emotional, occupational and social functioning [15-18]. Portals further aim to advance functionalities by providing patients with access to educational materials, (video) communication means to take part in e-consults with physicians and tools to monitor their own health indicators such as blood pressure and medication intake. Tethered patient portals are foreseen to include patient reported outcomes, such as medication side effects, progress towards treatments goals and concerns

regarding treatment [18]. Within the context of older patients, self-management is seen as a central aspect of integrated care for them, because of the increased occurrence of chronic conditions and need for medical care in older populations [19]. Being supported on this matter by means of a patient portal can thus be particularly useful tools for older patients.

Reported barriers of older adults to using patient portals are focused on (willingness to) access and interpretation of medical data in the portal. Older patients have limited technology or internet access or need help in using the internet or a patient portal [5, 9, 20-22]. Regarding older patients' willingness to access a portal, privacy and security are important aspects discussed in literature; if privacy and security are not ensured, older patients are less motivated to access a portal [20, 23-25]. Other reasons for not attempting enrollment are connectivity obstacles, for example of older African Americans [26]. They have the feeling that a portal would not be useful for them and they worry the portal could undermine their existing in-person relationships with their healthcare team [26]. Lower health literacy and numeracy levels, socio-economic status, less education, internet experience and cognitive abilities as well as older age influence patient portal use negatively [9, 20, 27-28].

### 3. Challenges of co-creation and user-testing

Consumer co-creation to optimize healthcare is an increasingly well-recognized management initiative in the health sector aiming at generating user-driven innovative solutions to real-world problems [29-31]. Advantages of co-creation are that it brings different parties together to produce a mutually valued outcome and that it builds upon the understanding of users' existing and future needs [29-31]. Within the development of software products to be implemented in healthcare settings, the need for conducting user tests with targeted end-users to improve the interface of these products is strongly supported in literature [32], and policy [33].

Yet, patient participation in co-creation and user-testing activities is affected by a key challenge: Patients must be willing and able to interact with representatives of a healthcare institution and other co-creation participants, such as physicians, to contribute to the process [31]. A review by Martínez-Cañaz et. al. explains that predicting engagement in co-creation activities, participants' autonomous decisions such as ethical values and their need to benefit society play an important role, apart from intrinsic (i.e. hedonic motivations) and extrinsic needs (i.e. financial rewards) [31]. In user-testing it is foremost challenging to select participants who resemble the target group in terms of health status and technology experience. Mostly healthy patients, with good cognitive and verbal skills are selected, due to the requirements of end-user tests [34-35]. Regarding healthcare co-creation in general, it

has been suggested that too much patient autonomy may lead to poor intervention choices, possibly resulting in a reduction of outcomes, and standardization across patients might be challenging [29]. This also accounts for portal design adjustments. An autonomous co-creation or user-testing participant can lead to design solutions that specifically benefit the autonomy of that patient, whereas it might not be suitable and beneficial to patients who are less independent. In that case, the gap between those who benefit from portal use and those who cannot may thus widen due to portal design adjustments derived from co-creation and user-testing. Consequently, instead of contributing to a more equitable healthcare system, co-creation in patient portal deployment might jeopardize equity by neglecting diversity aspects and thus missing the view of sub-groups of potential end-users whom would benefit from portal use.

## **4. Methodological considerations in co-creation and user-testing of patient portals**

To tackle the barriers of older patients in patient portal use and to optimize patient portals functionalities in such a way that they are beneficial to older disadvantaged patients, we propose three main methodological considerations in co-creation and user-testing of patient portals: 1) diversity in co-creation and user-testing participants; 2) efforts to stimulate participation of disadvantaged patients and 3) research into the contextual issues surrounding potential end-users to validate proposed information needs, functionalities and benefits.

### **4.1 Diversity in co-creation and user-testing participants**

To better understand the intrinsic aspects to barriers of older adults in patient portal use and adoption rates and to tackle these barriers in (future) patient portal developments, diversity in co-creation and user-testing participants is needed. Older and younger patients differ regarding their information and communication needs, which is relevant to the design of information and communication functionalities of a portal. For example, older people need more time to recall information that is presented via digital text compared to younger people [36] and unfulfilled information and communication needs of older (oncology) patients influence their quality of life more negatively compared to younger patients [37]. Regarding such aging differences, we identified four main aging barriers by means of a scoping review that may make it difficult for older people to use eHealth and mobile health: cognition, physical abilities, perceptual and motivational barriers [38]. In addition, medical conditions, for instance diabetes or a stroke, may serve as a catalyst to increase these aging barriers [38]. Since most EHR patient portals serve a broad target group, it is important to create an inclusive design of interfaces and functionalities that is appropriate to a variety of users, both younger and older as well as with a diversity of medical conditions and knowledge about these

conditions. For both co-creation and user-testing it is therefore important that the principles of Human Factor Engineering are pursued, in which the significance of including *representative* samples of end-users in the design process is stressed [33] and that an appropriate mix of participants is present in order to ensure representation of all stakeholder groups and interests in reflecting upon how healthcare aspects can be improved [39]. For example, a recent user-testing study including older patients with various health literacy levels, showed that their design solution of presenting health information in an audiovisual format, bridged the information processing gap between the low and high health literate participants [40]. The recall differences on the presented health information between the two groups were eliminated, whereas the presentation format did not negatively influence high health literate audiences [40].

#### **4.2 Efforts to stimulate participation of disadvantaged patients**

In our experience it is difficult to reach this type of diversity in these patient participation activities. In current co-creation and user-testing activities in relation to patient portal use, there are implicit expectations of participants. They have to be able to eloquently speak their opinion on healthcare services, their role in self-management and the role of physicians therein. Furthermore, they should be able to reflect on and express their ethical values regarding (improving) healthcare. If physicians are part of the co-creation activities, the patient's motivations and capacities should be strong enough to refute those of the physicians, who are often still regarded as a higher authority. Such physicians often want to collaborate with patients to hear their specific needs and beliefs, as opposed to what providers think from their own mental framework what would suit patients best. However, regarding patient participation in general, it may be difficult for patients to articulate their emotions and concerns due to, for instance, fears of burdening their provider or disrupting the therapeutic alliance [41]. As a consequence, less autonomous and disadvantaged patients are less likely to participate in these processes and a diverse group of participants is not easily reached. We therefore encourage organizers of such activities to put effort and time into reaching out to older and disadvantaged patients to include them as participants and to help them being able to participate effectively. This can be done by providing communication skills training to participants, similar to such trainings that are given to promote patient participation in healthcare interactions [41]. Although communication skills training targeted at patients' active participation behavior may not be appropriate for every patient, we nevertheless advise to consider such a training in co-creation activities since it can help to give patients essential skills in expressing their emotions and concerns that they would normally not easily disclose [41]. Furthermore, in-service courses can be provided to patient portal (software) developers regarding how to best perform co-creation and user-testing activities with older patients and how to adjust portal designs to their needs thereafter.

Several studies have reported on lessons learned while conducting intervention research with these populations, of which several are valuable for performing co-creation research [42-43]. It is important to have a stable point of contact for study participants within the development team, who communicates with the participants frequently and consistently during the project to avoid participant loss [42]. For the participants to openly express their health lifestyle and (digital) needs and to support appropriate self-disclosure, it is particularly important for the team to remain non-judgmental and to build trust [42-43]. Participants might additionally come to see the development team as a resource for solving problems that may not directly relate to the co-creation project; therefore it is important to define the scope of the project and to prevent the blurring of roles throughout the project [42]. These aspects seem to call for multidisciplinary teams that can optimally support and stimulate participation of disadvantaged older patients.

### **4.3 Research into the contextual issues surrounding potential end-users**

Co-creation or user-testing requiring the participation on location of sample populations, such as 'lab' or 'creative workshop' sessions, can be an extra obstacle for some patients. In addition, these settings provide little sight on how patients use a portal in their own context at home and during their daily life. Other co-creation techniques are focused on obtaining information from participants in their own habitat. Studies have asked participants to keep a diary on their experiences in using a digital health tool or went to their homes to perform interviews on web-based self-management support [44-45]. By this means data on the natural context of use is collected, which is an important design consideration when designing for older and disadvantaged patients [33]. For example, in a natural context it might become apparent which types of connectivity problems exist and which assistance and training on patient portals use is needed to support meaningful use by older patients. In addition, it is important to engage family caregivers since they often act as a proxy to older (disadvantaged) patients. A literature review by Byrne commissioned by The Change Foundation shows that the needs of family caregivers and co-creation involving caregivers were often the springboard for development of (digital) support initiatives to engage caregivers and healthcare providers [46].

## **5. Conclusion**

With healthcare organizations' efforts to expand patients portal functionalities, they aim to improve the quality of care for patient groups who frequently need healthcare services. In this reflective exploration on ethical aspects related to patient portal development we argue that present barriers of vulnerable patient groups, such as disadvantaged older adults, seem to be overseen in current patient portal designs. These patients' connectivity obstacles, old

age and multiple (chronic) diseases as well as disease specific barriers to technology use and context-of-use issues, hamper their chance to benefit from patient portal use. Patient participation activities, such as consumer co-creation and user-testing, to advance patient portals can address those barriers, yet currently there is an under-representation in participation of disadvantaged older patient populations in these efforts. As the phase of pilot projects with patient portals has passed and the deployment of portals is maturing, the decision-making and investments process on further advancing patient portals' incorporation in healthcare practices will take place in the upcoming years. To encourage researchers, policy makers and patient portal developers to use this momentum for including older patients' abilities, needs and context in portal use, we proposed three methodological considerations:

1) diversity in co-creation and user-testing participants; 2) efforts to stimulate participation of disadvantaged patients and 3) research into the contextual issues surrounding potential end-users. Further research in this field would be of great help in improving methods on how to overcome challenges of co-creation and user-testing with older patients regarding eHealth systems. Insights on this matter are highly important in advancing patient portals to the needs and characteristics of older patients and ultimately for patient portals to reach their aims in improving quality of care for these patients.

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