Vulnerable patients’ attitudes toward sharing medical data and granular control in patient portal systems: an interview study.

Short title: Vulnerable patients’ views on patient portals.

Authors: Jodie Bernaerdt, MPhil; Tania Moerenhout, MD, PhD; Ignaas Devisch, PhD.

1Department of Public Health and Primary Care
Research Group Philosophy of Medicine and Ethics
Ghent University; Ghent – Belgium

2Department of Philosophy and Moral Sciences
Ghent University; Ghent – Belgium

Corresponding author:
Jodie Bernaerdt
Department of Public Health and Primary Care
Ghent University - Campus Heymans (UZ Gent)
Corneel Heymanslaan 10 – Building 6K3; 9000 Ghent - Belgium
Jodie.bernaerdt@Ugent.be
+32 9 332 55 01

Abstract

Background: The collection, storage and exchange of medical information is becoming increasingly complex. More parties are involved in this process, and the data are expected to serve many different purposes beside patient care. This raises several ethical questions regarding privacy, data ownership, security and confidentiality. It is vital to consider patients’ moral attitudes and preferences in this digital information exchange. The voice of vulnerable patients is rarely heard in research addressing these questions. This study aims to address this void.

Method: Fourteen vulnerable patients without prior experience with patient portal systems were interviewed for this study. First, participants were introduced to the portal and given time to read their personal medical data. Afterwards, semi-structured interviews were conducted and analyzed thematically to explore participants' first experience with the portal and their views on sharing medical information with care providers and other parties.

1 Jodie Bernaerdt and Tania Moerenhout should be considered joint first author.
2 Jodie Bernaerdt’s present working address is Sint-Pietersnieuwstraat 25, Rectoraat 2, 9000 Gent. Department of Research Coordination, Doctoral Schools.
Results: Data analysis resulted in four themes: barriers to and benefits of portal access, emotional responses to reading medical information, diverging views on sharing information with third parties, and balancing granular control and the best possible care. First, participants appreciated access to their health information in the portal despite experiencing obstacles. Second, reading medical information online could evoke emotional responses. Third, patients were generally unaware of the meaning and value of medical data to third parties, resulting in inconsistent views on data sharing. Finally, although patients generally supported granular control, they were willing to give up on their autonomy if that would ensure them to receive the best possible care.

Conclusions: Patient portal design should take into consideration the obstacles that discourage vulnerable patients’ access and hamper meaningful use. There is a need for more transparency on secondary use of medical data by third parties. Patients should be better informed about the potential consequences of sharing data with them.

Keywords: Electronic Health Records, Patient Portal, Patient Access, Patient Preference, Vulnerable Populations.

Introduction

Electronic health records (EHRs) have gradually replaced their paper predecessors in the last two decades. In many European countries, a patient’s EHR can now be accessed by care providers across different organizations. Patients also have the opportunity to access their medical information via patient portal systems. Although specific functionalities vary widely, patients can usually read their medical history, access test results, communicate with health care professionals, and decide which providers have access to their EHR. Health information technologies (HITs) aim to make health care more efficient and to improve health outcomes by data exchange between care providers and by encouraging patients to actively engage in health care processes. Moreover, third parties hope to benefit from the data these HITs generate. It is expected that the amount of medical data collected in EHRs will only increase in the future. Data generation from genetic testing and input from wearables and health apps are two examples of this trend. As such, data analysis is expected to serve more purposes than just patient care (e.g. Big Data research). This will expand the ‘third’ parties involved in the collection, storage and sharing process: pharmaceutical companies, IT companies, app designers and research institutes could all be interested and benefit from access. The increase in digital health information exchange (HIE) raises several ethical questions regarding privacy, consent, data ownership, security, confidentiality, trust and changing roles in the patient-care provider relationship, and requires health care organizations to think about how they handle patients’ medical information. Here, patients’ perspectives and preferences should also be taken into account.

Several studies focusing on patient perspectives show that patients are concerned about privacy breaches, misuse and commercial use of their EHR data. Moreover, patients seem to have no or limited knowledge of how their medical data are exchanged—they express a desire to be better informed about these processes and uses. Despite their concerns and the existing lack of transparency, patients are generally willing to share their medical information with care providers and third parties. Their sharing preferences do vary. The decision whether or not to share medical data is
often influenced by the following three factors: the identity of the recipient, the level of anonymity and the sensitivity of the data\textsuperscript{19}. Some patients only want to share their health information if it serves clinical care\textsuperscript{18,21}; others would share their information with private or public researchers to serve the greater good\textsuperscript{20}. Patients generally do not want to share all information with all types of care professionals or third parties – in some cases, they prefer to share anonymized data only\textsuperscript{18,22–24}. They tend to favor an opt-in consent system over opt-out\textsuperscript{16,20,23,25}, unless their medical information is anonymized\textsuperscript{22}. Overall, research has shown that patients want more control over their medical information\textsuperscript{24}.

While research has shed some light on general patient views on sharing medical data, only a limited number of studies have considered vulnerable patients’ perspectives\textsuperscript{26–31}. Generally speaking, vulnerable patient populations express interest in and enthusiasm about portal use, but encounter more barriers and challenges to using these systems than other populations\textsuperscript{27–30,32–34}. A number of studies explore these barriers in more detail, and find limited prior knowledge of the system, low health and/or computer literacy, technophobia, limited computer and internet access, worries about privacy loss and security concerns may all play a role\textsuperscript{30,32,33,35}. However, vulnerable patients also indicate that portal use may improve the quality of care, strengthen the patient-provider relationship, bring more convenience and lead to better communication with clinicians altogether\textsuperscript{27–29}. Four studies suggest that in-person assistance or education on patient portal systems may increase its use and benefits among vulnerable patients\textsuperscript{29,35–37}. Although some papers mention privacy and security barriers\textsuperscript{27,30,32}, the preferences of vulnerable patients toward sharing information with clinicians and other parties have not been extensively examined\textsuperscript{38}. This research project wants to contribute to addressing this void. Since digital health information exchange is increasing, we believe it is also of paramount importance to explore vulnerable patients’ views on sharing EHR data with care professionals and third parties to contribute to the further development of these portals.

**Method**

**Participants**

This study aimed to interview vulnerable patients who have no prior experience with patient portal systems. ‘Vulnerability’ was broadly construed as at least one of the following: a fragile socio-economic position, low health or digital literacy, mental illness, disability and/or a chronic medical condition. To be able to recruit vulnerable participants, the study was conducted at two offices of a federal health insurance provider in Belgium (Bond Moyson). Here, patients most often consult with social security questions, e.g. regarding medical and hospital insurance and substitute income. All patients consulting the social service have one or more of the above mentioned vulnerabilities.

The reception staff (social workers) of the health insurance provider were briefed on participant eligibility. The following conditions applied: fluent in Dutch, 18 years of age or older, no prior experience with patient portal systems, has an e-ID card and pin code (to log onto the patient portal) and has one or more of the above mentioned vulnerabilities. The social workers informed eligible clients about the study and referred them to one of two researchers (JB or TM) if they were willing to participate. There, more detailed information was given and patients could make an appointment for an interview. Participation was voluntary and an informed consent form was signed. An overview of
the participants is shown in Table 1. The study was approved by the Ethics Committee of the Ghent University Hospital (2018/0699).

[insert table 1]

**Interviews**

The interviews took place at the offices of the health insurance provider in both a small town and larger city in Belgium between September 2018 and March 2019. Two researchers (JB and TM) conducted all interviews. Each interview consisted of two parts. First, patients were introduced to the patient portal system, CoZo, a Flemish patient portal tethered to the EHR. Participants were provided with a brief step-by-step guide explaining how they could log in and use the system. If necessary, the researcher helped them with any problems they encountered. Notes were taken by the researcher of this process. Then, participants were given time to read their online medical information and to familiarize themselves with the patient portal system. They could do this at their own pace and in the order they preferred. This introduction ensured patients had a clear image of what the patient portal entailed and allowed for a more in-depth and concrete interview afterwards. Second, participants were interviewed about their first experience with the portal and were asked about their preferences and moral attitudes toward sharing medical information with care providers and other parties.

A semi-structured interview guide (see addendum 1) asked participants about predetermined topics but also allowed them to bring new topics to the table. The first part of the interview consisted of questions related to their first experience with the portal. The second part presented participants with five statements on sharing medical information with care providers. The third and last part of the interview consisted of questions to probe the participants’ views on sharing medical information with third parties. A card exercise (eliciting technique) in which participants were presented with several types of third parties and a list of types of information they would or would not share with these parties. Third parties included public research institutions (such as universities), private research facilities (including pharmaceutical companies), insurers, employers and a blank card. The card exercise helped participants to reflect upon this topic in a more concrete way. All interviews were recorded digitally, transcribed ad verbatim and analyzed in NVivo 12. Pseudonyms were used to protect the participants’ privacy. The interviews lasted between 19 and 64 minutes. Data saturation was achieved after fourteen interviews.

**Data analysis**

We performed a thematic analysis in three phases. First, both interviewers (JB and TM) familiarized themselves with the material – striking results and outliers were discussed early in the analysis. Second, both researchers coded three interviews independently. These code books were discussed thoroughly until a consensus was reached. One researcher (JB) then continued the coding process with

---

3 CoZo (Collaboratief Zorgplatform) is a digital platform that allows patients, care providers and care institutions to consult, exchange and share medical information in a fast and secure way (https://www.cozo.be/). Patients can view test results, appointment scheduling, who has access to their records (with logging), which therapeutic relations they have, and give or withdraw their informed consent to share information with care providers. The medical information is limited to a summary of their family doctor’s record, test results and medical images. Care providers’ notes are not displayed. Some hospitals also upload discharge letters and specialist consultation reports. Each hospital and individual care provider determines what is available in the portal.

---
this code book, extending it with new codes where appropriate. Third, overarching themes were reviewed and further refined by both researchers. This process was used to ensure validity and reliability of the results. Priority was given to inductive analysis because of the exploratory nature of the interviews. The step-by-step guide of Braun and Clarke was used while analyzing the data set. Moreover, we adhered to the 32-item checklist presented by Tong et al. during the entire process. Throughout the results section, fictitious names are used to protect the participants’ anonymity.

Results

The results are presented in four themes: the barriers to and benefits of portal access, emotional responses to reading medical information, diverging views on sharing information with third parties, and balancing granular control and the best possible care. We will discuss these themes more in-depth below. The first theme explores how patients appreciate record access despite encountering obstacles in portal use. The second theme unravels how reading medical information online may evoke emotional responses in patients. The third theme explores how participants are generally unaware of, or confused about, the meaning and value of medical data to third parties, resulting in inconsistent views on data sharing. Lastly, the fourth theme analyzes how participants balance granular control and beneficence or the best possible care. Overall, they support patients having granular control over their data. However, they also hesitated to take up granular control if it would impede receiving the best possible care.

Vulnerable patients appreciate record access despite encountering barriers

To most participants it was quite challenging to log in and use the patient portal for the first time. They needed some time to familiarize themselves with the structure of the patient portal. Although most participants believed portal use would become easier with repeated use, they did encounter some specific barriers worth considering here. A first barrier was the complexity of the log-in procedure:

\[\text{Well, yes, I was able to do this because you were here, but it is frightening, because you, like I said, you need the eID and pin code and that card reader... (Lynn)}\]

To access the patient portal, one needs a computer, an e-ID reader, the e-ID card and pin code and a basic level of digital literacy (it is also possible to log in through a secured application, but none of the participants used that app on their smartphone). Although most of the participants had a personal computer at home, they often did not have an e-ID reader or they could not remember the pin to their e-ID. Several patients expressed they appreciated having someone guide them through the log-in procedure for the first time. At home, the lack of a smooth and user-friendly log-in procedure would cause them to give up on using the portal altogether. Within this research setting, they found access to be fairly easy, although most participants needed help in some way. A second obstacle was the medical jargon found in lab results and other test reports patients could read in their file. Most participants struggled to understand medical terms and to interpret test results without further explanation or a doctor’s interpretation. They often expressed the need for more background information. Third, participants were sometimes disappointed in the amount and type of information they were able to see. They experienced their access to the record as limited and incomplete. One participant was disappointed that psychology reports were not shown and would have appreciated online access to mental health information as well.
Despite these obstacles, the participants appreciated online record access and were eager to read what was written about them on the patient portal. They considered the portal to be a convenient tool for their personal administration and to be better informed about their health. Despite the barrier imposed by medical jargon use, some participants expected record access to improve their health literacy. Thea, for example, explained that she often forgets what her general practitioner (GP) has told her during a visit. She appreciated access to the patient portal to look back at her results and reports, and to look up medical terms and their meaning afterwards on the internet:

_They [care providers] all use very strange words and it’s in one ear and out the other, and then when you get home, you have forgotten. But now, you can check again and you can look it up on the internet._

Most of the participants would use the patient portal in the future and would recommend it to family and friends, although some mentioned they would not use it as frequently as social media. Other participants would not use it in the future, because they would rather consult their health information together with their GP. Interestingly, some patients specifically valued the ability to consult results when abroad and found it reassuring to have their medical information available worldwide through portal access.

**Reading medical information online may evoke emotional responses in vulnerable patients**

Reading the medical information online evoked an emotional response in some participants. Some found it confronting to see the overview of their medical history. Others were overwhelmed by the amount and detailed nature of the available medical data. Helena turned a bit quiet while scrolling through her past results and described her reaction of being overwhelmed:

> Considering my age, I have already had many medical exams and operations, and yes... [...]. Because you see them all together, you think, wow, this list, what have I [laughs nervously] already been through?

Myra on the other hand, did not feel comfortable being reminded of her previous admission to a psychiatric hospital:

> Well, yes, it happened, right? I cannot turn back the clock – you would like it to be different, but it has happened. On the other hand, do you always have to be reminded? Like, with every hospitalization that is completely unrelated, you are reminded in the end that you have been admitted to a psychiatric unit. [...] Yes, I do think that is annoying. Especially because I know a lot of nurses, there are a lot of nurses in my family, nieces for example, and, actually, they do not need to know. But they can see it.

Fae considered the invitation for population screening (for colon and cervix cancer) confronting. It made her realize that although she is currently healthy, she is at risk of developing cancer or another serious illness. Participants generally regarded their medical data as intimate and sensitive information. While some considered all information to be sensitive, others highlighted more sensitive
categories such as information on substance abuse, mental illness, cosmetic surgery, personal statistics and sexual and reproductive health.

**Vulnerable patients have diverging views on sharing medical information with third parties**

Most of the participants only wanted to share medical information when necessary to receive health care or to receive refunds from health insurers. A majority expected several pitfalls when broadening EHR access to third parties, such as having to pay a higher insurance premium or facing discrimination on the labor market. Therefore, they would prefer these data to be anonymized before being shared with third parties, or they would deny them access altogether. Below, Jenna talks about (not) sharing medical information with pharmaceutical companies, and Harold describes the potential risks of sharing data with employers:

> [Sharing data with] pharmaceutical companies is completely unnecessary because they will try to sell you things. I do not need that. For example, you had your blood tested and they say: “Oh, she has a vitamin deficiency, well, let’s call her and sell her our new product”. I do not need that. Period. It’s useless.

> It’s the same with employers. Once they know what is wrong with you, what [illness] you have, and they have access to that information, they may conclude you will no longer be able to work and say: “You’re fired, you’re out” and it’s over and done with for these people.

Other participants supported the idea of access to non-anonymized EHRs by third parties. Don for example, believed that employers would be more empathic when they know about the medical conditions of (future) employees via their EHR, or that insurance companies would not raise premiums.

Many participants wondered how their EHR data could be of value to private research institutions. They believed only medical data collected through clinical trials could be of use to them. More specifically, they believed that their medical condition would not be of interest to researchers and thus that it would be pointless to provide them with access to their EHR data. Thea stated this as such: “Well, they already conduct so many research trials and things, then, why would a record matter [to them]?

**Vulnerable patients balance granular control and beneficence**

Most participants were in strong favor of having control over what happens to their personal medical information. They expressed this view on granular control not only toward third parties, but also toward health care professionals. However, their views on how this granular control should be put into practice varied widely. First, they had different preferences for consent procedures: some preferred a one-time consent, others implicit consent, some participants thought no consent was needed if data were shared anonymously and still others wanted to see a consent procedure for each individual episode of care. Second, they had different preferences concerning how their medical data should be presented to others: whether it should be anonymized or not, or whether certain information should be hidden or not. They strongly believed that their preferences were not necessarily the same as those of other patients: overall, they shared a one-size-does-not-fit-all approach. Moreover, the participants considered granular control to be an expression of their right to privacy:
That depends on the patient, right? If they consider something, a bit, too sensitive, “I would keep that to myself or limited to certain doctors or just one”, well, they have to respect that of course. That has to do with privacy. (Harold)

Nonetheless, participants were also concerned about exercising granular control – or more specifically, hiding information – in encounters with care providers. They believed that hiding information and denying or revoking care providers’ access to their EHR could impede the quality of care they received. For example, sensitive information about medical problems in the past could still be relevant for current medical problems. Participants often considered themselves not in the right position to determine which information could be relevant to whom and believed that care providers are better suited to make these decisions. They strongly believed it is better to provide all care providers with as much information as possible. Some even felt they had no other choice but to reveal all information in their EHR to their providers. Lynn and Esther stated this firmly:

I would hurt myself if I said: “don’t look at the whole picture”, right? (Lynn)

In a way, you have your back against the wall, because after all, it’s for your health. Yeah. So it [information sharing] is sort of inevitable... . (Esther)

Also, some participants indicated that they trusted care providers to adhere to their deontological code of confidentiality and therefore believed patients should not hide medical information.

Maddie had a different view on the potential conflict between autonomy and beneficence. She thought that a patient’s autonomy should be respected at all times, even though it could have harmful effects. However, she also believed that patients should be clearly informed of the harmful effects hiding information may have, for example through a signed informed consent:

Well, maybe it should be clear to everyone that if you render that invisible – imagine something happens to you and they [care providers] cannot read it. Then they cannot act upon it. It may have to be included, it may be an option, for example, to have people sign off on that, where you explain they can [hide information], but if something happens or [care providers] need [that information] and they cannot access it, that it may be potentially harmful. (Maddie)

Finally, some participants explicitly referred to how a vulnerable patient position can influence autonomy choices. The circumstances of being ill, unwell and in need of medical care can put the patient in a frail position. Quite often, questions about granular control and record access are not a priority at that time:

Because you find yourself in a state where you don’t feel 100% well. You would more easily permit that [record access]. I believe that most people, if they need help, they want to be cared for in the first place, and I do not think they consider that [granular control] at all. (Esther)

Discussion

The vulnerable participants in our study experienced three specific barriers when using the patient portal: practical difficulties regarding log-in procedures and the user-friendliness of the interface, the challenge of interpreting medical jargon used in clinical reports, and the limited and incomplete access to their record information. Previous research has also shown that vulnerable patients experience
more difficulties accessing their record and interpreting health information in a meaningful way \cite{26,37}, which is similar to our findings. However, this particular research setting enabled participants to overcome the first barrier and most felt comfortable using the system after the introduction. This may mean that patients with specific vulnerabilities – especially a low health and digital literacy – need support in using patient portal systems, at least to overcome initial anxiety or unease \cite{32,33}. Unfortunately, patients who have the most to gain from having access to their health information also risk being excluded from the benefits of HITs \cite{4,7,43,44}. A recent systematic review has pointed out that patients with limited health literacy are less likely to use patient portals \cite{45}. On the other hand, technical assistance for first time portal use, education on the portal and advice from family and providers have been identified as facilitators to vulnerable people’s use and adoption of patient portals \cite{36,37,45,46}. Care providers often state a lack of time and resources to provide vulnerable patients with the necessary support to access their health information in a meaningful way \cite{29}. Without individualized support and a customized portal design tailored to the needs of vulnerable patients, it is highly unlikely that record access will actually improve patient empowerment, literacy and health outcomes \cite{35,37}.

Our finding that reading medical information online may evoke emotional reactions in patients has not been extensively described in previous literature. We believe it is important to raise awareness about this potential ‘side-effect’. Similar emotional reactions were described in a focus group study, where two patients “thought that seeing their diagnoses in writing would be stressful enough to ‘…put me over the top.’” \cite{30} An interview study focusing on accessing test results online also found that patients often experienced negative emotions when reading abnormal test results, and sometimes this occurred even with normal test results \cite{47}. Lastly, a minority of oncology patients reading their notes online described this experience as emotionally difficult: “Some described a sense of sadness when reading about their cancer, even wishing that the electronic medical record would restrict their access to notes” \cite{48}. One large scale survey study finds very few patients were left worried or confused after reading visit notes online \cite{49}. Overall, psychological outcomes of record access remain unclear \cite{50}.

Research has shown that patients have little to no knowledge about how their medical data are exchanged \cite{19,20}. Our study echoes this finding. Although previous literature shows that vulnerable patients express concerns about privacy and security risks \cite{27,30,32,46}, in real-life situations it may be difficult to grasp the potential (negative) consequences of sharing personal medical information for big data research, like disclosure of personal information after re-identification of data, discrimination on the labor market and financial disadvantages. Interestingly, patient portals could be an opportunity to increase transparency on how personal medical data are exchanged and to engage patients in decision-making regarding this exchange \cite{54}, especially when secondary use of medical data becomes a more widely incorporated practice. The question when and how patients should be informed remains
unanswered. Our study shows that many vulnerable patients do not consider decisions about secondary use to be a priority or major concern. Rather, it is far removed from their life-world and patient engagement and empowerment in this field remain challenging.

Patients, including vulnerable patients, prefer to have granular control over their medical information\textsuperscript{24,30}. Nonetheless, our participants believe that exercising granular control may negatively impact the quality of care that is provided to them. To avoid any negative outcomes, they tend to give care providers access to all information. In a way, participants sometimes confirmed paternalistic role models, where priority is given to beneficence over autonomy. In their consideration to hide information or to deny certain care providers access to their record, they weighed how this could damage the patient-provider relationship. The participants in this study worried about taking up too much time or asking too much effort from their care providers. Sometimes this would steer them toward the decision to share all information, or in other words, to give priority to beneficence and the patient-provider relationship over autonomy. This phenomenon has been described by Berry et al. as “becoming a hostage to one’s care”: “It is especially prevalent when […] patients become more dependent on clinicians and more likely to seek favor from them in a deferential manner. They believe that “the doctors knows best” and conform to a socially sanctioned role of reluctance to assert their interests in the presence of experts”.\textsuperscript{55} Instead of promoting patient autonomy and empowerment, digital information exchange thus risks perpetuating a helpless or powerless patient position, especially in vulnerable patient populations. Shared decision making, creating a true partnership and a context of mutual trust, could be an antidote to this risk\textsuperscript{55}.

Conclusion

Patient portal design should take into consideration the barriers that discourage vulnerable patients’ access to the system. An introductory (face-to-face) session for first time use could help vulnerable patients overcome practical and technical difficulties. There is a need for more transparency on secondary use of medical data. Patients should be better informed about the potential consequences of sharing data with third parties. Vulnerable patients may experience negative emotions when reading their record online. More research is needed to examine this effect.

Acknowledgements

We would like to thank the participants for their time and effort to participate in this study. We also thank the social workers of the Bond Moyson (health insurance provider) who helped in the recruitment process.

Funding
The first author (JB) was supported by the King Baudouin Foundation [grant number 2017-J5810430-207488].
The second author (TM) was supported by the Research Foundation Flanders – Fonds Wetenschappelijk Onderzoek [Clinical PhD Fellowship grant number 1700618N].

Conflict of Interest Statement
All authors declare no conflict of interest.
References

1. From Innovation to Implementation – EHealth in the WHO European Region. World Health Organization; 2016.


The


