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# Exploring the role of teams and technology in patients' medication decision making

Authors: Kathryn Mercer, MI<sup>1</sup>, Lisa Guirguis, BPharm, MSc, PhD <sup>2</sup>, Catherine Burns, PhD<sup>3</sup>, Jessie Chin, PhD<sup>4</sup>, Maman Joyce Dogba, MD, PhD<sup>5</sup>, Lisa Dolovich PharmD<sup>6</sup>, Line Guénette PharmD<sup>7</sup>, Laurie Jenkins MBA <sup>7</sup>, France Légaré, MD, PhD<sup>4</sup>, Annette McKinnon <sup>9</sup>, Josephine McMurray PhD<sup>10</sup>, Khrystine Waked, BSc<sup>1</sup>, Kelly Anne Grindrod, BScPharm, PharmD, MSc<sup>1\*</sup>

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#### **Contact:**

Kelly Grindrod 200 University Ave West Waterloo ON, N2L 3G1

Phone: 519-888-4567 ext. 21358 Email: kgrindrod@uwaterloo.ca

<sup>&</sup>lt;sup>1</sup> School of Pharmacy, University of Waterloo, Ontario, Canada

<sup>&</sup>lt;sup>2</sup> Faculty of Pharmacy and Pharmaceutical Sciences, University of Alberta, Alberta,

<sup>&</sup>lt;sup>3</sup> Systems Design Engineering, Faculty of Engineering, University of Waterloo, Ontario, Canada

<sup>&</sup>lt;sup>4</sup> Department of Biomedical and Health Information Sciences, College of Applied Health Sciences, University of Illinois at Chicago, Chicago, Illinois

<sup>&</sup>lt;sup>5</sup> Faculty of Medicine, Université Laval, Quebec, Canada

<sup>&</sup>lt;sup>6</sup>Leslie Dan Faculty of Pharmacy, University of Toronto, Ontario, Canada

<sup>&</sup>lt;sup>7</sup>Faculty of Pharmacy and Population Health and Optimal Health Practices Research Unit of the CHU de Québec Research Centre, Université Laval, Quebec, Canada

<sup>&</sup>lt;sup>8</sup> Healthcare Navigators

<sup>&</sup>lt;sup>9</sup> Patient Partner

<sup>&</sup>lt;sup>10</sup> Lazaridis School of Business & Economics/Health Studies, Wilfrid Laurier University, Ontario, Canada

#### Abstract (300 words vs. max 300 words)

Objectives: We know little about how electronic health records (EHRs) should be designed to help patients, pharmacists, and physicians participate in interprofessional shared decision-making (IP-SDM) We used a qualitative approach to understand better how patients make decisions with their health care team and, how this information influences decision making about their medications, and finally how this process can be improved through the use of EHRs.

Design: Participants from four regions across Canada took part in a semi-structured interview and completed a brief demographic survey. The interview transcripts were thematically analyzed using the Multidisciplinary Framework Method.

Settings and Participants: 30 Participants aged 18 and older with at least one chronic illness were recruited from across Canada. We interviewed participants in their homes, at the School of Pharmacy, or another location of their choosing.

Results: We identified four main themes: (1) Complexity of patient decision-making: who, where, what, when, why; (2) Relationships with Physicians and Pharmacists: Who do I trust for what?; (3) Accessing health information for decision making: How much and from where?; (4) Patients' methods of managing information for health decision-making. Across the themes, participants appreciated expert advice from professionals and wanted to be informed about all options, despite concerns about limited knowledge.

EHRs were perceived as a potential solution to many of the barriers identified.

Conclusions: Patients make decisions with their healthcare providers as well as with family and friends. The pharmacist and physicians play different roles in helping patients make decisions. We found that making EHRs accessible not only to healthcare providers but also patients can provide a cohesive and clear context for making medication-related decisions. EHRs may facilitate clear communication, foster inter-professional understanding, and improve patient access to their health information. Future research should examine how to develop EHRs that are adaptive to user needs and desires.

# **Key Points:**

# Background:

- This project was completed by a multi-disciplinary research team from across
   Canada that included engineers, clinicians, healthcare researchers, business and communication researchers, patients, and a patient navigator. Patient partners were involved throughout the research process.
- To best navigate health decisions, patients need to be active participants in managing and understanding their health.
- Weighing costs, benefits, preferences, and an abundance of information contribute to patients' lack of confidence about making the 'right' decision, perpetuating a cycle of limited agency, and low adherence to treatment regimes.
- There needs to more evidence around how electronic health records can facilitate shared decision-making.

#### Findings:

- For patients, the type and amount of information desired changes if a health situation is acute or chronic. Patients have a greater desire to access to EHRs with a long-term chronic condition.
- Patients value their relationship with their physician more than their relationship with a pharmacist. Pharmacists are viewed as a reliable source of information whatever their relationship with the patient.

• In addition to providing information for healthcare providers, EHRs should be accessible to patients and designed to help them navigate medication decision-making with their interprofessional care teams.

# Background

A good relationship between patients and their healthcare providers (HCPs) is essential for patient well-being. In the modern healthcare system, multi-setting electronic health records (EHRs), which refers to a digital version of a patients paper chart, available to authorized users, across multiple sites have emerged as a powerful tool to improve communication between HCPs and patients. <sup>1,2</sup> Nevertheless, the challenge across North America has been to incorporate EHRs in patient-centered care at all touch points, including visits with the physician, pharmacist, and emergent care. There has been increasing evidence that EHRs can successfully improve care coordination by improving communication and collaboration among HCPs. <sup>3,4</sup> However, it is still unknown how this can translate into both improved communication and collaboration among HCPs and improved communication and collaboration between HCPs teams and patients and their caregivers-families. While there is a strong awareness of what patient-centered care is, there is no standard approach to patient-centered communication and how EHRs can support it. <sup>5,6</sup>

One patient-centered communication approach for medication decisions is shared decision-making (SDM). SDM is defined as "an interpersonal, interdependent process in which the health care provider and the patient relate to and influence each other as they collaborate in making decisions about the patient's health care." While SDM supports patient-centered care, there is limited understanding of how to adapt EHRs to support SDM.

Pharmacist involvement in SDM falls under the auspices of interprofessional shared decision-making (IP-SDM)—an expansion of the physician-patient decision-making dyad. In IP-SDM, multiple HCPs and the patient contribute to the shared decision. 8–10 IP-SDM is particularly complex when it involves pharmacists, who are not typically colocated with physicians and are thus perceived to be outside the immediate circle of care. 11 Electronic health records (EHRs) have the potential to provide a platform for improved communications and understanding between HCPs and patients, emphasizing the importance of information continuity in primary care, and ultimately facilitating IP-SDM related to medications or treatments. 1,2,12 To accomplish this, EHRs must evolve from being a resource for HCPs to one that supports all members of the decision-making team.

At present, research suggests that patients typically rely on the expertise of one trusted HCP to make important decisions, especially when the situation is emergent or ambiguous (e.g., having surgery or starting a new medication). <sup>13,14</sup> For individuals living with chronic illness, those decisions are spread across multiple HCPs and time and are complicated by frequent diagnostic and monitoring tests, and complex treatment regimens. <sup>15–17</sup> Thus, to design EHRs that can help patients navigate the spectrum of complex care decisions, we must have a clear understanding of the types of relationships patients have with different HCPs, and the types of information both patients and HCPs need to share decisions.

# **Objectives**

Patients who have difficulty managing their care experience more preventable illness and suffering, suboptimal outcomes and can be more reluctant to participate actively in their care decisions. <sup>18,19</sup> There is potential for both EHRs and IP-SDM to support patients, and medications can serve as an exemplar of that potential. <sup>20</sup> Therefore we sought to describe patient perspectives on how people make medication decisions, what information is needed and desired by whom, and the ways EHRs can support patients in sharing medication decisions with HCPs.

# Methods

## Research Design

We used a qualitative approach that included a short demographic survey, a one-hour semi-structured interview and photographic field notes recording how participants currently organize their health information.<sup>21</sup> This project was part of a larger mixed methods study to analyze the state of IP-SDM and EHRs among patients, primary care clinics, and pharmacies.<sup>22</sup> This research received ethics approvals from the University of Waterloo, the University of Alberta, Wilfrid Laurier University, Université Laval, the University of Toronto, and Dalhousie University.

Recruitment & Participants

Participants were recruited from four Canadian provinces: Alberta, Ontario, Quebec, and Nova Scotia. We recruited a purposive sample of patients who were over age 18 and lived with at least one chronic illness. Participants were excluded if they were unable to speak English or French or unable to provide consent. We recruited through community-based advertising posters, online promotion in social media, and snowball sampling. Local and regional patient support groups were contacted to invite their members to participate.

#### Data Collection

Semi-structured 60 minute, in-person interviews were conducted and audio recorded by four trained members of the research team then transcribed verbatim. Interviews occurred where the participant felt most comfortable including their home, local university, or at another location of the participants choosing. All members conducted interviews in Ontario (KM, KG, JB, KW), with one research assistant conducting interviews in Nova Scotia (JB) and one research assistant conducting interviews in Quebec and Alberta (KW). French interviews were conducted by a bilingual member of the research team (KW) using a French version of the interview guide and were professionally translated.

The core research team (KM, KG, CB, LG) developed the interview protocol using a reflective case study by Dogba et.al. on the emerging paradigm of IP-SDM.<sup>10</sup> The

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<sup>&</sup>lt;sup>1</sup> Alberta & Nova Scotia HCPs had access to EHRs at the time of the study. In Ontario, HCPs in some health regions were beginning to gain access to the EHR.

interview protocol included open-ended questions and probes to help elaborate or clarify participants' answers as necessary.

Interviews gathered information on three areas (Appendix 1): (1) how participants make decisions about medications (e.g. "What is the most important thing on your mind when you're making the choice to take, or to not take that medication"), (2) how decisions are made with different professions (IP-SDM) (e.g. "Have you ever disagreed with your doctor about a suggested treatment?), and (3) participant understanding and perceptions of EHRs (e.g. Have you heard of electronic health records?). We recognized that most participants would have little to no familiarity with IP-SDM, so the interview protocol was designed to ask about elements of IP-SDM. The interviews focused on patient perceptions of how they communicate and interact with HCPs involved in their care, from the initial interaction through to diagnosis and medication prescribing, dispensing and refilling. Participants were asked to discuss their knowledge of health records and what potential they envision for EHRs. Field notes were taken during and after the interview to record the environment, external influencers, distractions, and photographs of how the medications were stored. <sup>23,24</sup> Participant data were anonymized in the transcripts.

#### Data Analysis

Data were stored and organized using NVIVO 11 software and analyzed using emergent coding.<sup>25</sup> Following qualitative research guidelines, we used triangulation of data rather

than inter-rater reliability."<sup>21</sup> Analysis involved the entire multidisciplinary team, including engineers, clinicians, health researchers, business and communication researchers, patients, and a patient navigator. A modified version of the *Multidisciplinary Framework Method* was used <sup>26</sup> according to the following process: (1) interviews were transcribed verbatim; (2) the core research team read interview transcripts and listened to the recordings; (3) Two team members (KM, KW) initially thematically coded the data; (4) Together the research team (KM, KW, KG, CB, LG, JM, LG, FL, AM, JC, MD, LD) thematically coded two patient interviews which allowed us to expand the coding framework to include a multidisciplinary, patient engaged perspective; (5) These team codes were used to develop a working analytic framework; (6) two team members recoded all data including patient interviews (KM, KW); (7) the coded data was returned to the team for discussion and refinement. Any disagreements were resolved through discussion. Collected field notes were not included in the thematic analysis, however, we did use field-note photographs to refine the themes and offer examples.

# Results

We conducted semi-structured interviews with 30 participants between 30 and 85 years of age (mean, 61 years), and 73% were women (**Table 1**). Participants had received a diagnosis of at least one chronic illness, including osteoporosis, hypertension, Crohn's disease, and cancer. We identified forty participants, with seven being lost to follow-up and three withdrawals due to changes in illness status, resulting in 30 interviews. None currently or had previously worked in the healthcare system. Participants managed an

average of four prescriptions (range: 2-13). Over the previous three months, participants averaged two visits to their family physician, three visits to a pharmacist, and two visits to a specialist.

#### **Table 1: Participant Demographics**

Using multidisciplinary coding, the codes were arranged into four main themes: (1)

Complexity of patient decision-making: who, where, what, when, why; (2) Relationships

with physicians and pharmacists: Who do I trust for what?; (3) Accessing health

information for decision-making: How much and from where?; (4) Patients' ways of

managing information for health decision-making. (Table 2). Ideas about EHRs and IP
SDM cross through all four themes.

## Table 2. Themes related to how patients make medication related decisions.

Complexity of patient decision-making: who, where, what, when, why

The context in which a person arrives at a decision is impacted by the type of health decision they are making (e.g., emergent or ongoing), past experiences whether positive or negative, external (e.g., HCP, friend) and internal (e.g., family values, past experiences) influencers, and information patients can access (e.g., patient portals, HCP, personal documentation, online).

"During an appointment [with my family physician] it's really hard [to decide about a medication]. I need time to think about it so I talk to my pharmacist, I go on the internet, I talk to friends, and I really check it out before I make a decision. I trust my doctor, but I still want to know more about the drug" Female, 77, 1016

Previous experience with complications from treatments or errors in medications, even if a single instance, shapes how participants approach decision-making. These lived experiences did not have to pertain to the same medication, treatment, or decision process to influence the context in which participants make future decisions.

"For my complaint I had to order my own chart, and I was shocked to death. I found oh, three or four other errors. I lost trust in the system. I have to go be going by something life threatening or I won't go to a hospital, period." Male, 54, 1021

Participants noted that they negotiate interactions with their various HCPs differently and were influenced by HCPs, family, and peers in different ways depending on the acuity of the health issue. In crisis situations, participants expressed a desire for an expert (i.e., an oncologist for a new cancer diagnosis) to define treatment decisions and to not overwhelm them with too much information. In these cases, participants describe a

mentality of immediate survival, rather than wanting to gather more information and discuss options.

"It was mostly [the doctors] giving me information because when you are first diagnosed [with cancer], you are just blown away and you just want to start and do something and they are mainly giving me information and telling me how it's going to go." Female, 57, 1004

Despite an initial preference for an HCP to make a decision in an acute situation, as time passed and the health situation changed to chronic, participants shift their preference to start gathering information from other sources.

"[Understanding medications post heart attack is] a learning process. I think any patient has to have a certain trust in the professionals. As the month's pass, you say, well wait a second now, is this necessary? Is there a supplement, a natural blood thinner that you could take rather than say, the rat poison they give you?" Male, 70, 1013

For chronic conditions, participants rarely describe having made a decision about their health in one location or at one time. While participants had little experience with EHRs, they envisioned EHRs would help them make decisions by providing access to their

health information, an understanding of why their physicians make recommendations, and improved information flow between HCPs.

"I'd like to see the data. For example, at least once a year, my annual, I'll go off and do blood work. All of the data that comes from that I'd love to see because I think it would help inform how I behave or how I think about myself." Male, 63, 1030

Relationships with Physicians and Pharmacists: Who do I trust for what?

We observed that participant perceptions about how they interact with their HCPs significantly influenced their engagement in the decision-making processes. This includes how they describe how they negotiate the responsibility for making medication related decisions with their HCP, and the type of relationships the patients' have with the physician and/or pharmacist.

Participants aligned feeling comfortable with their family physician with the quality of care they received.

"[With my family physician] generally it is the comfort from the initial meeting. If you are able to talk to each other and then they express a good competency of everything going on, then I make that good connection."

Male, 54, 1021

When participants discussed what they like about their physician, and what made them trust the physician, they most often brought up how a physician learned about them, their family, and their values. Participants who perceived a physician's lack of caring also had lower levels of trust with that physician.

"[My family physician] never asks about me. Never. You know, what was your job? How are you coping with the death of your husband? He had my husband as a patient too. What about your children? Nothing. He never asks me anything. As someone looking after my medication I trust him, but not as someone looking out for me" Female, 77, 1016

Participants perceived that pharmacists influence decision-making in a way that was different from family physicians. For example, several participants reported having more trust in their pharmacist's knowledge of drug information than in their physician's knowledge. None of the participants felt it was necessary to have a relationship with a pharmacist to be able to access the pharmacists' knowledge.

"Pharmacists I tend to trust more than the doctor, as far as pills go. Now as far as giving me something for the

heart attack, they're pretty well locked into [the prescription] ... Compared to my family physician, I would far more trust a pharmacist being aware of what drugs interact with what drugs." Male, 70, 1013

Most participants were not aware of any relationship between their pharmacist and their family physician. From the participant's perspective, the only connection between the physician and the pharmacist is the patient and the prescription.

"As individuals, I don't think the pharmacist and doctor interact. What I have noticed with my doctor is, years ago, you would go into the office, they'd write out the prescription, they'd hand it to you. You had the responsibility of taking it to the pharmacist to fill it. That's the only connection I truthfully see between the pharmacist and the doctor." Female, 63, 1005.

Accessing health information for decision-making: How much and from where?

Participants consistently reported that gathering information from others who had been through a similar experience helped to alleviate stress. Participants who were part of a cancer support group spoke at length about how they actively sought information about treatment and other options from their cancer support group, as did another who participated in a support group for people living with fibromyalgia.

"I have some friends who are very interested in health.

Some who are very interested in alternative medicine. I talk to them about my problem and come up with a decision that is based speaking to them, my physician, and online information. For better or worse." Female, 69, 1006

By comparison, another participant only wanted to know minimal information. Later, he discussed how he only spoke to his physician to get information.

"I like the basic information and any potential side effects or harm that might cause or drug interactions. Other than that it gets almost confusing and complicated" Male, 54, 1021

Participants expressed concern about how health information in an EHR, was interpreted by other patients. Although most participants expressed confidence in their own ability to understand health information, they were also concerned that *other* patients would be overwhelmed or not understand how to interpret health information.

"I think if we're going to give access to patients, we have to educate them. They have to know what they're looking for.

Normal is simple, what do we do with abnormal? There has to be a lot of education around it." Female, 42, 1017

While many of the participants stated they had heard of EHRs, the difference between EHRs and EMRs was not well understood.

"All [my oncologist] had to do was put in an access number, go online and she had my whole history of tests and results and everything and whatever. I think I would like to have that access. If doctors know about it, why on earth shouldn't we, as the patients, get to know about it?" Female, Female, 74, 1003

All of the participants interviewed identified a desire for an easier way to access health information, for both themselves and their HCPs. When prompted, participants thought EHRs had great potential.

Patient's methods of managing information for health decision-making

Participants have diverse experiences of receiving information, searching for additional information, and understanding their HCPs opinions about what information was valued. Participants want information because, in most cases, they did not feel like an expert, and found it difficult to be confident in making correct decisions. As a way of coping with

overwhelming information and concerns about incomplete health records, many participants developed independent ways of organizing their health information.

"I have my own copies of everything. When I went to my breast cancer oncologist for the first time, I made a summary of all of my treatment, so that she could see exactly what I've been through. If I'm doing it myself, I feel like I'm including all the important things that they need to know." Female, 57, 1007

How participants organize their health information changed depending on their priorities. One participant who had an emergent situation after a heart attack, spoke about keeping careful notes on their health interactions. Yet, during the home visit, all of their health and wellness objects (such as medications) randomly scattered in a drawer (Fig. 1). This speaks to the gaps in current tools available to assist patients and their caregivers with collection and management of health information. We keep isolated personal records of health interactions as there is no central, accessible digital record of care, and no reliable, affordable, universal system for managing in-home dispensing.

Figure 1: Medication Organization

Participants wanted access to EHRs to help transmit information among HCPs and to be aware of who had access to which information. In many examples, participants felt that transmission of health information between HCPs was delayed and that they were the one

responsible for communicating health information to ensure timely access. During the interviews, participants commonly describe a process of moving from the physician's office to a pharmacy to their home or another social location and discussing options with different people in these places. Participants describe an ideal world where the EHR would move information between HCPs.

"I would love to have access to my electronic health records because I know when I went to my osteoporosis specialist after I had cancer, I told her I had cancer. It was news to her and she wanted to find out what the results were." Female, 74, 1003

In our observations, patient-generated records included artifacts such as printouts of Wikipedia pages and medication information sheets from the pharmacy, typically organized into binders (Fig. 2), or written into notebooks, and often kept in a specific drawer or organized in an online file.

Figure 2: Health information binder

In many cases when we asked participants about what drugs they were taking, they showed us a printed list of medications from their pharmacist. Of note in provinces that had EHRs available to both the physician and pharmacist, participants still describe a lack of communication and understanding between their physicians and pharmacists. This list

only provides basic information about a prescription – the date dispensed, how many refills, and the drug name and dose. Patient-generated notations can be problematic, as illustrated by Fig. 3 where a participant highlighted Tecta (a proton pump inhibitor for stomach acid) as medication for cholesterol, and hydromorphone (an opioid with some antitussive properties) as a treatment for phlegm.

Figure 3: Pharmacy print out of medication list

#### Discussion

We examined patient perspectives on how they make medication decisions, what information is needed and desired, and the ways EHRs might support patients in shared medication decision-makings with HCPs. During the interviews, it became clear that even when participants were in a location that had EHRs, they did not have personal experiences with using or interacting with an EHR. This paper draws on participant perspectives on medication decision-making to provide insight into what should be included in the design of future EHRs so they and useful for SDM.

We observed that medication decisions are complex and that, from the patients' perspective, the decisions often occur without a formal connection between the physician and pharmacist. There are also two aspects to decision-making: (1) type of decision being made, and (2) sources of information. The decisions being made can range from 'do I take a medication?' to 'who do I listen to?' Our results show the potential that exploring

including a platform for aggregating health information from traditional and non-traditional sources and thusly fostering a patient's ability to work with different HCPs, EHRs can be used to foster IP-SDM.<sup>27</sup> This study identifies 1) what information patients are missing and (2) how EHRs could be designed as a mode of delivery for SDM tools and thusly improving patient information access.

Research is emerging on how to best incorporate IP-SDM into EHRs.<sup>27–30</sup> If information access is grounded in a single shared EHR, all who are involved in decision-making have a common platform to share information in a meaningful way. Lenert *et al.* have developed a model to incorporate SDM into EHRs.<sup>28</sup> The model emphasizes that EHRs need to accommodate the preferences and communication styles of patients and HCPs as they relate to IP-SDM.<sup>29</sup> However, this model needs to expand to include other HCPs, especially for patients who have less capacity to use the information in an EHR.

When making a decision, the amount of information that our patient participants wanted varied based on the nature of the situation -emergent or chronic. Our research expands on the idea that patients are more involved in SDM when they are offered a choice rather than a recommendation. We also identified that patients can shift between preferring different decision styles depending on the circumstances. For example, participants who were in emergency health situations mentioned wanting to be told what to do. By comparison, once participants had lived with a chronic illness, they preferred to lead or share in decision-making rather than to receiving a recommendation. As such, the

usefulness of an EHR for patients will likely also change over the course of an illness as well.

Participants show diverse ways of organizing their health information independently of formal medical records. The concept of a patient maintained 'shadow records' highlights three aspects of how people use, organize, and create health information. First, it shows that the participants' desire to have access to their own records motivates them to create their own information management systems. Second, there is a lack of awareness of how they can share this information with their HCPs. Third patients believe that information which may be valuable in decision-making is missing from their formal health record. Patient portals and personal health records have helped patients see what information their HCPs have access to, and what is missing from their record.<sup>32,33</sup>

Relationships are also an important component of IP-SDM.<sup>34</sup> Similar to other studies, we found that patients deeply value the relationship they have with their primary care physician but did find they may not see value in a comparable relationship with their pharmacist.<sup>35</sup> Furthermore, it was clear that participants were aware that their pharmacist and physician did not work together as a team. Thus, future EHR design needs to consider how to convey the role each HCP has played in a patient decision to start or modify treatment. By increasing transparency and providing a platform, EHRs have the potential to improve access to information for patients and HCPs.<sup>36,37</sup> Understanding the complexities of the IP-SDM process shows the potential for to support patients in sharing medication related decisions.

The main limitation of this study is that the national focus required the use of multiple interviewers. Despite training to ensure consistent approaches to participant interviews, unintended variance in interview style may have influenced participant response data. Further, the interviews were conducted prior to the launch of patient access to EHRs in two of the four provinces included in this study. As such, most interviewees did not have personal experience with an EHR. Those who were aware of EHRs, or identified as having used an EHR did not have substantial experiences interacting with them and were not aware of the full potential or purpose of them. This also meant that participants were not constrained by preconceptions of what an EHR looks like, leading many to describe a vision of an EHRs that was more consistent with their needs and desires. Finally, as with any qualitative study, the results should not be considered to be generalizable to all patients in all situations. Rather, the strength of our methodological approach was that it aimed to gather the perspectives of a diverse group of patients and to analyze the data with a multidisciplinary team. As such, our research provides insight into the design of EHRs that can support patients, physicians, and pharmacists in making complex decisions about medications.

#### Conclusion

We found that patients make decisions both with their HCPs and outside the healthcare setting with family and friends. We also identified that pharmacists and physicians have different roles in helping patients make decisions about medications. EHRs have the potential to facilitate clear communication, foster inter-professional understanding, and

improve patient access to their health information. EHR designers need to account for these different types of users.

Further qualitative research to understand the roles of other allied HCPs and caregivers.

Future research examining how to develop EHRs that are adaptive to user needs and desires and that lower barriers to SDM can provide context for medication decision-making.

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