Designing Health Interface Technologies to Support Patient Work

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2021

UNIVERSITY OF CALIFORNIA,
IRVINE

Designing Health Interface Technologies to Support Patient Work

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Informatics

by

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2021

DEDICATION

To my favorite partners in adventure, both every day and extraordinary, Katlego and Leo.
And to Terry, Diane, Abby, Kip, Nate, Lila, and Logan for their unwavering patience,
support, and love.

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ACKNOWLEDGEMENTS

Words cannot express how grateful I am to the many people who have been instrumental to my doctoral journey. First and foremost, to my advisor, Dr. Kai Zheng, for the thoughtful guidance and support provided across geographic locations and major life milestones. I have appreciated your time, kindness, patience, travel advice, etc. more than you can know. I am a better researcher and person for knowing you.

Thank you to the rest of my dissertation committee Drs. Yunan Chen and Scott Rudkin. Your feedback, advice, and support have been invaluable and meant so much to me. I am constantly inspired by both of you.

I am also grateful to all of my other collaborators for their various contributions to this work, including to designing, actually conducting the research, and providing insightful feedback on drafts of the manuscripts: Dr. V.G. Vinod Vydiswaran, Dr. Qiaozhu Mei, Dr. David A. Hanauer, Yuting Wu, Meghna Kaligotla,* Nida Ali,* Emma McGregor,* Trish O'Brien,* Dr. Christopher Longhurst, Dr. Andrew L. Rosenberg, and Jiawen Zhang.* It has been an absolute honor working with all of you. I'd especially like to acknowledge those marked with asterisks – the amazing undergraduate students with whom I have had the pleasure of working and without whom this dissertation would not be possible.

Thank you to Dr. Melissa Mazmanian for her feedback on parts of this dissertation, as well as her encouragement during a difficult time.

To HAI Lab, I love being a part of this group – you are all amazing.

I am forever grateful to my family, especially Katlego Mantu, for their support throughout this journey; I would not be here without it.

Thank you to the institutions that have supported this research: U.S. National Center for Research Resources and the National Center for Advancing Translational Sciences, NIH; U.S. Department of Education; and UCI Donald Bren School of Information & Computer Sciences.

Parts of this dissertation research have been published in AMIA Annual Symposium Proceedings and are included here with permission.

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ABSTRACT OF THE DISSERTATION

Designing Health Interface Technologies to Support Patient Work
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Health interface technologies enable digital data, information, and knowledge sharing to support the independent and collaborative health work of different entities (e.g., patients, healthcare providers, public health professionals). As healthcare has shifted towards a patient-centered approach, this class of technologies, which includes patient portals, is increasingly being used to facilitate patient participation in their care and patient-provider collaboration. Research suggests that using these technologies may have many positive effects such as increased patient engagement and improved health outcomes.

Unfortunately, despite the potential benefits, adoption and use of these technologies are often lower than expected. One of the primary barriers is that while the typical designs support certain aspects of patients' and providers' individual and collaborative work, it often does not support other important facets. This is especially true for patient-facing technologies such as patient portals and Apple Health Records. In addition, the lack of a clear definition of health interface technologies has resulted in a disconnected evidence base across numerous disciplines, including health informatics and human-computer interaction.

Given the significant investments made in these technologies, and their tremendous but underachieved potential, there is an imperative need for multi-disciplinary study of health interface technologies using human-centered approaches. My multi-method dissertation research addresses these needs by deriving insights from four studies focused on empowering patients through electronic access to their medical records. Study 1 is a systematic review of patient and caregiver suggestions for improving patient portals, which provide patients with electronic access to portions of their medical record. Study 2 investigates the extent to which recent U.S. Policy is currently benefiting patients through a review of the smartphone health application (app) landscape, with a particular focus on apps capable of automatically downloading medical records via a standards-based application programming interface. Studies 3 and 4 explore patient's interaction with their medical records, specifically laboratory test results, through a unique perspective – patient questions containing these data posted to an online health community – to understand how the design of technologies can be improved to better support patients as they view their medical records. Based on the results of these studies, I discuss implications for the design of health interface technologies to support patient work.

CHAPTER 1. INTRODUCTION

Worldwide, there are numerous ongoing and emerging challenges in health and healthcare. For example, more and more people are living with chronic conditions that require long-term care and management. In addition, the corona virus disease 2019 (COVID-19) pandemic has created new challenges for chronic disease management, as well as for acute care. Research suggests that collaboration across boundaries, especially across expertise, may be critical to addressing such challenges. A prominent example of this is patient-provider collaboration.

In 2000, the Institute of Medicine released the report, *To Err Is Human*, which became an impetus for action by exposing the shocking safety issues in the United States (U.S.) healthcare system (e.g., medication errors such as incorrect dosage administered).[1] Similar issues have also been identified in countries around the world.[e.g.,2,3] To address patient safety concerns, as well as to improve health outcomes and reduce costs, healthcare organizations have been shifting their focus to patients' needs, values, and preferences.[4–6] There is strong evidence suggesting that this patient-centered care approach has a number of benefits, including improved patient knowledge, accuracy of expectations, and concordance between values and choice.[7] However, realizing the benefits of the patient-centered approach relies upon the willingness of both patients and healthcare providers to collaborate.[5]

There are unique issues inherent to cultivating and maintaining such collaborative relationships. For instance, although the collaborators have a shared goal (e.g., maintaining a patient's health), they may have somewhat different expectations or priorities (e.g., a patient may need to temporarily prioritize managing a personal financial crisis over their health).[8] The collaborators may also have independent goals and work that depend upon the collaborative work, but that are not directly aligned (e.g., billing-related). In addition, the disparities in knowledge between healthcare providers and patients, traditional patient-provider roles, and the resulting power dynamics that usually favor the professional, can all make it difficult for patients to participate in their healthcare.[e.g.,9,10] Furthermore, factors such as time constraints, healthcare provider attitudes, and policies that inadvertently disincentivize collaboration with patients have been identified as barriers for providers.[e.g.,8,11] Such challenges must be addressed in order for these collaborations to be successful and for the shared goal, as well as larger societal goals, to be achieved.

Increasingly, technologies are being designed and used to facilitate such collaborations. I refer to these as *health interface technologies*, which enable digital data, information, and knowledge sharing to support the independent and collaborative health work of different entities, such as patients, healthcare providers, public health professionals. In my dissertation research, I particularly focus on patient-facing health interface technologies that facilitate patients'[*] electronic access to their own medical records, use of the clinical data

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[*] Throughout this document, I often refer to people as patients. This is because clinical data are generated through interactions with the formal healthcare system, and having clinical data usually means you are receiving care from one or more healthcare providers.

(e.g., clinician's notes, laboratory results) contained in that record, or both. This type of health interface technology offers some level of support both for (i) patients' individual work (e.g., health information management) and (ii) their collaborative work (e.g., shared decision making[11]). For instance, patient portals – a web- and smartphone-based technology linked to a healthcare organization's electronic health record (EHR) system – have become widely available and are designed to facilitate patients' active participation in their healthcare by reducing the patient work required to access their medical records. In addition, beyond access, health interface technologies such as patient portals may also offer additional features for collaboration (e.g., secure email). Overall, the extant literature suggests that using this type of health interface technology could have many positive effects, including improved data quality of medical records,[12] increased patient engagement,[13–15] improved health outcomes (e.g., blood pressure and hemoglobin A1c control[16]), and reduced healthcare costs.[16,17]

A number of factors, including evidence of benefits and cultural changes in healthcare, as well as subsequent policy provisions that incentivized adoption, have resulted in a rapid increase in the availability of these patient-facing health interface technologies. For instance, initiatives like the Open Notes movement, which has encouraged healthcare organizations to offer patients electronic access to clinicians' notes,[18] and philosophies like "nothing about me without me"[19] have contributed to the trend towards providing patients with increased access to their own medical records. In addition, studies have found that a growing number of patients *want* electronic access to their clinical data[e.g.,20] and to be more involved in healthcare decisions.[21–24] Such evidence has led countries around the world to invest in strengthening their health information technology infrastructures to facilitate the practice of patient-centered care, including through patient engagement efforts.[9,25]

Two U.S. health information technology-related Policies offer prominent examples. First, the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act through which the United States invested over $35 billion to encourage the adoption and meaningful use of EHR systems.[26,27] Meaningful use was defined through the "Meaningful Use criteria," which included objectives such as "Improve quality, safety, efficiency, and reduce health disparities" and "Engage patients and family."[28] This legislation is a major reason for the widespread adoption of EHR systems in the U.S.[29,30] It has also led to healthcare organizations offering patient portals, as these were promoted as one of the primary tools to achieve objectives focused on electronically sharing personal health information with patients.[31,32] Second, as a part of efforts to address the persistent problem of a lack of interoperability between healthcare organization information systems, more recent legislation has gone even further to ensure greater patient access to their clinical data. The 2016 21st Century Cures Act prohibits information blocking – any practice that "is likely to interfere with, prevent, or materially discourage access, exchange, or use of electronic health information" – and requires certified EHR systems to enable standardized application programming interfaces (APIs) that can be used to drive the flow of clinical data to patients and feed an ecosystem of patient-oriented health applications (apps).[33]

Unfortunately, despite their potential benefits, and the increased availability, research has generally found low adoption among patients and has identified persistent challenges to using these technologies to facilitate patient-centered care in practice. One of the primary barriers is that while the typical designs support certain aspects of patients' and providers' individual and collaborative work, it often does not support other important facets. For instance, the extant literature suggests that many patients have reported a *lack of useful information despite the abundance of data* when viewing their medical records. More specifically, studies have found that many patients' needs are not just for accessing the data, but for obtaining personalized and actionable knowledge about their health and medical conditions.[e.g.,34,35] Such misalignments in patients' needs and what is provided through the technology can actually result in increased burden for the patient, their provider, or both; limit the extent to which these technologies are used; and, ultimately, limit their effectiveness. Such design issues are likely due, in part, to the lack of a clear definition of health interface technologies. This has resulted in a disconnected and siloed evidence base across numerous disciplines, including informatics, health communication, computer-supported cooperative work (CSCW), human-computer interaction (HCI), and computer science.

In the next sub-section, I will introduce the concept of health interface technologies in more depth, including the process for developing a working definition to unite the siloed evidence bases across disciplines and key concepts such as patient work and boundary objects that are essential to understanding this class of technologies. I will then discuss examples of the currently underwhelming levels of patient adoption and use of health interface technologies, as well as existing evidence of barriers, which motivates my dissertation research. Finally, I will end this introductory chapter by presenting an overview of my research.

1.1. Health Interface Technologies

1.1.1. Defining Health Interface Technologies

The working definition of health interface technologies is: technologies that enable digital data, information, and knowledge sharing to support the independent and collaborative health work of different entities (e.g., patients, healthcare providers, public health professionals). I developed this definition iteratively by reviewing existing descriptions from the extant literature, identifying and analyzing potential examples, and reviewing relevant research for cross-cutting characteristics and themes.

Existing Descriptions

Existing literature depicts a variety of health interfaces such as public health-healthcare and physical health-mental health interfaces.[36–39] In this view, a health interface refers to points of interaction between groups with different expertise collaborating to achieve certain goals. Take the example of public health institutions and healthcare, which includes healthcare organizations and entities like health insurance plans.[37,38] These groups may interface through partnerships and shared activities such as providing care for marginalized populations (e.g., for services such as family planning), disease surveillance (e.g., state- or federally-mandated reportable diseases), and community outreach (e.g., campaigns to improve cancer screening).[37] Central to these interactions, as well as interactions between other health entities such as patients and providers, is the exchange of data, information, and knowledge.[37] In today's world, this is usually mediated by technologies.

Despite the important role that technologies are playing in these interfaces, there are few descriptions of their unique characteristics, benefits, and challenges. An exception to this is a 2018 conference track, which described "health technologies that interface patients and providers" as "a class of health technologies that serve as an interface between patients and their medical providers. These technologies not only help patients gain easier access to their own medical records, but also help providers obtain patient-generated data as well as extend their care services to patient homes."[40] This description, along with specific examples in this space such as displays showing healthcare professionals self-tracked data for the purposes of diabetes remote monitoring,[41] considers technologies as a point of connection between the two collaborating groups, with the connection facilitating the flow of data in at least one direction (e.g., patient to provider or provider to patient). This also aligns with the use of the broader definition of the term "interface" in computing, as a "shared boundary" across which software, hardware, devices, or humans exchange data and information.[42]

Although these descriptions provide an important foundation, it is insufficient to capture the multitude of health interfaces in which this class of technologies exist and falls short of offering a clear definition. Thus, in the next two sub-sections I first explore several examples and then articulate the key concepts underlying health interface technologies.

Potential Examples of Health Interface Technologies

To articulate a working definition of health interface technologies, I examined potential examples, including any available literature, that connect different types of stakeholders. Figure 1.1 highlights just a few of these examples representing a range of technologies used for sharing data, information, and knowledge between different health entities, including research environments for securely sharing clinical data with researchers; mobile applications such as MyDataHelps[43] that enable individuals to join health research studies and to donate their health and clinical data to researchers; a public health dashboard that filters social media posts of public health interest, such as those with indicators of foodborne illness,[44] and enables a public health professional to follow-up with the social media user; and an interface for sharing the clinical data necessary for public health work.[45] However, here, I focus specifically on technologies that connect patients and healthcare providers. I will present three types of health interface technologies in this context in more detail, technologies that facilitate sharing (1) electronic clinical data with patients (e.g., patient portals) and (2) patient-generated data with healthcare providers, as well as (3) standalone digital healthcare platforms, which enable completely virtual patient-provider interactions without being linked to a traditional healthcare organization model.

<u>Technologies that facilitate sharing electronic clinical data with patients</u>: As mentioned above, many healthcare organizations are providing patients with electronic access to the clinical data generated during, or in conjunction with, healthcare interactions (e.g., clinicians' notes). In fact, a 2019 survey reported that 76% of primary care physicians offer patients

online access to at least some of their clinical data.[46] The most common mechanism for sharing these data is currently patient portals; however, more and more healthcare organizations are partnering with developers of mobile interconnected personal health record apps to offer patients the opportunity to download their clinical data onto their smartphone via standards-based APIs.

An interconnected PHR (iPHR) is a web- or app-based technology "through which patients can maintain and manage their health information (and that of others for whom they are authorized) [from multiple healthcare organizations] in a private, secure, and confidential environment."[47] Although commercial companies such as Google have made unsuccessful attempts to form partnerships with a large number of healthcare organizations to realize the idea of iPHRs in the past, recent technological and Policy advancements have made this more feasible.[48] At the time of writing, Apple Health Records, a mobile iPHR (miPHR), has partnered with 688 healthcare organizations across the U.S. to leverage standardized application programming interfaces (APIs), which certified EHRs must offer per the 21st Century Cures Act,[33] to enable Apple users to download their medical records into the Apple Health app on their iPhone.[49] They have also partnered with six Canadian and two U.K.-based healthcare organizations to offer this service outside of the U.S.[49] This offers new opportunities for patient-accessible electronic medical records, including integrating clinical data from multiple healthcare organizations, viewing medical record data side-by-side with patient-generated data such as from fitness tracking, and enabling other health apps to access the computable medical records to improve their functioning (e.g., automatically importing prescription data into a medication management app). It is not just Apple either. An Android-based app called CommonHealth has been developed for a similar purpose and is making progress in gaining healthcare organization partners; for example, recently announcing that the Veterans Affairs will be offering its patients the option to download their records to this app.[50]

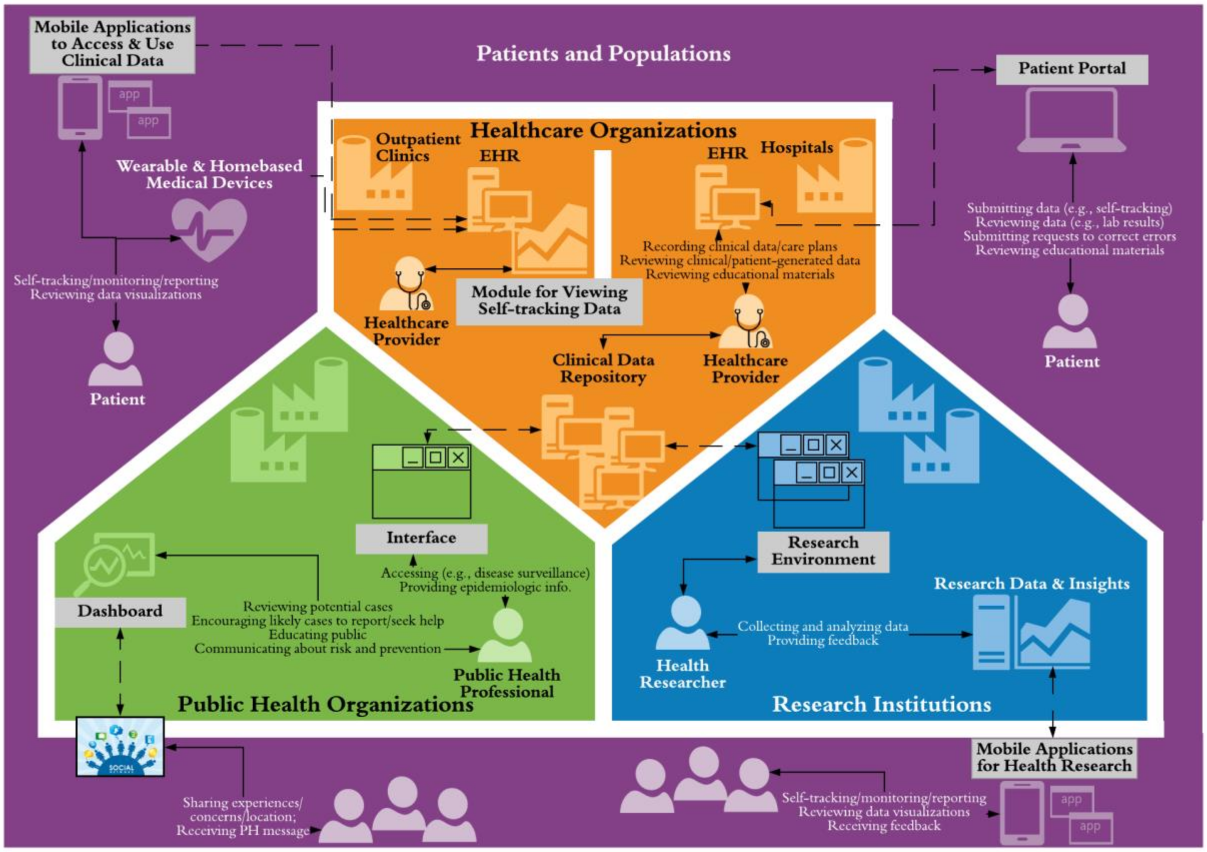

Figure 1.1. Example health interface technologies (highlighted with gray boxes). Dashed lines represent connections between technologies.

Although miPHRs are currently limited to unidirectional flow of clinical data, some healthcare organizations' patient portals enable patients to contribute to their medical record in several ways, including (i) electronically requesting a record amendment if a mistake is identified;[12] (ii) submitting secure messages which healthcare providers may then attach to the patient's medical record;[51] (iii) contributing to clinicians' notes;[52] and (iv) submitting patient-generated data through structured forms (e.g., vaccination history) or other means such as uploading the fitness data automatically collected by commercially available devices (e.g., fitbit™).[53] In other words, patient portals support core components of patient-provider collaborative work, including data and information exchange, *and* also reduce the patient work required to access and contribute to their own medical records. Research suggests that this has many benefits such as improved quality of the records,[12] patient-provider communication,[54,55] and adherence to provider recommendations.[55] Furthermore, there is evidence that this access may increase patient engagement[15,56,57] which, in turn, has been associated with improved health outcomes (e.g., blood pressure and hemoglobin A1c control) and reduced healthcare costs.[16,17]

However, despite the potential benefits of using these technologies to facilitate patient participation and patient-provider collaboration, they have tended to be underutilized by patients. Detailed adoption and use rates are presented in Section 1.2 but, briefly, a 2020 nationally representative survey found that only about 39.5% of U.S. adults had accessed their "personal health information online through a secure website or app" in the last year,[58] and miPHR adoption appears to be far lower.[59] Studies have also consistently found that populations with existing health disparities (e.g., based on race and ethnicity) are even less likely to utilize patient portals (disparities in miPHR uptake and use have yet to be explored).[60,61]

I present a detailed overview of the literature on factors affecting patient adoption and use of these technologies in Section 1.3. However, one of the primary barriers is that while the typical designs support certain types of patient work (e.g., clinical data access), they do not support other important aspects. For instance, the pervasive designs of these technologies often do not fully meet patients' needs, especially for personalized recommendations (e.g., next steps after receiving an abnormal laboratory test result)[e.g.,34,35,62] and patient decision support.[e.g.,35,63] Research also indicates that health information needs and capacities differ throughout the disease cycles and trajectories of patients with chronic conditions,[64–66] but the designs of this type of health interface technology often do not support patient learning over time. Instead, the information provided tends to be simple, early-stage information most appropriate for those newly diagnosed (e.g., brief definition of problem on problem list).[e.g.,62] In addition, data tend to be presented to patients in a similar way as it is presented to healthcare providers, even though research consistently shows that patients experience difficulties understanding it, especially medical jargon[e.g.,67,68] and laboratory test results.[e.g.,69] It then usually becomes the patient's responsibility to address gaps, often leading to information work (e.g., information seeking),[66] with many patients going online to try to meet their health information needs – both general (e.g., decoding a medical acronym) and individualized (e.g., what laboratory results *mean for them*).[70] According to a Pew Research Center survey, nearly three quarters of U.S. internet users reported looking online for health information.[70] However, existing research also suggests that while there may be benefits to using online sources of information to supplement traditional healthcare resources, such as ease of access[71] and increased patient participation in care,[72] there are also inherent challenges to this patient work, especially for the many patients with low health literacy.[†] These challenges can include finding information that satisfies their needs and that is of sufficient quality,[e.g.,74,75] as well as making sense of this information.[76,77]

Technologies that facilitate sharing patient-generated data with healthcare providers: While generally in a more nascent and exploratory stage of development and, thus, not as widely available, health interface technologies to facilitate clinically meaningful sharing of patient-generated data with healthcare providers are emerging. Examples include EHR modules for viewing patient self-tracked data[e.g.,41] and EHR modules or standalone platforms for monitoring patient-reported outcomes (PROs, such as quality of life metrics).[e.g.,78,79] This type of health interface technology is a response to the growing interest in identifying ways to capitalize on the 70% of U.S. adults who track one or more health indicators,[80] often utilizing mobile applications that enable individuals to electronically capture, review, and reflect upon health-related data (e.g., diet, exercise, symptoms, PROs). These data may be continuously, regularly, or sporadically collected outside of healthcare visits, may be structured or unstructured, and may be manually entered or automatically captured via a device. Of note, PROs are more likely to be structured, regularly collected, and specifically

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[†] "The capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[73]

defined by healthcare providers[78,79] compared to self-tracked data. Regardless, these devices and applications can reduce the amount of patient work required to collect and leverage these data, including for their own awareness, to identify trends in symptoms, and to support behavior change.[e.g.,81,82] In fact, this may explain why one study found that those using electronic tools, including mobile applications, were more likely to self-track routinely.[83]

There are thousands of these mobile applications available,[84,85] and they are increasingly being used to share patient-generated data with healthcare providers.[8,86] When these data are shared with providers such as by uploading to an EHR through a patient portal[87] patients and providers will often try to collaboratively review and make sense of the data.[e.g.,8] There are many potential benefits to such uses, including increased patient engagement in their healthcare and improved patient-provider communication.[e.g.,88,89] These data can also offer both patients and their healthcare providers a broader view of the patient's health than can be captured during clinical visits alone.

Unfortunately, because an overwhelming amount of data can be generated and, in the case of self-tracking data, they were not necessarily collected for clinical use, there are a number of barriers to provider use of these data, including lack of integration into EHRs, lack of organizational support, workflow disruption, and difficulty leveraging these data for clinical decision-making.[90] For instance, one study found that providers often felt overwhelmed by the self-tracking data and that patients' specific questions about their data frequently went unanswered.[8] Such barriers to use for providers can negatively affect the patient-provider interaction around these data and make collaboration more difficult.[e.g.,8]

For these reasons, there are significant opportunities for provider-facing health interface technologies to more effectively harness these data for clinical use. However, there is some existing evidence to suggest that, while health interface technologies may address some of the aforementioned issues, challenges may remain. For example, another study found that, even when providers were involved in the development of the PROs questionnaire and the data were integrated into the EHR, many providers were still hesitant to use these data in practice.[79] The authors hypothesize that this may be due to other factors cited in the literature such as being skeptical of the clinical value and perceived impact on workflow.[79,91,92]

Standalone digital healthcare platforms: There seems to be even less existing independent research (but some published internal research[e.g.,93]) on completely digital healthcare platforms – i.e., websites or smartphone apps that offer virtual access to medical professionals without necessarily being a patient of a traditional, physically located healthcare organization. For example, virtuwell is marketed as an online clinic where patients answer a series of structured questions for concerns such as acne, allergies, asthma, and certain infections (e.g., bladder).[94] The patient's responses are reviewed by a medical professional, who then prepares a care plan sending it directly to the patient and any prescriptions to the patient's preferred pharmacy. Although the care delivery mode may vary, questionnaire-based versus video chat, there are also a number of smartphone apps with a similar model such as Amwell, Carbon Health, and DrOnDemand.[95–97] Health insurance is accepted by these healthcare service providers, but even when it is not (or a patient does not have health insurance), the cost of a visit is usually considerably lower than some alternatives such as an urgent care visit.[93] There is some evidence to suggest that the care provided through these platforms is of sufficient quality.[e.g.,98]

These virtual platforms support the exchange of data, information, and knowledge that has traditionally taken place through in-person healthcare visits, and also reduce the effort required by patients to seek and receive care (e.g., finding a doctor). Some of these tools also enable patients to share self-tracking data and, rarely, clinical data to, as they broadly claim, improve the care provided. While some appear to be well received having over a million downloads and excellent patient ratings,[e.g.,99,100] others appear less popular.[101] It is currently unclear what factors drive success of this type of platform, provider perceptions of these technologies, and how this might affect established patient-provider relationships.

1.1.2. Key Terms and Concepts

Through the analysis of potential examples, several overarching concepts emerged as important to understanding and describing health interface technologies: participation and individual work, collaboration and collaborative work, and shared information objects. Again, here, I focus specifically on the patient-provider context.[‡] I also focus on patient participation and work, here and in this dissertation research as a whole, because patients often have more choice in whether they adopt a technology; the work that they do is often

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[‡] The broader concepts underlying health interface technologies (e.g., boundary objects) are seen across contexts.

burdensome[e.g.,102,103] and invisible and, thus, often not adequately supported in the design of technologies;[e.g.,34,35] and they often have unique barriers to overcome to be able to effectively use these technologies such as low health literacy and numeracy (i.e., "the ability of patients to understand and use quantitative health data"[104]). Figure 1.2 is a working conceptual framework I developed to help explain patient interactions with their data and patient-facing technologies, their information and help seeking processes and, to a far lesser extent, some aspects of patient-provider collaborative work. I use it to structure the discussion in the following sub-sections.

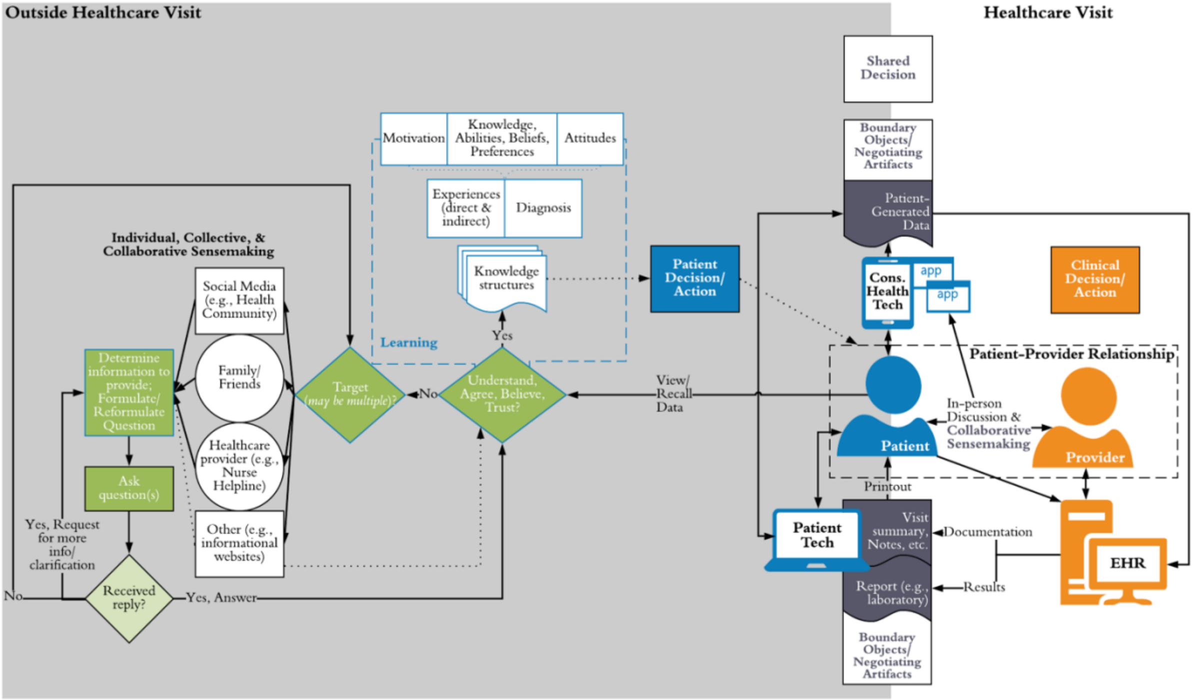

Figure 1.2. Working conceptual model of how patients (blue) handle clinical data.

Patient Participation and Work

A patient-centered approach to healthcare requires that patients participate in their care. This participation requires significant patient effort. There are many different types of patient work – the visible and invisible work that patients do, including self-monitoring and self-care activities, as well as more interactional endeavors with doctors such as negotiation.[105–107,108(pp194-195)] This includes illness work (e.g., work related to diagnosis, treatment, crisis management), everyday life work (e.g., cooking, caring for children), biographical work (e.g., reshaping one's identity in the context of an illness), and articulation work (e.g., coordinating tasks).[109] Other types have also been identified in the literature. For example, Seear described the work of becoming an expert patient, which includes finding, accessing, and making sense of information (both individually and socially such as in online health communities).[110] In addition, Gui and Chen identified infrastructuring work, which is the effort patients put into addressing gaps in the healthcare infrastructure such as sharing medical records between healthcare organizations when there is a lack of interoperability.[111] Data and information work are critical to all the aforementioned types of work.[112,113] Data work has been defined as "any human activity related to creating, collecting, managing, curating, analyzing, interpreting, and communicating data,"[112] while information work is seeking, receiving, and sharing information.[113]

The remainder of this section focuses on two important examples of patient work related to health data and medical records that are critical to patient participation in their healthcare, have received considerable attention in the literature, and which are particularly relevant to my dissertation work: personal health information management and health information seeking and learning.

Personal health information management: PHIM "refers to activities that support consumers' access, integration, organization, and use of their personal health information."[114] Uses of medical records by patients include monitoring their own health, making personal and medical decisions (e.g., diet), and sharing data and information between different doctors and informal caregivers.[115,116] PHIM has been described in the literature as invisible work that can be quite burdensome, especially for those with complex care needs (e.g., multiple chronic conditions) and managing records for multiple people (e.g., caregivers).[102,117] As Figure 1.2 highlights health interface technologies such as patient portals are increasingly being utilized for PHIM and particularly for accessing, reflecting upon, and using, especially to share personal health and clinical data with others to enable social sensemaking processes.

To effectively share these clinical data, as well as leverage them for health management, these data need to be portable. Patient portals, miPHRs, and similar technologies often include a feature, which is sometimes referred to as "Blue Button," to offer patients more control over their medical record by downloading it – either for their personal use or to share with others, including healthcare providers and caregivers.[e.g.,13,118,119] As mentioned previously, the 21st Century Cures Act has sought to make leveraging clinical data easier by requiring that certified EHRs provider standards-based API access to clinical data. This enables patients to allow third-party applications to download and make use of these data such as in the course of illness work and to facilitate learning.

Health information seeking and learning: As also highlighted in Figure 1.2, managing medical records is one of the many activities patients perform that can lead to experiencing a gap in knowledge (or doubt caused by a lack of trust) and, subsequently, information seeking to try to fill that gap.[66] There has been significant study of various aspects of online health information seeking behavior, including addressing questions such as who is seeking health information online;[e.g.,120] why do patients turn to the Web;[e.g.,121] for what are they searching;[e.g.,122] where do they search;[e.g.,70] how do they search (e.g., number of queries);[e.g.,123] do they perceive online resources to be easily accessible,[e.g.,124] useful,[e.g.,125] credible,[e.g.,126,127] understandable;[e.g.,124,126,128] are patients' comprehension and evaluations of health resources accurate;[e.g.,129,130] and how do they use the information that they find.[e.g.,131] Several of these topics are relevant to, or aspects of, the learning process.

One definition of learning is, "the activity or process of gaining knowledge or skill by studying, practicing, being taught, or experiencing something; knowledge or skill gained from learning."[132] While not explicitly stated, information is at the heart of this definition—it is what is studied and taught. Brookes' (1980) fundamental equation of information science, $K[S] + \Delta I = K[S + \Delta S]$, makes the relationship between knowledge and information acquisition more explicit.[133] At any moment in time, a person has a state of knowledge. When information is changed (novel information introduced, previously held information corrected or restructured to represent a deeper understanding), the resulting state of knowledge is the previous state plus the change in knowledge state caused by the change in information. As Cole explained, “Essential to this information definition is that new data or stimuli from the environment interact with the user’s preexisting knowledge about the topic, which is stored in packets or clumps of knowledge called knowledge structures, schemata, frames, or mental models.”[134] Thus, learning can be considered a change in knowledge state, which can be considered the development of, or a change in, a mental model.

This idea of changing knowledge structures also underlies the concept of *sensemaking*. The term *sensemaking* has been used in a variety of fields, and was originally described as an individual, cognitive process. For example, in organizational science, Weick defined it as the process of creating “order when the current state of the world is perceived as different from the expected state.”[135] In information science, Dervin described sensemaking as people building bridges when they encounter gaps (i.e., experience uncertainty) using materials such as ideas, attitudes, beliefs, values, intuitions, and stories.[136] Dervin also theorized that, when an individual is faced with a question or confusion, they will seek information (from, for example, the Internet or family/friends), and then undergo a sensemaking subprocess to try to reconcile the information with their existing knowledge.[137] In other words, the sensemaking subprocess involves building a new mental model or altering an existing model based on one’s interpretation of how the information fits (or does not fit) with existing knowledge structures.

Social sensemaking processes have also been defined in recognition of the fact that people are inherently social and are often not seeking and making sense of information in isolation.[138] This has led to the relatively newer terms: collective sensemaking and collaborative sensemaking (*discussed in the Patient-Provider Collaboration and Collaborative Work sub-section*). Collective sensemaking, as defined by Wenger in the course of studying communities of practice, is primarily concerned with how a group of peers creates shared understandings together.[139] In addition, and relevant to my research approach described in Chapter 4 and Chapter 5, this concept has also been used in the study of peer-to-peer interactions in online communities.[§e.g.140,141] Different communities may have different norms and goals, which may affect their collective sensemaking. For example, while Swarts found that Wikipedia editors strove for consensus,[141] Mamykina, Nakikj, and Elhadad discovered that, often, members of an online health community appreciated multiple perspectives – in this case, the discussion itself was the end goal, not identifying a "right" answer.[140] This likely reflects differences in the nature of the problems bringing members of these two communities together. The goal of Wikipedia users is to find facts, such as the biographical information of celebrity X or the definition of concept Y. In this case, the information provided can be right or wrong (although there may be shades of grey as well). Similarly, there are clear-cut indicators of right/wrong answers to questions posed on question and answer sites like Stack Overflow (e.g., does the code run or not). The questions

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[§] Of note, others have also described sensemaking in online health forums as collaborative sensemaking,[e.g.,81] suggesting there may be significant overlap in these concepts. Here, I distinguish between the terms in recognition that there may be a somewhat different mechanism for creating shared understandings among groups compared to more one-on-one interactions (as is typical for the patient-provider context).

and needs of users of online health forums, on the other hand, are often more personal and complex;[81] there may not be one "right" answer. Users may gain unique insights from various personal experiences, and facts are often necessary, but not sufficient, to solve a user's problem.[142]

In sum, patient work, such as personal health information management (e.g., of self-tracked data, laboratory test results) and health information seeking and learning, can engage patients in their healthcare.[e.g.12,143,144] It is also likely a mechanism by which lay-people become experts on their bodies and their health.[e.g.,8] This expertise, as well as the accumulated data, information, and knowledge, enables their participation in healthcare – both within clinical settings and outside of them (e.g., self-management activities).

Patient-Provider Collaboration and Collaborative Work

A patient-centered approach to healthcare also requires effective patient-provider collaboration. However, there are many challenges to practicing patient-centered care. For instance, increasing time pressures[145–147] often mean that healthcare providers face the difficult task of trying to do more with less. Indeed, providers often cite time as a key barrier to performing collaborative work in routine practice.[e.g.,11] Patient-provider collaborations can also be complicated by factors such as the significant heterogeneity among patients (e.g., knowledge, preferences) and providers' assumptions and biases.[e.g.,148] Despite such barriers, when the healthcare provider and patient are both willing and able, the patient-provider relationship can be highly collaborative.[5] As with all relationships, communication is the key.

Through this communication patients and providers create and review shared information objects, develop shared understandings, and make shared decisions.

Shared information objects: Boundary objects, standards, and boundary negotiating artifacts are well-defined concepts that describe the shared information objects and artifacts that are at the center of collaborations. Star introduced *boundary objects* in 1989, stating, "these common objects form the boundaries between groups through flexibility and shared structure…"[149–151] Since then, objects that move between groups and individuals with different expertise have been described, including in healthcare.[e.g.,152] Additionally, Star related boundary objects to standards, stating, "… when the movement between the two forms [ill-structured when shared and tailored for use in a single context] either scales up or becomes standardized, then boundary objects begin to move and change into infrastructure, into standards (particularly methodological standards)…"[151] In other words, and as others have noted,[e.g.,153] the exchange of boundary objects may become standardized over time. At the other end of the spectrum, though, Lee discovered that not all of these objects are simply seamlessly exchanged between these different groups but, instead, some objects can serve to help form new or disrupt existing processes; she referred to these as boundary negotiating artifacts.[153]

As previously discussed, and highlighted in Figure 1.2, data, information, and knowledge exchange are core components of patient-provider collaborative work; for instance, patients share symptoms, past medical history, and their lived experiences with a medical condition and healthcare providers may share clinical data (e.g., laboratory test results) and their medical knowledge (e.g., their interpretation of the test result). Medical records are composed of these information objects, and remain the chief product of, and central to, the interactions that take place between patient and healthcare provider. Traditional patient-provider interactions during in-person healthcare visits are often fairly formulaic, and the rigid structure of EHRs can lead them to be even more so (e.g., through the use of structured templates). In addition, the widespread adoption of EHRs has driven the development and worldwide use of standards for electronically capturing (e.g., ICD[154]) and transmitting (e.g., HL7[155]) health information. As a result, much of healthcare provider-generated data is structured, enabling secondary uses (e.g., billing, public health).[**] EHRs have also made it easier to share these clinical data, as well as unstructured data such as clinicians' notes, with patients.

In addition, clinical or patient-generated data may be collaboratively reviewed during in-person visits, and the shared understanding developed may be added to the patient's record in the form of a clinician's note.[e.g.,8,157] This can add non-standard elements to patient-provider interactions, resulting in the information objects being used "to navigate tensions and boundaries between the patient and provider spheres of expertise."[8] For instance, Chung et al. conducted surveys and interviews to study patient-provider collaboration around

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[**] There are, of course, exceptions such as clinicians' notes, which can document aspects of patient-provider collaborative work (e.g., the co-created interpretation) and have also been collaboratively viewed as they were created to support shared decision making.[e.g.,8,156]

patient-generated data, specifically data collected through self-tracking.[8] They identified a number of boundary negotiating artifacts created and used to navigate and structure the patient-provider interactions around these data; for example, compilation of the discussion of the shared review of the data in a clinician's note.[8] Overall, health interface technologies often serve as channels, providing one or both collaborators with access to the boundary objects and boundary negotiating artifacts that make up a patient's medical record.

Shared understanding: Through the aforementioned processes, including creating, maintaining, and reviewing information objects, the patient's medical record is becoming a shared resource that may be used in the sensemaking activities of patients, their healthcare provider(s), and others (e.g., caregivers). For example, boundary negotiating artifacts may be generated through, and at least partially support, individual (*discussed in the Patient Participation and Work sub-section*) and collaborative sensemaking processes, respectively. *Collaborative sensemaking* has been defined as individuals working together to address "a shared information need."[158] Paul and Reddy studied collaborative sensemaking in an emergency department and found that it occurred in response to ambiguous information (e.g., two different medical record numbers for the same person), unequal distribution of information, and lack of individual expertise (e.g., to understand why a pediatric patient is having a reaction to a certain medication).[138] This same study also identified characteristics of collaborative sensemaking, including prioritizing relevant information (i.e., individuals prioritize which information to share with their collaborators based on their personal judgement of relevance), sensemaking trajectories (i.e., collaborative sensemaking often has a temporal aspect; both the product and process are passed from person-to-person over time), and activity awareness (i.e., awareness of the larger goal throughout the process).[138]

For patients and providers, one of the most common shared activities is collaborative review of health and clinical data during synchronous healthcare visits, which may be achieved in many ways, including through sharing data via health interface technologies (see Examples in Section 1.1.1), patients showing providers patient-generated data in an app on their phone, or providers mirroring their EHR screen for the patient.[e.g.,8,157] Regardless, it is through the collaborative sensemaking process that patients and providers can build a shared mental model of the patient's health issues that can form the foundation for their individual and collaborative work.[157,159]

Shared decision making: There are three primary models of decision making in healthcare: the traditional paternalistic; informed; and shared.[160] Briefly, in the paternalistic model, healthcare providers typically make decisions independently, providing patients with the minimum information that is legally required.[160] The informed model is similar to the paternalistic model in that communication is largely one-way, with providers usually conveying information to patients; however, in the informed model, providers share all the information necessary for *patients to make their own* decision.[160,161] Finally, like the informed model, health care providers share all the information necessary for decision making, but unlike the other models, shared decision making (SDM) tends to involve two-way communication and, ultimately, patients and providers make decisions together.[160]

Légaré and Witteman describe SDM as follows, "At its core, shared decision making is 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."[11] There is strong evidence that SDM improves patients' knowledge, expectations, engagement in decision-making, and concordance between values and choice, and reduces decisional conflict and the proportion of people who remain undecided.[7] There is also some evidence that it may result in improved health outcomes (e.g., asthma control[162]). Furthermore, studies have found that a growing number of patients, in a number of countries, have a desire to be more involved in decisions.[21–24] As a result, shared decision making is now considered the ideal model when there is some scientific uncertainty (e.g., insufficient evidence).[11] The patient-centered care approach, which includes shared decision making, is also encouraged through Policies – both national and state or provincial.[e.g.,9] There is the potential to improve shared decision-making through health interface technologies.

1.2. Adoption and Use of Patient-facing Health Interface Technologies

To illustrate the relatively low adoption and use rates of patient-facing health interface technologies, I will focus on the two key examples of health interface technologies for empowering patients through access to their medical records – patient portals and miPHRs – that are centered in this dissertation research.

1.2.1. Patient Portals

As mentioned, the most recent nationwide evidence of patient portal use indicates that 39.5% of U.S. adults used a patient portal at least once in the past year.[58] However, this singular number hides the considerable variation that has been observed by different healthcare organizations implementing portals. When I systematically examined enrollment and use rates reported in the literature, I focused on studies that objectively assessed portal engagement (e.g., analyzing portal use logs), as opposed to other methods such as self-report. Overall, there was wide variability in the published rates of portal engagement and based on patient population and healthcare organization. Enrollment among special patient populations (i.e., elderly, patients with chronic conditions) tended to be higher compared to general populations (N=16, Median=31.4%, Range=5.9-77.1% vs. N=26, Median=23.9%, Range=4.8-43%). However, even within a single health system, registration rates could differ greatly. For instance, Ketterer et al. found that while the overall enrollment among 13 affiliated pediatric primary care practices was 38%, some practices enrolled more than half of their patient panel.[163]

In addition, registering for a patient portal account, does not guarantee use. Among registered patients, the proportion signing on at least once ranged from 13% of patients over an 18-month period in one VA medical center[57] to about 90% of patients over a four-month period in a non-profit academic health system.[87] Interestingly, published rates for signing on at least once also tended to be higher in special patient populations (N=7, Median=62%, Range=16.6-80.5%; General: N=15, Median=51%, Range=13-90%), but there was little difference for higher-level use, which was defined as frequent use, long-term use, or uses beyond viewing data and information such as sending a secure message to one's healthcare provider (General: N=19, Median=45.5%, Range=0.8-86%; Special: N=13, Median=45.2%, Range=7.9-94%).

Finally, when patients use a portal, they do not access all of the content and features to the same degree, with the most common being: viewing medical record,[35,164–173] especially laboratory or imaging results[35,60,67,163,165,169,171,174–188] and medications;[34,163,169,171,174,180,181] sending secure messages;[60,67,163,165–167,170,171,174–177,180,182,184,185,187–189] requesting medication refills;[60,67,163,165,169,170,174,179] and managing appointments.[163,165,169,170,173,174,188] At the other end of the spectrum, some studies found that generic content, such as educational resources, tended to be relatively less popular.[e.g.,190,191]

1.2.2. Mobile Interconnected Personal Health Records

As also mentioned above, an interconnected PHR (iPHR) is an application "through which patients can maintain and manage their health information (and that of others for whom they are authorized) [from multiple healthcare organizations] in a private, secure, and confidential environment."[47] There have been attempts made by EHR vendors and other commercial companies to develop iPHRs in the past, but recent technology and policy advances make the mobile iPHRs, such as Apple Health Records and CommonHealth, more likely to be successful than their predecessors.[48] As stated in Section 1.1, a growing number of healthcare organizations are partnering with the developers of these miPHRs to enable patients to download their medical records onto their smartphone via standardized APIs.[49,192] While having a critical mass[193] of healthcare organizations adds to the value proposition of these mobile medical records, even if this is achieved, it is still far from guaranteed that patients will adopt and use them. Indeed, a study of 12 "geographically diverse" healthcare systems in the U.S. found that, on average, <1% of patient portal users had downloaded their electronic health information to their smartphone via the available APIs.[59]

These examples of relatively low adoption and use rates are likely due to the myriad barriers to uptake and use that this type of health interface technology faces, and which I discuss more in the next section.

1.3. Barriers to the Adoption and Use of Patient-facing Health Interface Technologies

Since miPHRs are just starting to become more widely available to patients, less is known about why adoption thus far is so low. One study focused on the healthcare administrator perspective suggests that it is likely due to a lack of patient awareness, as healthcare organizations have not advertised the availability of this service.[59] However, much of the existing knowledge of barriers to patient adoption and use of health interface technologies comes from the extensive patient portal literature.

Detailed methods are presented in Section 2.3. Briefly, after systematically reviewing this evidence base (N=1,390 unique articles identified through multiple literature database searches and supplementary sources), I found 202 empirical studies that reported one or more barrier to patient adoption or use of patient portals. Overall, my qualitative analysis of these papers underscored the complex ecosystem into which portals are implemented, revealing positive and negative factors affecting patient acceptance at multiple ecological –

patient, healthcare organization, provider, social network, and technology – and engagement levels. Figure 1.3 presents an overview of all the identified factors from the literature, which was developed using existing theories as a foundation, including Technology Acceptance Model (TAM, e.g., perceived usefulness and perceived ease of use), Unified Theory of Acceptance and Use of Technology (UTAUT2, e.g., age and experience), and Information Systems Success model (e.g., information quality and system quality).[194–196] However, given my focus on design, here, I specifically emphasize the technology-level factors, which fell into three categories: Design and Configuration, Information Quality, and System Quality.

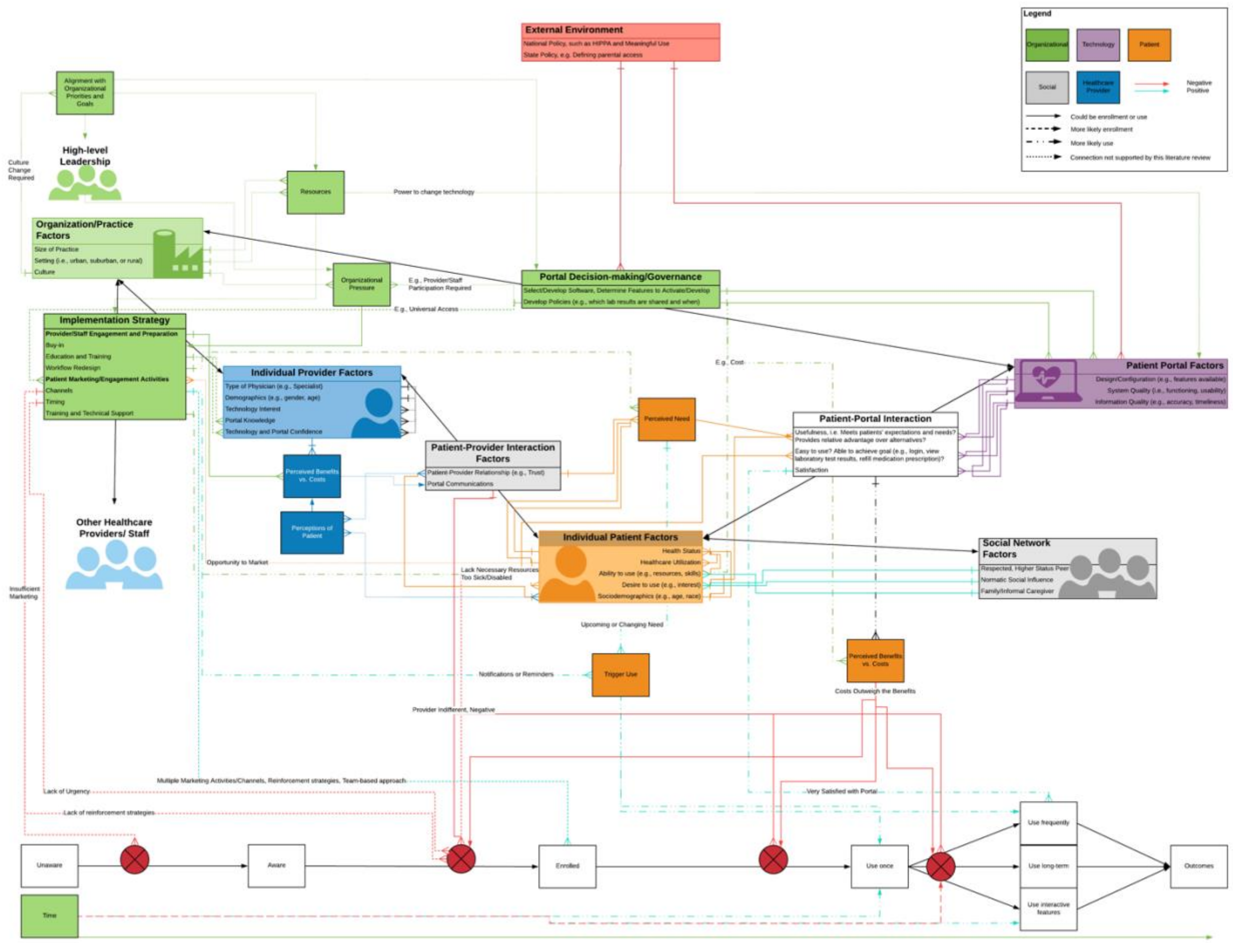

Figure 1.3. Multi-levels factors affecting patient portal awareness, adoption, and use based on a systematic review of the literature.

1.3.1. Design and Configuration

The design or configuration of the portal can positively or negatively affect patient acceptance of the portal. Specifically, although the features available may positively affect enrollment[168,179,197–201] and use,[202] when the portal *fails to meet users' expectations or needs*, it has negatively affected portal use.[34,35,69,174,180,181,199,203–208] For instance, a qualitative study explored portal use among parents of children with autism, and found that it was common for this pediatric population to have multiple healthcare interactions per week; however, the commercial portal available in the tertiary academic hospital was not designed for this, especially its appointment management feature.[204]

1.3.2. Information Quality

The quality of the information provided in the portal can also negatively or positively affect use. When *information is incomplete, inadequate, or not up-to-date*, patients may discontinue their use of the portal.[35,180,181,204,205,209] This is also true when the information provided in a portal is not *patient-friendly* (e.g., includes medical jargon) and, thus, difficult for patients to understand.[35,57,67,69,204,209–215] Two of these studies also reported that other participants cited high quality information, e.g. timely and accurate, as an advantage of portal use.[35,210] In addition, Silvestre et al. found that perceived quality was a predictor of frequent portal use.[200]

1.3.3. System Quality

The quality of the system, particularly in terms of its functioning and usability, can positively and negatively affect portal acceptance. When technological and connectivity issues (e.g., software glitches) disrupt portal functioning, it impedes use.[35,180,181,190,209,211,216,217] In addition, portal usability issues, e.g., difficulties performing certain tasks, were identified as a barrier to both registration[168,214,218–221] and use.[34,167,174,189,191,204,208,209,222–226] For example, Wilcox et al. qualitatively evaluated a medication monitoring tool within the portal, and reported that the poor content organization resulted in overwhelming participants, and seemed to be a barrier to "information discovery."[34] Conversely, participant perceptions that a portal is easy to use or learn was positively associated with use.[35,181,208,209]

1.4. Human-centered Design

To address such complex and multi-level barriers, and in order to improve the design of these technologies and, consequently, the uptake and use rates, there is an urgent need to study these technologies using a human-centered design approach. This is sometimes referred to as a user-centered design approach when specifically discussing technologies. Human-centered design is a problem-solving approach that includes the intended audience at all stages of the design process – inspiration, ideation, and implementation – and is especially useful when designing for collaboration across boundaries.[227–229] Central to human-centered design is empathy – a deep understanding of the people who will use the system, product, or services, including their needs and barriers.[229,230] There are multiple ways to achieve this deep understanding; traditional methods include user interviews, user focus groups, expert interviews, and card sorting activities.[231]

Many health informatics and HCI studies have utilized a human-centered design approach at various stages of health technology development.[e.g.,227,232–234] For instance, Farinango et al. a survey, interviews, and a focus group to gather user input, resulting in three prototypes of a personal health record for metabolic syndrome management being built and tested.[234] Similarly, Epstein et al. conducted formative interviews to understand how to facilitate more effective self-tracking data sharing through social media, developed and tested a mobile apps, and then evaluated the app among users.[232] While often effective, these traditional methods can be resource intensive and limited by sample size. Here, I use the human-centered design philosophy to understand how the design of health interface technologies can be improved to better support patient work.

1.5. Dissertation Overview

This research aims to generate insights into how to address barriers and improve the design of health interface technologies, and specifically those that empower patients through electronic access to their medical records, to better support patient work through a human-centered lens and a multi-method approach. Study 1 is a systematic review of the literature on patient portals, which is currently the most common mechanism for sharing clinical data with patients. This review includes 42 studies published between 2003 and 2019 that collected patient and caregiver suggestions for improving patient portals. Through my analysis of the literature, I[††] found that patients and caregivers want better data and information through portals and this technology to do more (e.g., facilitate virtual visits) and to be easier to use.

Study 2 investigates the current state of the envisioned future clinical data-powered ecosystem that will not only provide patients with opportunities to integrate their medical records across healthcare systems on their smartphone, but also give patients the control to

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[††] Though I use 'I' throughout this document, because it is research primarily conceived of, led, and conducted by myself, many people have significantly contributed to this research (see Acknowledgements).

share select clinical data with other apps to potentially improve their functioning. I found that, at the start of the 21st Century Cures Act, this nascent ecosystem currently offers patients few opportunities to leverage their computable clinical data. This suggests that there may be barriers to developing apps that are able to access clinical data via the standards-based APIs offered by certified EHRs or through mobile, smartphone-based personal health records (miPHRs). In addition, this research provides evidence of the difficulty patients may have in identifying existing third-party apps with this feature, suggesting the need to improve the discoverability of these apps.

Studies 3 and 4 explore patient's interaction with their clinical data, specifically laboratory test results, through a unique perspective – patient questions containing these data posted to an online health community (OHC) – to understand how the design of technologies such as patient portals and miPHRs can be improved to better support patients as they view their digital medical records. I found that patients seek information, advice, and emotional support on the OHC to understand and use their laboratory test results at multiple points in medical care. In the diagnosis phase, patients are trying to comprehend their data, are more often receiving emotionally charged results and, of course, are engaging the OHC in identifying the cause of their medical issue. In the treatment phase, patients tend to ask more focused questions to identify their treatment options, to seek treatment guidance from peers, and to predict the likely course of their disease. Throughout both phases, individuals are highly engaged in the medical process and put in substantial effort to proactively prepare for their care and interactions with doctors. They enlist the OHC in these efforts for many reasons such as a lack of confidence in their doctor. Peer-patients on the OHC fill gaps in the healthcare infrastructure (both human and technological) by sharing their patient expertise in the form of personal experiences, advice, and information, as well as offering encouragement and other types of emotional support.

Overall, and based on the findings from these studies, I discuss recommendations for health interface technologies, particularly patient-facing technologies, to better support patient work along three themes (1) Designing for true patient empowerment, (2) Designing for ecosystems, and (3) Expanding the view of human-centered design in healthcare. Ultimately, I argue that in order to have true patient empowerment patients need more supports in their roles as partners in their health and for the patient-provider interface, both in-person and technological, to be re-imagined to encourage the development and sharing of patient expertise. The emerging integrated health app ecosystem may offer solutions, including opportunities for patients to develop personalized micro-ecosystems, but an evaluation framework for interconnected apps is needed as is more research to understand how these technologies can be effectively leveraged to engage human support systems (both online and offline). Finally, healthcare organizations and health IT developers need to consider new, exploratory human-centered methodologies to help them gain a broader view of patient needs and barriers, which can be used to more effectively direct health IT development resources.

This dissertation significantly contributes to the health informatics literature in three main ways:

1. Conceptually by providing a working definition of health interface technologies and bringing together relevant concepts and literature from multiple streams of research. This is critical to knowledge accumulation and to improving this class of technology.
2. Empirical evidence of the limited opportunities for leveraging one's clinical data using third-party apps, as well as for how to better support patients at the point of viewing their medical record through patient-facing health interface technologies.
3. Design recommendations for improving health interface technologies so that they better support patient work and, as a result, are more likely to be adopted and used and to realize their promise of improving health outcomes.

CHAPTER 2. What Do Patients and Caregivers Want? A Systematic Review of User Suggestions to Improve Patient Portals

2.1. Motivation and Summary

Significant investments have been made in patient portals in order to provide patients with greater access to their medical records, as well as to other services such as secure electronic communication with their healthcare provider(s). Unfortunately, and as detailed in Section 1.2.1, patient adoption and use of patient portals has been lower than expected. According to the user-centered design philosophy, including end-user voices in all stages of the design process is critical to a technology's success. Since there is a considerable existing body of literature on patient portals, and as a part of a larger systematic review, I identified and examined 42 studies that reported patient's or their caregiver's suggestions to improve patient portals. The results suggest that patients and caregivers want patient portals to (i) support human connection (e.g., virtual patient-provider interactions), (ii) give patients more control (e.g., over their medical record) and be designed for the variation in patient and caregiver experiences, and (iii) be innovative (e.g., provide contextualized medical advice).

2.2. Introduction

Patient portals – a patient-facing, web- or mobile phone app-based technology offered by healthcare organizations to provide patients with read-only access to their medical records and also often provide additional features to engage patients in their healthcare (e.g., secure messaging) – have been in development now for at least 20 years. In that time, there have been hundreds of patient portal-focused studies published. These studies have contributed to this technology becoming more mature and widely available. They have also established the potential of patient portals to have benefits such as improving patient-provider communication.[54] Unfortunately, in general, patient adoption and use rates have been lower than expected.[235]

User-centered design (UCD) is defined as "an iterative design process in which designers focus on the users and their needs in each phase of the design process."[236] This focus on the user is essential to developing technologies, as well as redesigning technologies, that are useful and that will actually be used. Indeed, the extant patient portal literature has found that the design of portals is a key factor in their adoption and use – when portals fail to meet patients' or caregivers' expectations or needs, such as inadequately supporting multiple healthcare interactions, it negatively affects use.[e.g.,204,205] In addition, patients *want* to be heard. For instance, Smith et al. reported, "An underlying finding was the need for patients to be listened to and taken into account when thinking about improving the tool [patient portal]."[237] Thus, using the UCD philosophy may provide insights into how to improve the design of patient portals and, subsequently, into how to improve patient adoption and use of this technology. This is likely why following user-centered design principles is outlined as a key strategy to "advance the development and use of health IT [information technology] capabilities" in the draft 2020-2025 Federal Health IT Strategic Plan.[238]

In other words, there is a critical need to better understand what patients and their informal caregivers want from portals in order to capitalize on the investments that have been made in this technology and to achieve its potential. While Nazi et al. recently examined the Veterans Affairs' (VA) UCD efforts over the last decade, to which they attribute their portal's relatively high adoption and continued engagement, they do not consider patient voices outside of the VA context.[239] I address this gap through a systematic review of the patient portal literature. Through my analysis, I aim to gain an understanding of how patients and their caregivers believe that portals should be improved in order to better meet their needs and to use this understanding to develop patient portal (re-)design recommendations. What I found was a desire among patients and caregivers for portals to offer better data and information (e.g., more explanation of clinical data), to do more (e.g., facilitate virtual visits), and to be easier to use, as well as for organizations to offer more training and ongoing support for portal use and to improve the portal deployment process. I discuss themes in these findings that offer insights into how to improve portals, including designing for human connection, giving patients more control, and calling for continued innovation.

2.3. Methods

This systematic review follows the PRISMA standard of reporting. It is a part of the larger systematic review of the patient portal literature exploring the barriers to and facilitators of patient adoption and use of portals mentioned in Section 1.3. Briefly, for this larger systematic literature review, I used the queries in Table 2.1 to search three databases: Scopus, PubMed, and ACM Library. The last search was conducted in May 2019. In addition to these databases, I reviewed the reference lists of publications and collaborators also sent potentially relevant literature.

Table 2.1. Search queries submitted to database.

Database	Query
Scopus	TITLE-ABS-KEY((("patient portal" OR “personal health record”) AND ("evaluation" or "adoption" or "barrier") OR ("effective" OR "useful" OR "utility")) AND NOT (“online medical consultation” OR “evisit” OR “portal vein” OR “portal pressure” OR “portal venous stenosis” OR “transjugular intrahepatic portosystemic shunt” OR “doppler”))*
PubMed	Search ((((health records, personal[MeSH Terms]) OR "patient portal")) AND ((evaluation studies as topic[MeSH Terms]) OR (barrier OR barriers OR facilitator OR facilitators OR effective OR useful OR utility)))
ACM Digital Library	("patient portal" OR "tethered personal health record" OR "patient accessible electronic health record" OR "patient accessible health record")

*The exclusion terms in the final query are based on review of the results from preliminary queries.

I included empirical studies of technologies meeting the definition of patient portals presented in the Section 2.2, regardless of the term used (e.g., personal health record, PHR, versus patient portal), and addressing at least one of our two main research questions: (1) Are patients registering for and using patient portals? and (2) What are the barriers to and facilitators of patient registration and use? Articles were excluded if they met one or more of the following criteria (i) literature reviews; (ii) non-electronic or non-web-based PHRs (e.g., paper, USB); (iii) web-based PHR not connected to a particular healthcare organization; (iv) exclusively discuss functionalities, frameworks, architectures, policies, internet access, or patient attitudes towards a hypothetical/future portal; (v) lack direct evidence of an effect on patient enrollment or use (i.e., study does not include patients or their portal enrollment and use data); (vi) use simulated data (e.g., pilot tests); and (vii) non-English language articles. All types of study designs were eligible for inclusion (e.g., controlled trial, observational). In addition, while there are unique aspects of inpatient portals (e.g., discharge checklist), many of the factors that affect patient engagement with this technology are similar to outpatient portals (e.g., health status). Thus, studies of inpatient portals were also included in this review.

An undergraduate research assistant and I first independently assessed the title and abstract of all identified articles for relevance. We then compared our judgments and resolved any disagreement through discussion. For articles not excluded based on title and abstract, I obtained and reviewed the full-texts, and excluded additional articles based on our criteria.

The data extracted from included articles were pre-determined. Data items included details of the technology (e.g., features and functionalities), methods (e.g., study design, how enrollment or use were defined/measured), results (e.g., barriers to and facilitators of patient engagement), conclusions, and risk of biases (e.g., selection bias). Importantly for this paper, we also systematically extracted any patient or caregiver suggestions for improvements to the portal.

We analyzed the subset of papers that reported these suggestions using an inductive qualitative approach to identify emerging categories and the constant comparative method of data analysis.[240]

2.4. Results

Using the search strategy outlined above, and after de-duplication, I identified 1,390 unique potentially relevant articles. Almost 850 of these were excluded based on a review of the titles and abstracts, with the most common reasons being that they reported patient attitudes towards portals only or on the design and development process only as opposed to actual use. I then reviewed the full text of the remaining 542, and determined that 202 were relevant and were, thus, included in the larger review. Among these, I identified 42 publications (21%) that reported asking their participants for suggestions to improve the organization's patient portal. I focus on this subset of the literature in the remainder of this chapter. Figure 2.1 presents an overview of the identification and screening processes.

2.4.1. Study Characteristics

Studies that reported patient or caregiver perceptions of how the patient portal could be improved (N=42) were published between 2003 and 2019, with over half (n=28, 66.7%) being published in the last 5 years. The most common study setting was a hospital or medical center (n=10, 23.8%), followed by two or more primary care practices (n=9, 21.4%) and health systems (n=6, 14.3%). A large majority of studies focused on adult patient populations (n=25, 83.3%). Among these, five specifically studied older adults (most commonly defined as 65 years and older), three on veterans, one on pregnant women, and one on patientcouples. Only two of the studies that focused on adult patient populations explicitly included caregivers. In addition, half of the included studies did not concentrate on a particular condition. Among the remaining 21 articles, 15 focused on chronic conditions (71.4%), with diabetes mellitus being the most common (n=7, 33.3%). Finally, qualitative study designs were most frequently used (n=12, 28.6%), followed by cross-sectional (n=10, 23.8%) and mixed methods (n=7, 16.7%). Thirty of the 42 included studies reported collecting data through surveys or questionnaires (71.4%) and 18 through interviews (42.9%), other methods were less commonly reported (e.g., focus groups).

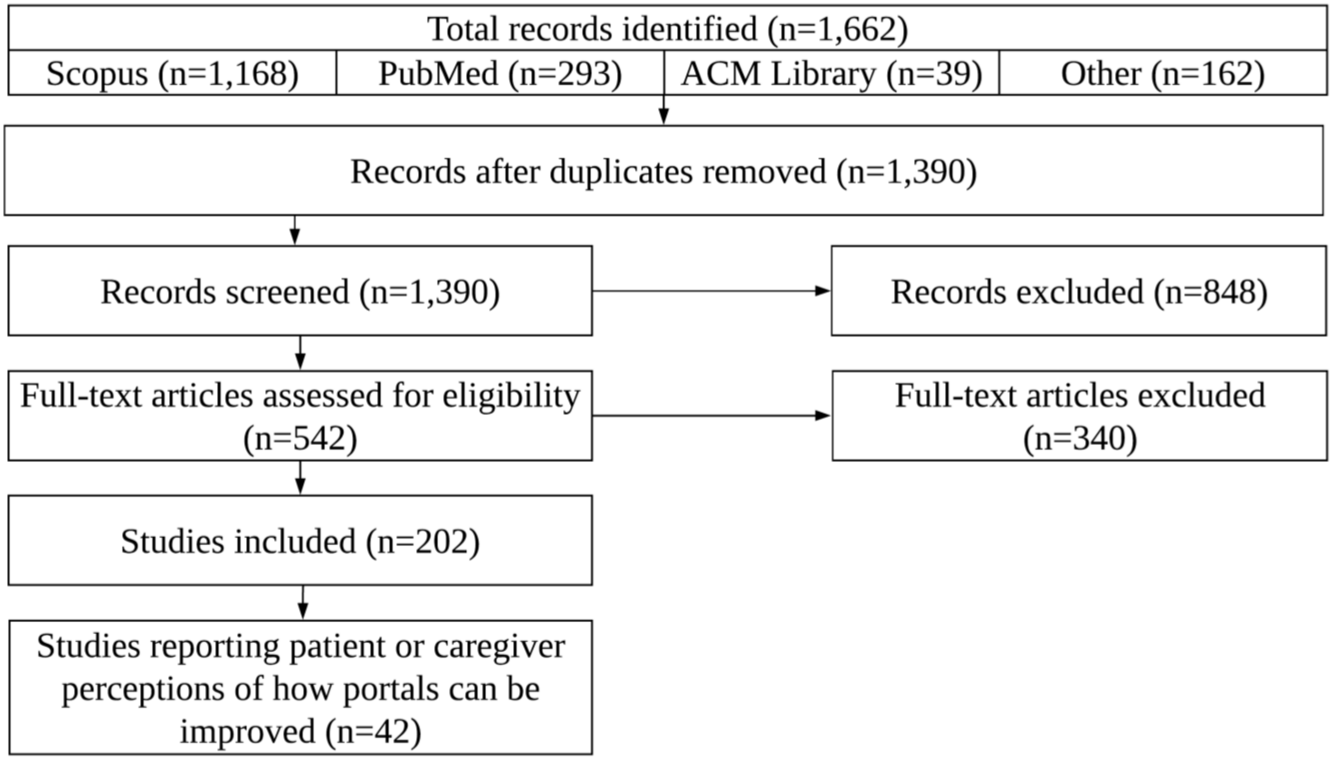

Figure 2.1. PRISMA flow diagram for the selection of literature reviewed.

2.4.2. Patient and Caregiver Suggestions for Improving Patient Portals

Five main categories of patient suggestions for improving patient portals and patient portal engagement emerged (N=42): Information (n=28, 66.7%), Features and Functionality (n=26, 61.9%), Usability (n=17, 40.5%), Training and Ongoing Support (n=11, 26.2%), and Implementation (n=2, 4.8%). I present my findings related to each of the main categories in the sub-sections below; they are also summarized in Table 2.2.

Information

The most commonly reported recommendation was to improve the information provided in the portal (N=28). Specifically, patients want faster information (n=5, 17.9%), better or more explanations (n=13, 46.4%), more personal health information (n=15, 53.6%), more personalization (n=8, 28.6%), detailed information rather than simplified (n=3, 10.7%), more resources and education (n=5, 17.9%), and more transparency (n=4, 14.3%).

Patients desire faster information, including more timely email responses, release of test results, and updates following clinic visits.[69,173,204,209,239] They also want better or more explanations of medications, laboratory results, and medical terminology.[34,178,202,209,221,223,245–251] For example, Pillemer et al. reported that their participants wanted at least minimal provider interpretation with their laboratory results,[202] while O'Leary et al. found that their participants wanted additional information about medications such as both the brand and generic names.[223] In addition, many studies reported that their participants wanted more personal health information,[69,173,178,180,181,209,214,219,223,239,241–244,250] including doctor's notes, care plans, test results from other healthcare organizations, radiology results, and cardiology reports. Dalal et al.'s participants also specifically noted the importance of keeping the personal health information in the portal up-to-date.[180]

Eight studies reported that patients want more personalization – in terms of the information presented to them or that is requested from them through the portal. For instance, through qualitative interviews, Gee et al. found that their participants wanted to customize the portal to see only the data and information relevant to their specific chronic condition.[69] Similarly, de Jong et al. asked their participants to regularly submit questionnaires (e.g., pain level), but some of their participants did not find the questionnaire relevant to their condition, and recommended requesting condition-specific information in the future.[250] In addition, one study found that patients wanted contextualized medical advice[219] and another reported that patients wanted the portal to predict their information needs.[237]

Although some studies found that their participants wanted the explanations or their personal health information in "patient-friendly" or "lay" language,[e.g.,34,244] other studies reported that their participants wanted detailed information as opposed to simplified patient versions.[68,248,249] Indeed, even within studies this sometimes varied. For instance, Kim and Fadem received polarized feedback from their older adult participants – some strongly preferring simplicity and others comprehensiveness.[248] This suggests that it may be preferable to provide patients with the raw clinical data with an easily accessible interpretation of that data and explanations of medical jargon rather than just a simplified patient version. Given the desire for personalization, another possible solution may be to allow patients to customize their view of their information.

Five studies found that patients wanted more resources (e.g., facility information such as maps and quality of care information[181,239]) and/or education (e.g., online education programs[239]) – either integrated into the portal or links to additional information and resources outside of the portal. Finally, patients want more transparency around portal use.[173,208,247,251] For instance, King et al.'s mixed methods study of 18 caregivers of children with physical and developmental disabilities revealed that caregivers wanted more transparency around the "scope of confidentiality" and portal access after discharge from the pediatric rehabilitation hospital.[173]

Features and Functionality

Patients want additional features and functionalities, as well as existing features and functionalities to be improved (N=26). These generally fell into five main categories: Support for key activities (n=15, 57.7%), More control (n=23, 88.5%), Reminders and notifications (n=7, 26.9%), Other features and functionalities added (n=5, 19.2%), and Other features and functionalities improved (n=7, 26.9%). First, patients want more support for communication with their provider(s), including virtual healthcare tools such as messaging and videoconferencing[180,204,223,239,249,251,252] and features that inform their healthcare provider(s) of their status, such as provider notifications related to the patient's medication adherence.[180,246] In fact, one of Kim and Fadem's main findings from their mixed methods study was that communication with providers was the main focus of their older adult participants, and that they viewed the portal as "one part of a larger communication system."[248] In addition, patients and caregivers also want support for the administrative work associated with being a patient, including scheduling appointments, paying bills, and filling prescriptions.[204,205,214,221,239,245,252] Finally, less commonly identified, but critical for patients and caregivers with more complex situations were support for caregiver and family care coordination (e.g., family calendar)[204,247,249] and complex care (e.g., check for medication interactions).[239,248]

Second, although patient portals are owned by healthcare organizations and tend to be primarily populated with clinical data generated by healthcare providers (e.g., doctor's notes, laboratory results), patients want more control. For example, they would like to be able to contribute to their health record by adding or correcting data.[69,205,209,214,221,245,252,253] They also want the ability to share their record with and among others, including caregivers,[180,239,252] healthcare providers within and outside the healthcare organization,[173,204,205,214,239,244,246,248,252,253] and trusted institutions.[252] Nazi et al. specifically investigated patient preferences for the type of access they want delegates to have, and found that most of their participants wanted their delegates to have read access with print and download capabilities.[239] In addition to control over their health record, patients would also like more control over communication with their healthcare provider(s), including what is submitted to their physician (e.g., ability to create own topic as opposed to having to choose from a dropdown menu);[253,254] when and how information is received[247,248,255] and requested;[250] and more options for and control over with whom they are communicating.[34,69,173,208]

Third, seven studies reported patient or caregiver suggestions related to reminders and notifications. Specifically, four found that their study participants wanted reminders for events such as upcoming appointments, when it is time to refill a prescription(s), and when preventive care is due.[239,245,246,252] In addition, four studies reported that patients or their caregivers suggested providing notifications when new content or features become available such as new test results.[208,209,239,251]

Finally, there were also several less commonly reported features/functionalities requested, including tools for self-tracking,[250,252] decision making,[239] peer-to-peer support,[239] and inpatient stays (e.g., ordering food/room service),[180,181] as well as requests to improve certain portal features and functionalities such as for reviewability (e.g., ability to record videoconference visits),[250] convenience (e.g., automatic upload of home readings from different types of devices),[245,250] flexibility (e.g., adjust the frequency of reminders[250]), and awareness (e.g., ability to track the status of a question[34]).

Usability

The most common suggestion related to usability was to make the portal more user-friendly and, in particular, easier to use and navigate.[69,208,209,237,239,248,250,254,256–258] The studies that reported more detail found that patients wanted the portal's organization to be clear and intuitive and navigation to be simple, especially for completing common tasks, while not obscuring any of the portal's functionality (e.g., important tabs and features should be visible).[208,237,239,248,258] Patients also commonly requested better display of information in general, and particularly of laboratory results (e.g., highlight abnormal values) and large amounts of information.[34,180,208,243,248,257] For example, one mixed methods study of older adults found that many of their participants wanted to be able to filter out medications that they took for only a short time (and are no longer taking), so that they could view a list of only the medications that are relevant (i.e., the ones that they are currently taking).[248]

Patients or their caregivers also requested more platform options, especially a smartphone application.[204,239,250,254] In addition, the burden to log-in should be minimized, such as enabling automatic log-in from an email message,[209,219,247] and accessibility should be improved (e.g., larger font). Patients want portal designers to be especially cognizant of the many users with challenges, including visual impairments and multiple co-morbidities.[208,209,247] Finally, other less commonly mentioned usability improvements include reduced constraints (e.g., days and times blocked from online appointment scheduling)[247] and notification before automatic actions (e.g., log-out).[239]

Training and Ongoing Support

Eight studies reported that patients or their caregivers want more portal education, training, or support.[69,173,212,219,221,237,247,259] Two studies found that their participants want human connection as they learn about the portal and how to use it, as well as when they encounter issues.[237,259] These users do not feel that a web-based video or guide is sufficient. Price-Haywood et al. found that patients believe that someone outside of the busy clinical team may be best able to provide an introduction to the portal, especially for those with low computer self-efficacy.[247] In addition, patients want more or clearer instructions for using the portal and its features.[247,257,258] For instance, Wilcox et al. found that their participants wanted examples of appropriate questions and comments to send through secure messaging.[34]

Implementation

Two studies reported patient suggestions related to implementation. Of note, one of these studies reports suggestions from a patient advisory board, which includes patients that are portal users and non-users, based on the results from a survey of 247 older adult patients.[247] The advisory board recommended marketing that captures patient stories to show the benefits of using the portal and that promotes proxy users to help address concerns about patient self-efficacy in using the portal.[247] They also recommend screening for computer literacy to identify individuals who may need additional assistance.[247] Finally, patients want a consistent experience, including the features available and response times, across providers.[173,247] This suggests that organization-wide acceptance is critical.

Table 2.2. Summary of patient and caregiver suggested improvements reported in the 42 included studies.

Improvement Categories	**No. (%)***	**Patients want:**
Information	28 (66.7%)	• Faster information (e.g., updates from clinic visits)[69,173,204,209,239] • Better or more explanations, especially of medications, laboratory results, and medical terminology[34,178,202,209,221,223,245–251] • More personal health and healthcare information[69,173,178,180,181,209,214,219,223,239,241–244,250] that is kept up-to-date[180] • More personalization, including more personalized information (e.g., condition-specific) provided[69,173,209,244,245] and requested,[250] contextualized medical advice,[219] and information needs anticipated[237] • Detailed information rather than simplified patient versions[68,248,249] • More resources (e.g., facility information) and education (e.g., online education programs)[173,181,209,239,244] • More transparency (e.g., will they be able to access after discharge, why days/times are blocked from online appointment scheduling)[173,208,247,251]

Features and Functionality	26
	(61.9%)
		• Support for:
		  ○ communication with their provider(s), specifically adding virtual healthcare tools (e.g., messaging, video conferencing)[180,204,223,239,249,251,252] and informing their healthcare provider(s) (e.g., status of discharge checklist viewable to providers;[180] notifications to provider specifically medication/adherence-related[246])
		  ○ administrative work (e.g., scheduling appointment, paying bills)[204,205,214,221,239,245,252]
		  ○ caregiver and family care coordination (e.g., family calendar)[204,247,249]
		  ○ complex care (e.g., check for medication interactions,[239,248] ability to request multiple medication refills at once,[246] ability to prioritize medications[250])
		• More control over:
		  ○ their health record, including the ability to correct or add data;[69,205,209,214,221,245,252,253] the way data is displayed and the type of data collected;[249–251] where and when they can access it (e.g., ability to access outside hospital);[244] and the ability to share with and among others,[239] specifically caregivers,[180,239,252] healthcare providers (within and/or outside healthcare organization),[173,204,205,214,239,244,246,248,252,253] and trusted institutions[252]
		  ○ communication, including what is submitted to physician (e.g., ability to create own topic);[253,254] when and how information is received[247,248,255] and requested;[250] and more options for and control over with whom they are communicating[34,69,173,208]
		• Reminders (e.g., upcoming appointment, refill prescriptions, preventive care)[239,245,246,252] and notifications when new content or features available,[239] including new data such as laboratory results[209,251] and secure messaging activity[208]
		• Other features/functionalities added, including for self-tracking (e.g., diary),[250,252] decision making (e.g., advance care planning),[239] peer-to-peer support (e.g., online health forum),[239] and inpatient stay (e.g., more entertainment/non-health content and the ability to order food online/room service)[180,181]
		• Other features/functionalities improved, including for reviewability (e.g., ability to record and store videoconference visits[250]), convenience (e.g., automatic upload of home readings from different types of devices[245,250]), flexibility (e.g., printer-friendly formats,[244,253] ability to set different reminders for weekdays and weekends,[255] to have reminders work in different time zones,[255] and to adjust the frequency of reminders[250]), and awareness (e.g., preview of messages[250] and the ability to track status of a question[34] and delivery of filled prescriptions[239])

Usability	17 (40.5%)	• More user-friendly format, easier to use and navigate (e.g., important tabs/features visible, keep simple, include standard email features)[69,208,209,237,239,248,250,254,256–258] • Better display of information,[257] especially laboratory results (e.g., provider annotations, highlight abnormal, graph)[180,243,248] and large amounts of information[34,180,208,248] • More platform options (e.g., smart phone application)[204,239,250,254] • Burden to log-in to be minimized (e.g., automatic log-in from email)[209,219,247] • Improved accessibility (e.g., visual impairment, multiple co-morbidities)[208,209,247] • Other usability improvements,[243] including reduced constraints (e.g., days/times blocked from online appointment scheduling),[247] and notifications before automatic actions (e.g., before a session times-out)[239]
Training and Ongoing Support	11 (26.2%)	• Education, training, or support[69,173,212,219,221] (person, not web-based video or guide,[237,259] and someone outside of the busy clinical team[247]) • More or clearer instructions,[247,257,258] including examples of appropriate questions and comments (secure messaging)[34]
Implementation	2 (4.8%)	• Organization-wide acceptance, with portal use embedded in routine practice, and uniform patient experience (e.g., implementation of features, response times)[173,247] • Marketing that captures patient stories[247] and that promotes proxy users[247] • Computer literacy screening[247]
*NOTE: Percentages do not add to 100%, because many studies reported more than one category.		

2.5. Discussion

A relatively small proportion of the patient portal literature reported patient or caregiver suggestions to improve patient portals. Among those that did, the most common requests were to improve the information provided through the portal (e.g., more timely information, better or more explanations of medications and laboratory results) and its features and functionalities (e.g., support for communication with providers). These desired improvements underscore the gaps between the work patients are doing, including illness work (e.g., learning about their condition), infrastructuring work (e.g., sharing medical records between different providers), and articulation work (e.g., advanced care planning), and the predominant design of patient portals. While there are several logistic and organizational policy implications of these findings, such as related to the timing of the release of laboratory results through portals (i.e., in general, sooner is better), I am going to focus my discussion around three key overarching recommendations based on these findings and for better supporting patient work: (1) support human connection; (2) give patients and caregivers more control and design for variation; and (3) keep innovating.

2.5.1. Support Human Connection

First, whether it is features that connect them to their healthcare provider(s), caregivers, or peer patients or how they are introduced to the portal and receive technical support, patients and caregivers want human connection. This may be especially true for certain populations that have been less likely to adopt and use patient portals (e.g., older adults).[e.g.,248] In terms of connecting patients and providers, many portals offer secure messaging, and videoconferencing tools are also becoming more common.[260] However, in addition to usability issues with portals that can make it difficult for patients to find and use these features,[e.g.,208] healthcare provider acceptance of these tools varies significantly, which also affects patient acceptance.[e.g.,208,221,261,262] Thus, it is important to continue to improve these features, including by making them intuitive to use (e.g., making the secure messaging feature similar to commonly used email clients[208]) and by making all virtual interactions reviewable so that cognitively and emotionally burdened patients and caregivers are able to revisit the interaction at their convenience.[250] Furthermore, taking steps to promote provider acceptance is critical. For instance, research suggests that pre-implementation efforts such as reassuring providers that the organization is ready for the change was associated with healthcare provider support for a portal.[263] It also includes addressing the common provider concerns about disruptions in workflow, increased workload, and reimbursement for virtual interactions.[e.g.,264,265]

Unfortunately, there can be tensions inherent to balancing patient and healthcare provider needs. For example, one of the ways that many healthcare organizations have addressed physician concerns about secure messaging is to have another member of the healthcare team (e.g., medical assistant, nurse) first review and triage the messages, reducing the number of messages to which the physician must respond. However, this can be contrary to patients' desire to have more control over with whom they communicate through secure messaging. In this case, one potential solution that also aligns with the results of this review is simply increasing the transparency around how a particular provider handles secure messages (i.e., do they personally review and respond to all messages?). Exploring patient perceptions of such compromises is a key avenue for future research.

Beyond connecting patients and healthcare providers, patient portals also have the potential to provide social supports (e.g., informational, emotional)[266] to patients and their caregivers, among families, and among peer patients. Supporting existing relationships and providing a space to build new ones around shared health experiences and needs, especially for those with complex situations (e.g., families with multiple children with health conditions), are important ways that patient portals could be improved to better meet patients' needs.

2.5.2. Give Patients More Control and Design for Variation

Second, many patients and caregivers want more control over their health record and, as mentioned above, communications with healthcare providers. Part of this control includes being able to contribute to their medical record both in terms of adding data (e.g., patient-generated health data such as self-tracking data) and making changes (e.g., if a mistake is identified). While there may be barriers to giving patients more control (e.g., liability issues with allowing patients to amend their record without any restrictions), in some cases it may be possible. For instance, early research suggests that co-authoring clinician's notes could be feasible, acceptable, and beneficial.[52,267] Opportunities for more patient contribution to and ownership over their medical record should continue to be explored. Not only does this align with what patients want, but also respects their autonomy and empowers them to be a true partner in their healthcare.

With that said, patients are not a monolith. Even among patients that share similar characteristics (e.g., in the same age group), there can be significant variation in what patients want (e.g., simplified versus comprehensive).[e.g.,248] Now consider the vastly different contexts of the spectrum of patients and caregivers – from patients who only interact with the healthcare system when they have an acute illness (e.g., influenza) to patients that generally only need annual preventive care visits to patients with a chronic condition to patients with multiple chronic conditions to parents of multiple children with chronic conditions (and everything in between). A portal that meets patients' and caregivers' needs must be designed for this variation and must be flexible, enabling customization based on the user's needs, preferences, and values. This could also give users some of the control that they desire.

2.5.3. Keep Innovating

Finally, our findings suggest that patients and caregivers recognize the unmet potential of patient portals and want them to do and be more to better align with their needs and work. For example, patients want access to medical records from multiple providers regardless of institutional boundaries.[e.g.,209] In addition, they also want to receive contextualized medical advice[219] and decision support[239] through the portal. Rather than just meeting minimum requirements set forth through Policies such as the 2009 HITECH Act,[27] continued innovation, both in terms of the technology and policies at the organizational level and beyond, is needed in order for portals to truly achieve their potential.

2.5.4. Limitations

This systematic literature review has several limitations. One of the most important is that research suggests that key voices are largely missing from the patient portal literature (e.g., low-income patients) and, thus, we likely have an insufficient understanding of what these patients and their caregivers want. More research focusing on these populations and how to improve their adoption and use of patient portal technology is needed.[268] In addition, while users recommended these improvements to patient portals, and there is some evidence to suggest that implementing user suggestions is correlated with improve adoption and use,[239] few studies have evaluated the effects of making these improvements. Future research should investigate which improvements are most effective in different contexts. Finally, while two reviewers participated in the screening phase of the review (where the majority of papers were excluded), only one reviewer assessed the full texts, which could have introduced bias. Despite these limitations, this systematic review provides important insights into what patients and their caregivers value in portals, which is important for a user-centered design approach. A natural next step would be to assess to what extent major electronic health record vendors' portals meet the patient and caregiver needs described in this paper.

2.6. Conclusion

Understanding what users and potential users want from patient portals, and improving portal design accordingly, could be an effective way to increase adoption and use. Existing research suggests that patients and their caregivers want more human connection and control over their health record and their communications with their provider(s) through the portal, as well as more innovation. However, more research is needed to ensure that all patient voices are heard and to evaluate the effects of improving portals based on patient and caregiver suggestions.

CHAPTER 3. The Interoperable Health App Ecosystem at the Start of the 21st Century Cures Act

3.1. Motivation and Summary

While Chapter 2 focused on patient and caregiver perspectives of how to improve the predominant method of patient access to their electronic medical record (i.e., patient portals), this chapter concentrates on a newer method promoted through the 2016 21st Century Cures Act – standards-based application programming interfaces (APIs). Figure 3.1 highlights the relationship between these two methods of access, illustrating that, unlike patient portals, this method has the potential to feed an ecosystem of mobile health applications (apps) that leverage that data for the benefit of the patient or populations. Unfortunately, little is known about the current status of this technological ecosystem.

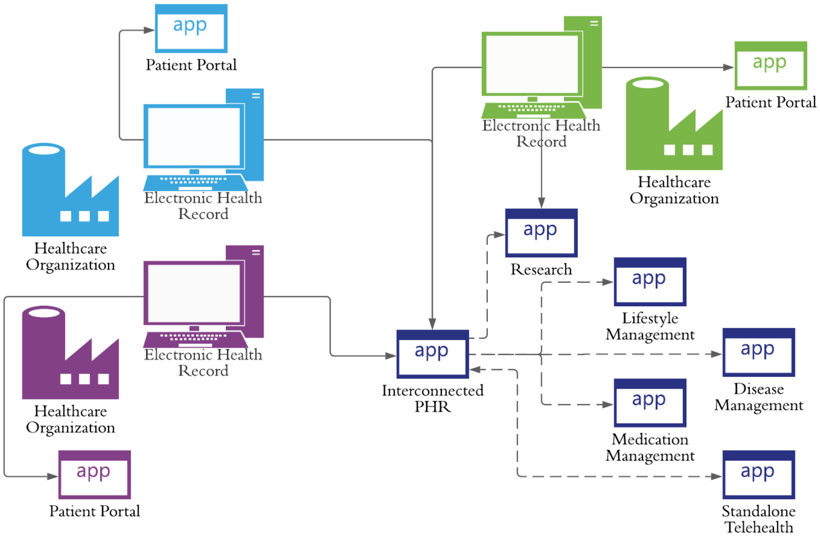

Figure 3.1. Flow of clinical data to patient portals linked to specific healthcare organizations (purple, blue, and green) compared to the envisioned interoperable mobile health app ecosystem (dark blue).

The objective of this study was to investigate the state of the interoperable mobile health application ecosystem at the start of the 21st Century Cures Act to understand the opportunities currently available to patients for accessing and using their computable clinical data. Towards this end, I sought to identify third-party mobile health apps in the Apple App and Google Play Stores capable of automatically downloading clinical data via a FHIR-based application programming interface through a targeted review of health apps. I found that seven of the 599 consumer-oriented iOS health apps (1.2%) and only one of the 513 Android apps (0.2%) had this capability. Ultimately, my results suggest that this is a nascent market space. If barriers to app development are not identified and addressed, and efforts are not made to educate patients and improve discoverability of apps, it could mean that patients will not benefit from these interoperability measures.

3.2. Introduction

Providing patients with access to and control over their own clinical data is critical to empowering them to be partners in their healthcare, which research suggests has numerous benefits such as improved health outcomes.[269] It also presents opportunities for patients to contribute these data for the benefit of society (e.g., public health surveillance, clinical research). Although the 1996 Health Information Portability and Accountability Act (HIPAA) gave patients in the U.S. the right to access their clinical data,[270] barriers have remained, including cumbersome processes, costs, and long turn-around times.[271–273] Recent U.S. policies have sought to address such barriers. The 2009 HITECH Act, for example, not only significantly increased electronic health record (EHR) adoption among healthcare organizations, but also required healthcare organizations to provide patients with electronic access to their data.[27,29,30] This was primarily achieved through web- and mobile phone application (app)-based patient portals linked to healthcare organizations' EHR systems. Unfortunately, siloed patient portals provide very limited options for patients to combine their data across healthcare organizations in order to have a complete record and to make effective use of these data.

To address these problems and in acknowledgement of the 85% of U.S. adults owning smartphones,[274] the 2016 21st Century Cures Act, along with the 2020-2025 Federal Health IT Strategic Plan, emphasizes the importance of facilitating patient access to and use of their computable personal health information through an interoperable mobile health app ecosystem.[33,238] A robust ecosystem could reduce administrative burdens such as manual data entry into apps, offering patients opportunities to more efficiently and effectively manage their health and healthcare, as well as facilitating participation in public health and medical research efforts. To achieve this vision, certified EHR systems are now required to use the HL7 Fast Healthcare Interoperability Resources (FHIR®) standard to provide third-party health apps access to clinical data through application programming interfaces (APIs).[238]

Although there are a number of existing studies on third-party health apps, these are largely focused on self-tracking apps that collect data (e.g., steps, diet)[275–277] or apps developed for research purposes and only available to study participants.[278,279] These studies provide valuable knowledge, but do not offer insights into the broader health app markets nor on third-party apps that can import clinical data. In addition, other studies have reported on the development and evaluation of information technologies that provide FHIR capability,[280–282] but less is known about the apps that can leverage this capability.

To address these gaps and to understand the status of the clinical data-driven app ecosystem as the 21st Century Cures Act goes into full effect, I conducted a targeted review of health apps from the Apple App and Google Play Stores. I aimed to identify and characterize third-party apps capable of automatically downloading clinical data either (1) directly through a FHIR-based API, or (2) indirectly through a mobile, smartphone-based interconnected personal health record (miPHR) such as Apple Health Records (AHR)[283] and CommonHealth.[50] I was particularly interested in whether there are differences in the digital health app ecosystems that are emerging for iOS and Android users.

3.3. Methods

I used a three-stage approach to identify and characterize relevant apps: (1) sampling health apps in the Apple App and Google Play Stores, (2) categorizing all sampled health apps, and (3) identifying and characterizing the relevant apps among the consumer-oriented health apps in the sample. This approach also enabled us to get a broader understanding of the current health app markets, offering insights into opportunities for expanding the digital health app ecosystem.

3.3.1. Sampling Health Apps

I created two samples of health apps. The first from the Apple App Store and the second from the Google Play Store. To create an initial sample of iOS apps, I used a similar approach to Kim, Lee, and Choe, who focused on the most popular iOS health and fitness apps to understand the data accessibility of self-tracking apps.[275] I defined "popular" based on Apple's "Top Free" and "Top Paid" health and fitness and medical category-specific charts;[284,285] this resulted in a list of 600 apps. In addition, early discussions of the digital health app ecosystem included four use cases for third-party apps that may be able to use imported clinical data to improve their functioning: (i) "medication tracking," (ii) "disease management," (iii) "nutrition planning," and (iv) "medical research."[286] Thus, I also did targeted searches of the Apple App Store using the keywords: "medication," "disease management," "nutrition," and "research." Only apps categorized as health and fitness or medical in the app store were included in the sample. This approach resulted in 200 unique apps added to the list for a total of 800 iOS apps.

I followed a similar procedure for the Google Play Store. The initial list included 14 popular health and fitness and medical apps. Of note, there did not appear to be category-specific lists for the Google Play Store, so these apps are from the overall list of popular Android apps. I then did the same targeted searches as described above. I identified 597 additional unique apps for a total of 611 Android apps.

3.3.2. Categorizing Health Apps

I used a qualitative content analysis approach[287] to categorize the sampled health apps. First, a research assistant and I created an initial coding scheme by reviewing iOS app descriptions and discussing emerging categories. In particular, we noted that not all apps were consumer-oriented health apps (e.g., study materials for medical students). We developed high-level categories to capture this: Consumer, Healthcare professional, Veterinary care, Not available (e.g., not available in the US, not in English), and Not health focused (e.g., aptitude test). Only available consumer-oriented human health apps were eligible for further analysis. Second, we used a primarily inductive approach to identify emerging categories within the consumer app category; however, we did also include three of the four previously mentioned use cases (disease management, medication management, and research), with the nutrition use case being combined with other lifestyle management apps such as those focused on fitness. The research assistant and I used this coding scheme to independently categorize 10% of the iOS apps (N=80) and the Android apps (N=62). The Scott's pi coefficient was about 0.8, which is considered substantial agreement.[288] We resolved all differences through discussion and continued to refine the coding scheme accordingly. We then each coded half of the remaining iOS and Android apps using the final coding scheme presented in Figure 3.2. Apps could be placed in more than one category.

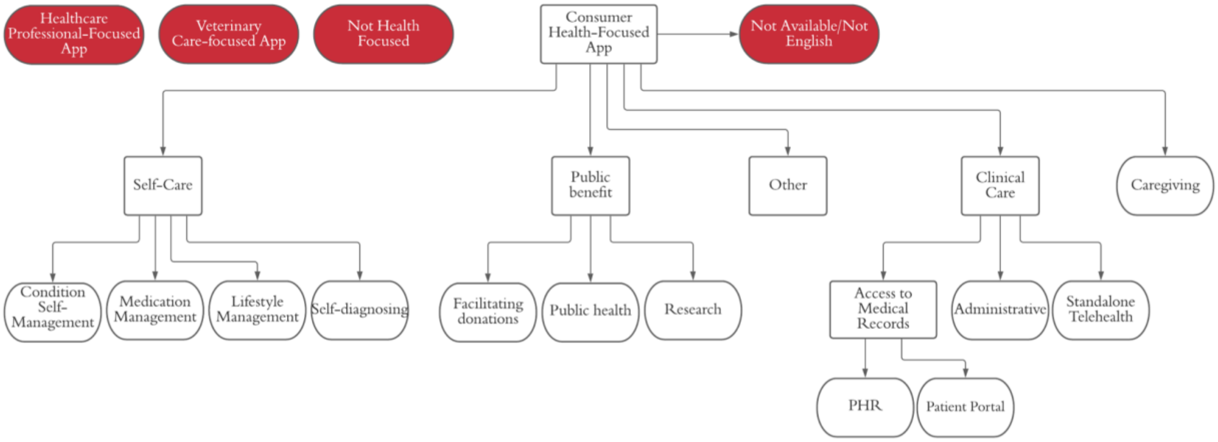

Figure 3.2. Final Health and Fitness and Medical iOS and Android app coding scheme.

3.3.3. Identifying Relevant Health Apps

The research assistant and I first used an iterative, keyword-based approach to identify potentially relevant consumer-oriented health apps. In reading iOS app descriptions, we developed the following list of keywords: "apple health," "apple health record," and "healthkit." We focused on Apple Health Records-related keywords because it is one of the most widely available miPHRs with connections to nearly 700 healthcare organizations across the US and eight in Canada and the United Kingdom,[49] making it the most likely mechanism by which other iOS apps will gain access to clinical data. In addition, given our focus on identifying apps using FHIR-based APIs, we included the keywords "fhir" and "api." We also used these two keywords to search Android app descriptions and added the term "commonhealth." We included CommonHealth because it is an Android-based miPHR with connections to a growing number of healthcare organizations that, similar to Apple Health Records, also aims to enable patients to grant other apps access to their clinical data. To ensure that we did not miss relevant keywords, we took a 10% random sample of iOS apps that were not retrieved through keyword search and reviewed the descriptions for relevance. If we had found relevant apps that were missed, we would have tried to identify additional keywords to include in our search. However, we did not identify any relevant apps through this process.

For apps with keywords, the research assistant and I independently reviewed the descriptions of all the apps and, if necessary and possible, screenshots of the app and the downloaded app itself, and judged whether it appeared to be able to automatically download clinical data directly through a FHIR-based API or indirectly through a miPHR. We discussed and resolved any differences in opinion, resulting in a final list of apps that seem to be relevant. I then characterized these apps by extracting pre-defined elements, including average rating, number of reviews, types of clinical data used, method of clinical data access, and privacy policy.

Finally, we also initially sought to understand user perceptions of the capability of granting access to their clinical data to these apps through studying app reviews. However, after reviewing a sample of 140 of the over 1,200 most recent reviews for five relevant apps and conducting searches for terms such as “medical records” and “EHR,” we found that users did not seem to be discussing this feature in their reviews. This could suggest that this feature is not available as stated in the app description; it is available, but those who chose to write reviews were not aware of the feature; the reviewers were aware of the feature but chose not to use it; or they were using the feature but did not have strong feelings about it. End-user perceptions should be directly investigated in future studies.

3.4. Results

Figure 3.3 presents an overview of our process and results. Specifically, we found that 599 of the 800 iOS apps (74.9%) and 513 of the 611 Android apps (84.0%) were consumer-facing human health-related apps. Two hundred and seventy-seven of these iOS apps and 4 Android apps contained keywords, with 'apple health' being the most frequently identified. After manual review, we determined that only seven iOS apps (1.2%) and one Android app (0.2%) appear to be capable of automatically downloading clinical data either directly through a FHIR-based API or indirectly through a miPHR (referred to as relevant apps).

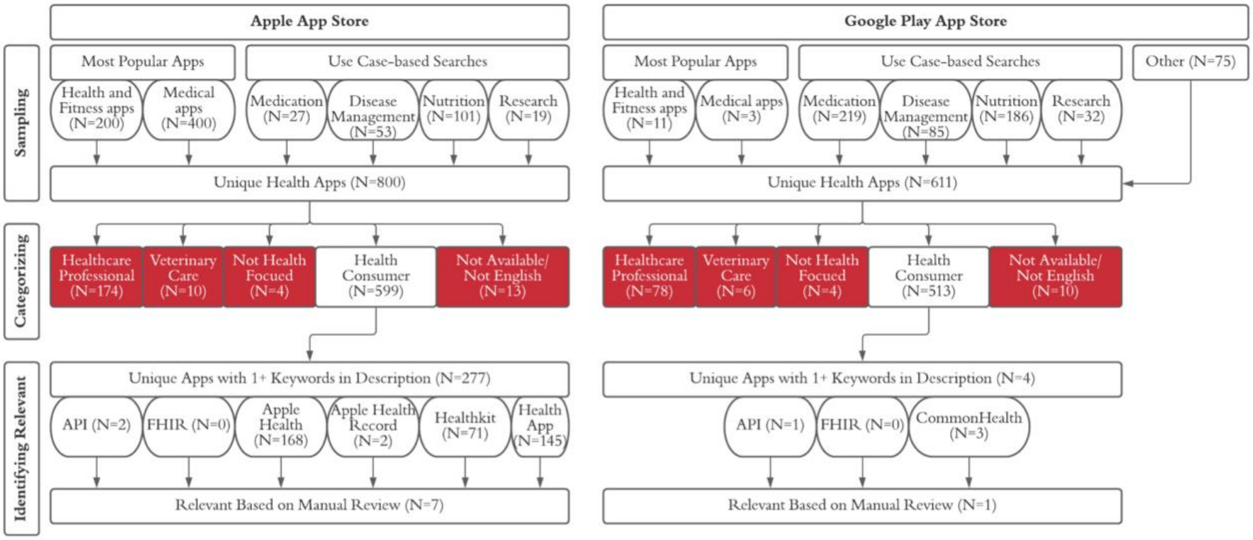

Figure 3.3. Summary of research process and results.

Among all consumer-oriented human health apps, and as Figure 3.4 shows, self-care apps were the most common for both iOS (N=451) and Android (N=389). However, the distribution of apps within this category was different, with Android having a larger percentage of medication management apps (33% vs. 5%) and iOS having a larger percentage of all other self-care sub-categories. Relevant apps fell into five categories: PHR (iOS: DrOwl-Med Records & Telehealth[289]), condition self-management (iOS: Livongo[290]), medication management (iOS: Medisafe Medication Management[291]), standalone telehealth (iOS: MDLIVE,[292] DrOwl-Med Records & Telehealth[289]), and research (iOS: doc.ai,[293] All of Us Research,[294] All of Us Research Program;[295] Android: Research by doc.ai[296]).

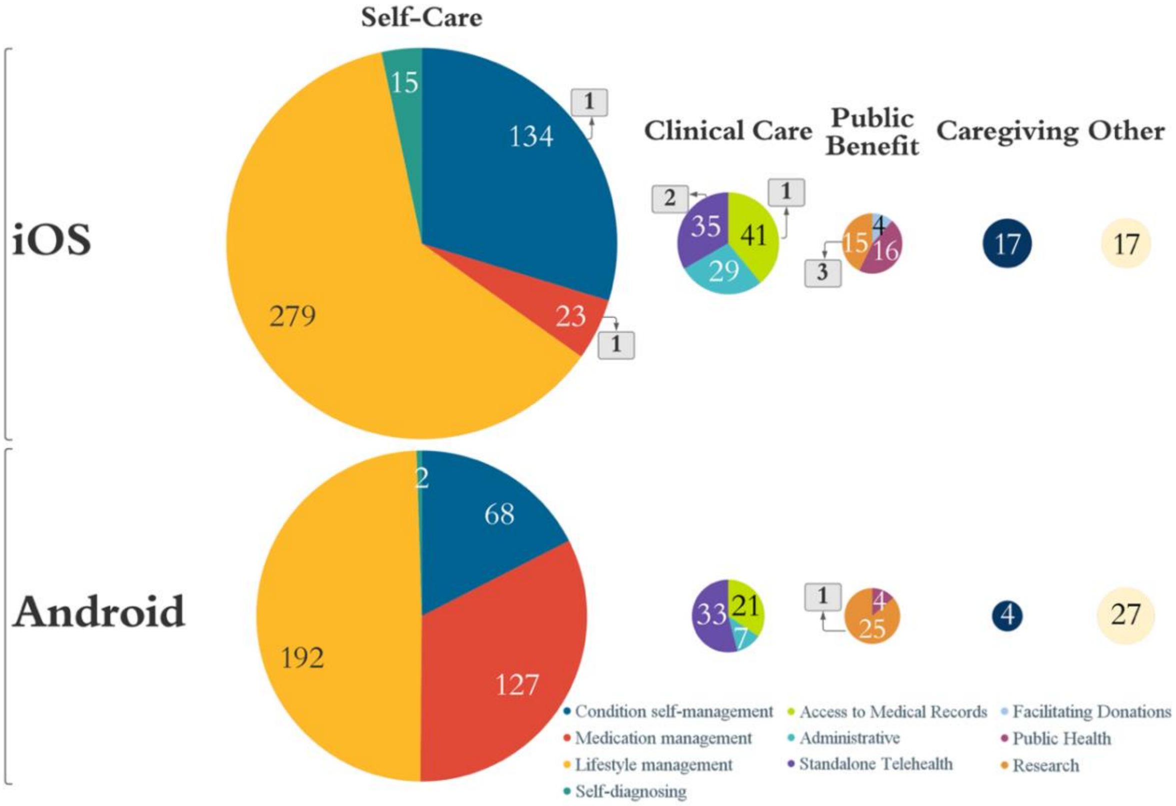

Figure 3.4. Summary of categories of consumer health iOS and Android apps. Numbers in circles are total category counts. Numbers in gray boxes are number of relevant apps identified in that category.

Table 3.1 presents an overview of these apps and their characteristics. Three of the seven iOS apps, as well as the one Android app, were originally identified through the "research" App Store searches and the remaining iOS apps were on the "Top Free" Medical

Chart. Livongo (Average Rating: 4.8, N=13,200), MDLIVE (Average Rating: 4.7, N=49,200), and Medisafe (Average Rating: 4.7, N=53,400) are the highest rated iOS apps with this feature and also have the most reviews. The one Android app, Research by doc.ai, has an average rating of 4.2 (N=5). All of the relevant apps were classified as free in the app stores; however, Medisafe offers in-app purchases.

Table 3.1. Summary of iOS and Android apps that appear to be capable of automatically downloading clinical via a FHIR-based API.

App Name	App Store	App Store Category	Category	Originally Identified (Sampled)	Keywords in Description	Method of Clinical Data Access	Clinical Data Elements Imported	Average Rating (N)
Livongo[290]	Apple	Medical	Condition Self-management	Top Free Medical	'apple health', 'healthkit'	Indirect (AHR)	Lab results	4.8 (13,200)
Medisafe Medication Management[291]	Apple	Medical	Medication Management	Top Free Medical	'healthkit', 'health app'	Indirect (AHR)	Medications	4.7 (49,200)
MDLIVE[292]	Apple	Medical	Standalone Telehealth	Top Free Medical	'healthkit', 'health app'	Indirect (AHR)	Medications, Allergies	4.7 (53,400)
DrOwl-Med Records & Telehealth[289]	Apple	Medical	PHR, Standalone Telehealth	Top Free Medical	'apple health', 'healthkit'	Direct	Medical records	3.2 (27)
doc.ai[293]	Apple	Health & Fitness	Research	App Store Search	'apple health', 'healthkit'	Indirect (Human API, AHR)	Lab results	3.9 (435)
Research by doc.ai[296]	Google Play	Medical	Research	App Store Search	'API'	Indirect (Human API)	Medical records	4.2 (5)
All of Us Research[294]	Apple	Health & Fitness	Research	App Store Search	'apple health', 'apple health record'	Indirect (AHR)	Medical records	3.9 (26)
All of Us Research Program[295]	Apple	Health & Fitness	Research	App Store Search	'healthkit'	Indirect (AHR)	Medical records	3.5 (111)
Abbreviations: PHR= Personal Health Record, AHR=Apple Health Records								

In terms of importing clinical data, two of the relevant apps claimed to pull in laboratory test results, two medications, and one allergy information. Four simply stated that they import medical records, presumably meaning that they pull all available clinical data elements. Almost all of the relevant apps appear to use an indirect method to obtain these data, with only one seeming to directly connect to healthcare organizations' EHRs via API access (iOS: DrOwl-Med Records & Telehealth[289]).

Table 3.2 highlights privacy aspects of the relevant apps. Only four of the relevant apps had privacy policies that mentioned the Health Insurance Portability and Accountability Act (HIPAA), which is the legislation that protects individuals' medical records.[270] In addition, two apps did not provide details of the data elements that are linked to the individual and those that are not at all, and two others claimed that elements such as 'identifiers' were not linked to the individual. While it seems that some app stores, namely Apple App Store, are trying to put in place mechanisms for making the data practices of app developers more transparent, there may be gaps in oversight that limit the effectiveness of these efforts. It remains unclear from the publicly available policy details to what extent these apps protect users' clinical data.

Table 3.2. Summary of the privacy policies of iOS and Android apps that appear to be capable of automatically downloading clinical via a FHIR-based API.

App Name	App Store	Policy Mentions HIPAA?	Data Elements Linked to Individual	Data Elements Not Linked to Individual
Livongo	Apple	Yes	Health & Fitness, Contact Info, Identifiers, Usage Data	Diagnostics
Medisafe Medication Management	Apple	No	None	Health & Fitness, Contact Info, User Content, Identifiers, Usage Data, Diagnostics
MDLIVE	Apple	Yes	None	Usage Data, Diagnostics
DrOwl-Med Records & Telehealth	Apple	Yes	Health & Fitness, Contact Info, User Content, Identifiers, Usage Data, Sensitive Info	Location, Contact Info, Search History, Usage Data
doc.ai	Apple	No	No Details Provided	No Details Provided
Research by doc.ai	Google Play	Yes	No Details Provided	No Details Provided
All of Us Research	Apple	No	Health & Fitness, Contact Info, User Content, Search History, Identifiers, Usage Data, Sensitive Info, Diagnostics	None
All of Us Research Program	Apple	No	Health & Fitness, Contact Info	Sensitive Info, Diagnostics

3.5. Discussion

Through this study, I sought to investigate the current state of the envisioned ecosystem of health apps capable of automatically downloading clinical data via FHIR-based APIs at the start of the 21st Century Cures Act. While a thriving ecosystem may have the potential to reduce some patient health information management and infrastructuring work (i.e., to access, integrate, and use their clinical data from different healthcare contexts and over time) and offer patients flexible, convenient tools for managing their health and illness, as well as opportunities for donating their clinical data for public benefit,[297,298] the results of our extensive search show that there are currently limited options for patients. Among the available apps with this capability, most use an indirect method of access via a miPHR such as AHR. This study has implications for healthcare organizations, health IT developers, app stores, and researchers.

First, increased patient awareness of the new access method (standard-based APIs) and improved discoverability of apps with this capability are essential to creating the demand that could encourage health IT developers to leverage automatic importing of clinical data. Existing research suggests that many patients may be unaware of the new approach for accessing their medical records established via the 21st Century Cures Act as healthcare organizations have not advertised it.[59] While it is understandable that healthcare organizations may not want to appear to be endorsing specific apps, it is unlikely that these provisions of the 21st Century Cures Act will benefit patients without educating them on the new approach and the corresponding opportunities and potential risks. Some third-party apps seem to be taking on this role; for instance, one PHR app states in its description, “Download the app to see the complete list of healthcare organizations we support. If you've visited healthcare organizations that aren't in the app yet, just ask the organizations to connect to Coral Health and they will be legally required to do so."[299] However, the reach of such education efforts is limited. Thus, healthcare organizations have a critical role in increasing patient awareness of these key aspects of the 21st Century Cures Act.

In conjunction with these education efforts, app stores should consider adding a discrete flag for easier patient identification of third-party apps that are capable of leveraging FHIR-based APIs to automatically import clinical data. Our study showed that it was incredibly difficult to identify apps with this capability in the Apple App and Google Play Stores, suggesting that patients may also have trouble finding apps with this feature. Including a flag would improve discoverability of these apps for patients, reducing the work patients must put into finding this type of technology, and also facilitate future research, which is critical for both Policy and technology evaluations. A public registry of trusted apps with this capability could also serve a similar purpose but may not be as convenient for patients.

Second, our results suggest that there may be barriers to health IT developers leveraging this capability in their apps. There are a substantial number of health apps available in the Apple App and Google Play Stores. However, few offer the opportunity for patients to use their own clinical data to personalize and improve the experience of these apps, especially for personal health management. There seems to be substantial room for growth. For example, only one of the 150 medication management apps included in our study seems to have this capability. So, why are more third-party apps that might be able to make use of clinical data not yet offering this feature? It is possible that some app developers do not see the value or have other priorities. Perhaps some are hesitant due to privacy concerns surrounding clinical data. Understanding the barriers to app development is a critical topic for future research.

In addition, the Android-based options seem to be lagging behind iOS. This may simply be because AHR has been available longer than the primary Android-based option, CommonHealth. However, even many of the early adopters that download clinical data from

AHR do not seem to offer this same capability for Android users. It is possible that these app developers are waiting for CommonHealth to have a larger user-base (at the time of writing it had 5,000+ installs[300]). The CommonHealth website also states, "only approved applications will be allowed to request data from CommonHealth."[301] Although this may be important for protecting users' privacy, perhaps this additional process is creating a delay for Android-based third-party apps hoping to download clinical data through this mechanism. To avoid digital health disparities, it is critical for future research to identify and address any Android-specific barriers and for Android app developers to make it a point to offer this feature.

Finally, in terms of use cases for third-party apps that may benefit from automatically downloading clinical data, there appears to be an emerging opportunity for making clinical data more accessible and useful for patients by importing existing patient medical records into standalone telehealth apps for use in the provision of digital healthcare services, which could reduce patients' infrastructuring work. This type of app appears to be becoming more common and, uniquely, could offer the two-way flow of clinical data, with data produced during these virtual visits also flowing back into the miPHR. I identified a number of standalone telehealth apps, but most with data sharing capabilities currently seem to be focused on self-tracked data, with only one integrating clinical data. Developers of this type of app should consider offering patients the option of incorporating clinical data as well. Apple and CommonHealth should consider whether and how to include records from digital healthcare visits not associated with the traditional physical healthcare organization model.

3.5.1. Limitations

This study has similar limitations to Kim, Lee, and Choe, and other studies of the dynamic app market.[275] Specifically, there are two major limitations. First, over the study period descriptions of apps evolved and some apps became unavailable; thus, this study provides a snapshot and baseline at the start of the 21st Century Cures Act. Second, while I did download apps and review websites for additional details when necessary and possible, I was primarily limited to what was stated in the app description and shown in the screenshots, which may not always be very clear or detailed. For example, in the case of several standalone telehealth apps, they stated that they connected to the Apple Health app to share data elements such as weight. Since weight can be manually input by the user, automatically input by a smart scale, or recorded by a healthcare provider and stored in Apple Health Records, I had to test these apps in order to determine whether it was relevant to our study. In addition, it is possible that some apps simply do not include whether they are able to automatically retrieve clinical data in their descriptions. I feel this is unlikely, though, given (1) the competitive advantage it could give the apps, especially for users with chronic and complex conditions and (2) the push towards greater transparency in data collection and use across apps. Regardless, I urge app developers to be clearer in their descriptions about the flow of health data into and out of their app, especially clinical data, so consumers can make an informed choice based on their privacy and security preferences.

3.6. Conclusions

Research is needed to understand why more app developers do not appear to be leveraging the APIs that must now be offered by certified EHRs to incorporate clinical data into third-party health apps and why the iOS and Android app markets seem to differ. If these questions are not addressed and the markets do not pick up, it is possible that patients will not benefit from the direct patient access interoperability measures of the 21st Century Cures Act and that the vision for an integrated digital health ecosystem may not fully come to fruition. Even worse, this legislation could end up creating digital health disparities by benefiting iOS users more than Android users.

CHAPTER 4. Typology of Confusion related to Laboratory Test Results and Support Received in an Online Health Community

4.1. Motivation and Summary

While easy patient access to their medical records, such as through patient portals and miPHRs, is necessary for patient engagement in their healthcare, it is not sufficient to enable patients to thrive in this role – they must be able to understand and act upon the data in these records. As Section 1.3 surfaced, patients often have trouble understanding the information provided through patient portals[35,57,67,69,204,209–215] and, correspondingly, Chapter 2 showed that patients and caregivers want more and better explanations with their medical records, especially laboratory test results, medications, and medical jargon.[34,178,202,209,221,223,245–251] Although there have been fewer studies of miPHRs, they tend to present clinical data in a simple form with limited explanation and, thus, may have similar barriers to adoption and use. So, how can we improve technologies that offer patients access to their clinical data to better meet their needs at the point of viewing?

This pilot study sought to address this question through a unique perspective – exploring (1) questions containing laboratory test results posted to an online health community (OHC) and (2) the answers from the OHC. Our qualitative content analyses revealed a typology of confusion (i.e., topics of their questions) and potential gaps in traditional healthcare supports (i.e., patients' requests and situational factors), as well as the supports patients may gain through the OHC (i.e., what the community provides). These results offer preliminary evidence of opportunities to redesign technologies such as patient portals and miPHRs.

4.2. Introduction

The clinical data (e.g., laboratory results, clinician notes) contained in medical records have long been a product of, and central to, the interactions that take place between patient and physician in a clinical encounter. These data were traditionally created, updated, and used almost exclusively by physicians. However, research suggests that providing ready access to medical records facilitates patient engagement,[143] which can lead to improved health outcomes and reduced costs.[269] While patients have had the right to access these records since 1996,[270] the process of requesting a paper copy has tended to be prohibitive and, once obtained, can soon become difficult to manage and are easily lost.[302] To address these barriers, U.S. health IT policies such as Meaningful Use,[303] and initiatives such as OpenNotes,[18] have encouraged that patients be given direct, electronic access to their medical records. In response, many healthcare organizations have deployed patient-facing technology, commonly referred to as patient portals, connected to their electronic health record systems. The literature suggests that patient use of these portals may have numerous benefits, including improved quality of patient records,[12] home monitoring infrastructure,[8] satisfaction with patient-provider communication,[55] and health status.[305] However, despite these potential benefits, patients have not accessed the portals[306] at the rates predicted based on the high level of interest.[307] In fact, according to the 2020 U.S. Health Information National Trends Survey, only about 39.5% of Americans had used a patient portal in the past year.[58] Newer mechanisms of patient access to electronic clinical data, such as miPHRs, appear to have far lower adoption rates.[59] Even more concerning is the significant disparities in access, adoption, and use found among certain groups, including based on race,[306] age[308] and, as Chapter 3 showed, the type of smartphone one owns.

So, why has ready access not resulted in *more access*? According to the literature, a key barrier to realizing the full potential of patient portals is patients' perception of a lack of *useful information*; for example, a recent study found that many patients' needs for online portals were not just for accessing data, but for obtaining *personalized and actionable knowledge*.[35] These needs, however, have not been adequately met in the pervasive patient portal design. Relatedly, low health literacy and numeracy, meaning a lower "capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,"[73] can be a barrier to patient portal use.[67] Many portals present data to patients in the same or similar way that it is presented to healthcare providers; however, studies have shown that patients may have difficulty understanding medical jargon used in free-text documents, such as clinician notes,[67] and interpreting quantitative data, such as laboratory results.[69] These findings suggest that current patient portals may have been designed at too high of a level of health literacy and numeracy, or do not provide enough, or the right, support to aid patient understanding. It is possible that some of these issues may be compounded in miPHRs where data from multiple healthcare organizations may be integrated and there are often even fewer explanations.

At the same time, there is often not enough time during a clinical encounter to fully meet patients' needs for knowledge. While it varies by healthcare setting (e.g., primary care, specialty care), there is evidence suggesting that, on average, healthcare providers are spending less time with each patient – from over 20 minutes per patient in 1998, to around 17, or even lower, in 2016.[145,147] A related issue is that studies have found that some doctors frequently interrupt patients,[309] which may make it difficult for patients to get their questions answered. These factors can also negatively affect the patient-provider relationship,[310] which may reduce the likelihood that patients will trust their healthcare provider. In sum, while healthcare organizations are expanding patients' access to clinical data, the technologies available for viewing these data often do not adequately meet patients' knowledge needs, and access to healthcare's traditional social supports,[266] including informational, is shrinking.

Therefore, in order to actually use the available data for personalized decision-making, patients must often tap into supplemental sources of knowledge. Increasingly, this means searching online for both general and individualized health information.[70] In fact, according to one study, 72% of U.S. internet users reported doing this.[70] There are, of course, a variety of online resources of varying levels of interactivity and quality from which patients may choose, but OHCs have been growing in popularity (e.g., CrowdMed[311]). These online communities provide users with a platform to ask their health-related questions, so that others (typically peer patients) can provide assistance.

Among the myriad patient questions, I was particularly interested in questions accompanied by data that appeared to be directly copied from the individual's medical record and pasted into the OHC post (or in some instances transcribed; *referred to just as copy and paste below*). Examples of such data include laboratory test results, vital signs, and excerpts from radiology reports and discharge summaries. This content is usually posted publicly, which provides an opportunity for researchers to understand the nature of patients' questions related to their clinical data. This offers direct evidence of comprehension issues, as well as additional forms of support that may be needed. Similarly, the nature of the answers to these questions, especially those that patients find useful, point towards the supports those patients may gain through the OHC discussions. While the insights from these analyses may have broader implications for patient-provider communication, in this study, I focused on the opportunities to improve the design of technologies that offer patients access to their clinical data with the goal of better meeting patients' needs at the point of viewing their medical records.

In this study, I preliminarily assessed the feasibility of this approach by focusing on a particular type of clinical data, laboratory results, which are widely available and frequently viewed in patient portals,[67] are a common source of questions,[312] and tend to be easier to identify in question posts than other types of clinical data. Similarly, I focused on one popular OHC.

4.3. Methods

4.3.1. Dataset

All questions and threaded replies from the OHC were downloaded in September 2016. This dataset contains over 2 million questions and over 8 million answers posted by over 2 million unique users on numerous health conditions (e.g., diabetes, asthma) and health-related topics (e.g., healthy recipes). Question posts on the OHC are very diverse; for example, patients may present symptoms and laboratory results in order to determine whether a clinic visit is necessary or request emotional support during a stressful time.

4.3.2. Identifying Potentially Relevant Posts

Before I could address my research objective – to understand the nature of question posts containing laboratory results that seem to be copied and pasted from medical records, and their threaded replies – I first needed to identify relevant posts. I did this in four steps.

The goal of Step 1 was to iteratively develop a list of keywords and determine the number of posts containing copied and pasted results from a test of biological samples such as blood, urine, and tissue (i.e., laboratory test results, relevant posts) returned by each. To do this, a research assistant and I utilized the live OHC website. Specifically, for each keyword (e.g., "lab result help"), we reviewed the first 90 posts (3 pages) of the results to (a) count the number of relevant posts; and (b) examine the "Related Questions" section for additional keywords to test.

Since it is difficult to develop a comprehensive list of keywords, and missing keywords could result in missing relevant posts, in the second step, I sought to identify features (patterns) that distinguish relevant posts from other posts. To do this, I translated the three keywords with the highest number of relevant posts ("Lab," "Blood work," and "Profile"), and their common alternative spellings, into three queries in the Indri Query language.[313] The final queries were run against an inverted index built over all the OHC question posts. Along with a research assistant, I then manually reviewed the retrieved results to identify the patterns indicative of copying and pasting (e.g., specific test name plus numeric result, such as TSH 0.11). During the review of the last 100 results (a total of 600 were reviewed), no additional general patterns were found, suggesting theoretical saturation had been reached.[314]

In Step 3, I encoded the identified patterns as regular expressions in Python v2.7. These regular expressions were tested against the annotated corpus created in the second step, and iteratively refined until at least 80% recall was achieved – i.e., if there are 100 relevant posts in the annotated corpus, at least 80 are retrieved.

In the fourth step, I applied the final regular expressions to the entire dataset, which returned almost 65,000 potentially relevant question posts – matched a pattern indicative of laboratory results copied from medical records and pasted into the question posted to the OHC.

4.3.3. Analyses

I generated an initial random sample of 1,000 of the potentially relevant question posts, and then retrieved all the threaded replies. At least one research assistant and I independently (1) reviewed posts for relevance, and (2) analyzed relevant posts, using a qualitative content analysis approach,[287] until no new information was emerging (theoretical saturation).[314] In addition, where possible, a "satisfactory" response(s) was identified based on the feedback of the person posting the original question (e.g., *"Thanks for info explains a lot."*), and the codes assigned to these posts were eventually compared to the codes assigned to posts not identified as "satisfactory" responses. The content analysis team met weekly to discuss and merge category lists; all disagreements were resolved through discussion. Importantly, if we had not reached theoretical saturation[314] after reviewing all posts in the initial sample, we would have repeated this procedure until we reached theoretical saturation.

For (1), question posts were determined to be irrelevant, and therefore excluded, if they did not contain any laboratory results, or contained results that were not from the individual's medical records (e.g., from a scientific study). Of the 400 question posts reviewed before theoretical saturation, 146 were relevant and, therefore, further analyzed (in 2). Likewise, when reviewing the threaded replies to relevant question posts, any duplicate posts or posts not attempting to answer the original question (e.g., using the thread to ask their own related questions) were excluded. Of the 500 reply posts reviewed before saturation was reached, 417 were eligible for further analysis (in 2), including 289 answers to questions and 128 replies from the original question poster.

Of note, I use the singular they/their throughout this Chapter, as gender identity is usually not apparent in posts even where biological sex can be inferred (e.g., individual talks about menstrual cycle in the course of asking their question). Finally, in reporting the results here, I take extra precautions to protect OHC users whose posts were included in this study.

Specifically, I have removed idiosyncrasies from posts (e.g., grammatical errors) and tested all quotes in a search engine. If the original post was retrieved through this search, I paraphrase the idea rather than directly quote.

4.4. Results

4.4.1. Question Posts

The reviewed sample of posts contained an average of 2.1 questions per post, with a range of zero questions (e.g., just providing an update) to six. Questions covered laboratory results not pertaining to any specified conditions, as well as to a wide range of identifiable conditions or concerns, including sexually transmitted infections (e.g., herpes); heart-related concerns (e.g., hypercholesterolemia); liver conditions (e.g., hepatitis); kidney and pulmonary function; hormone imbalances (e.g., testosterone); cancers (e.g., breast); and autoimmune (e.g., lupus) and thyroid disorders (e.g., hyperthyroidism). Furthermore, while some posts included questions exclusively about the laboratory results, many asked about laboratory results in the context of their medical history, symptoms, or both. I present the results of this analysis in three sub-sections: Topics, Requesting, and Situational factors.

Topics

While some posts included questions pertaining to more than one topic, most (~71%) focused on one of the following topics: diagnosis and cause, management and treatment, laboratory report, test/diagnostic, risk, and prognosis (see Table 4.1). In addition, sub-topic categories emerged as more specific descriptors of patients' questions. In this sample, questions were most commonly about medications, symptoms, and next steps. For example, the subject line of one post reads, *"Please tell me what to do next."* In the body of this post, it becomes evident that they are requesting help *"...pulling this [relevant medical history, laboratory test results, symptoms, etc.] information together..."* in order to get a step closer to identifying the cause of their symptoms. Less common sub-topics include effect of treatment (e.g., potential adverse effect), comorbidities (i.e., existing diagnoses), timing (e.g., how far apart treatments should be), risk behavior (e.g., alcohol use with certain conditions), and lifestyle (i.e., diet and exercise).

Table 4.1. Topics of copying and pasting question posts, and representative quotations.

Topics	**Representative quotation**
Diagnosis and Cause	"I am VERY afraid that the hypercalcemia [high level of calcium in blood] is being caused by a malignancy, but the Endocrinologist [specialist] is not worried…"
Management and Treatment	"What should my Armour thyroid [medication] dose be? Do I need a T3 level [another laboratory test]? Should I also be on Cytomel [medication]? What dose to start?"
Laboratory report	"What language would you expect to find in a [pathology] report for a patient who has not previously been diagnosed with cancer via biopsy?"
Test/Diagnostic	"… To my knowledge it [immunophenotype test] would get a stain of the cells in the sample and look for antibodies for HPV [Human Papilloma Virus], and if it found some it would try to find the type or strain?"
Risk	"I have been advised to do RAI [radioactive iodine] therapy, and told that if the uptake is the same, that the nodule will be the only area affected, but that there is a 10% chance of the whole thyroid being affected and the possibility that my thyroid will become underactive [hypothyroid] over the following year(s)."
Prognosis	"… Just received my week 6 results. HCV [Hepatitis C Virus] RNA PCR Taqman 2.0<25 IU/ml detected. This was after 4 weeks with SOC [standard of care] and an additional 2 with BOC [Boceprevir, another treatment] added. Is it looking good that I will beat this [HCV]?"

Requesting

Several categories emerged describing what patients were requesting with their post to the online community; specifically, patients requested opinion, advice, generic information, emotional support, and personal experience (see Table 4.2). Requests for opinions and advice were by far the most common in this sample. Those requesting opinions tended to provide their laboratory results and, often, relevant medical history and symptoms, and ask the community to interpret it in some way (e.g., likely diagnosis). Those requesting advice were asking for actionable opinions, and a sub-set of these were asking for the community's assistance in deciding between two or more, often treatment-related, options. In addition, less frequently, posters requested information that was not necessarily personalized to them; for instance, one patient wrote, *"Looking for information about chest aches or pain..."* Others included language indicative of distress, fear (e.g., *"I am terrified"*), or other strong emotions, and were categorized as requesting emotional support. Finally, some posters explicitly invited other patients to share personal experiences so that they could learn from them.

Table 4.2. Categories describing what patients are requesting and representative quotations.

Requesting	**Representative quotation**
Opinion	"Now after showing these results to the doctor, he simply increased my dosage of thyroxine sodium [medication] to 100mcg once a day. Can you please give me second opinion?"
Advice	"Would you recommend more testing?"
Decision support	"I'm vacillating between having the right breast re-excised and awaiting the biopsy results or just having a mastectomy without awaiting any further test results. Your advice is welcomed!"
Information (generic)	"What treatments are available?"
Emotional support	"I am really upset now to think that I have something really wrong with me"
Personal experience	"I'd like to hear others' experiences so I can better understand all this."

Situational factors

Two main situational factors emerged; specifically, (1) whether patients are posting prior to a visit with their healthcare provider, which usually means that they have not yet discussed their laboratory test results with a medical professional, or after, and (2) whether they have a diagnosis or not. These situational factors, as well as sub-categories and representative quotations, are summarized in Table 4.3.

Table 4.3. Situational factor categories and sub-categories with representative quotations.

Situational factors	**Representative quotation**
Healthcare – Pre-consultation	
Waiting	"Can't get a doctor's appointment for 2 months. Any of you doctors have any ideas?"
Preparing for appointment	"Any suggestions about what I should ask the doctor? Learning every day."
Determining if need medical follow-up	"Do I need to see a doctor sooner than my heart doctor appointment in a month?"
Healthcare – Post-consultation	
Second opinion	"My general practitioner is telling me I need to have my thyroid removed… Do I have my thyroid removed?"
Clarification or explanation	"My doctor stopped the Armour Thyroid [medication]… He also said the elevated T3 can have the same symptoms as hypothyroidism. I've read a lot, but I still don't understand how?"
Doctor does not know	"Although my numbers look OK I am still very tired. My doctors are unsure of why or what to do…"
Options	"I have a choice whether I want to go back on PegIntron [treatment]… or Pegasys [another treatment]…"
Diagnosis status	
Diagnosed: Not questioned	"new labs, I'm still so frustrated… This is 2.5 grains of ERFA [medication] and 6.25 mg of levothyroxine [another medication]. The labs look a little better but are still not good."
Diagnosed: Questioned	"The doctor's office said my results were great, but I don't think that's right… Does this not suggest I am borderline in hyper or hypo?... My doctor is insisting I am depressed."
Not diagnosed	"My husband has had an abnormal blood test. Could you let me know what could be his diagnosis?" "For quite some time, I have had a number of 'issues' and have not gotten to the bottom of it."

When it was possible to identify the motivation, patients posting questions prior to a healthcare consultation (also referred to as pre-consultation) did so for several reasons, namely waiting, preparing, and determining the need for an appointment. Many patients were waiting for an appointment with their physician, which often was not for several months, but wanted answers or to take action now. These posts tended to exhibit language indicative of distress (*as described above*). Others were preparing for their upcoming appointment – trying to obtain information that they could utilize in their consultation. In one such post, after presenting their most recent laboratory test results, the patient wrote, *"I have gained the weight all over, but especially my belly. I have an endocrinologist [specialist] appointment coming up… I want to request any lab that may shed light on my weight issue. Also, should I get checked for any hormone or vitamin deficiencies… My endocrinologist is pretty conservative but does let me make suggestions."* Still others were trying to understand their results to determine if they needed to make an appointment with a physician at all.

Similarly, patients posted questions about their laboratory test results to the OHC after discussing them with their physician (also referred to as post-consultation) for many reasons, including seeking a second opinion, asking for clarification or explanation, searching for a way forward when their physician is at a loss (referred to as 'Doctor does not know' in Table 4.3), and assistance in making a decision when they have been offered options. In this sample, seeking a second opinion was by far the most common reason for post-consultation questions – patients wanted another opinion on their physician's interpretations or recommendations. In many cases, patients seem to doubt, disagree with, dislike, feel uncomfortable with, or mistrust their physician or their physician's conclusions. In other cases, though, they received conflicting opinions (e.g., from different specialists). Other patients just wanted clarification or explanation of information provided or a decision made by their physician. For example, in one post a parent stated their child's thyroid functioning test results and a subsequent change in the medication dosage and wondered what this implied about their child's health: *"15mg Tapazole once a day [medication and dosage before laboratory test]. Free T4=0.80, TSH=1.09 T3 Total=130. After this report, her*

Endocrinologist [specialist] reduced to 10mg a day. Is my child still a little hyperthyroid?" On the other hand, some patients reported that their physician did not know what their results meant or what to do next. Often these patients were still experiencing bothersome symptoms, and they seemed to be seeking fresh ideas. Finally, some patients' physicians had given them options, and they were struggling to make a decision.

Finally, three different diagnosis statuses were identified in the reviewed posts – diagnosed: not questioned, diagnosed: questioned, and not diagnosed (See examples in Table 4.3 above). Some patients posting questions had a diagnosis that they did not question (at least in the post), and were instead often questioning management and treatment aspects, prognosis, or another facet of their care. On the other hand, some patients had been diagnosed by their physician, but had doubts as to whether that was indeed the issue, and as such often asked diagnosis questions in their post. Finally, there were patients that did not have a diagnosis, and then this tended to be the focus of their post as well. Some were receiving abnormal test results for the first time, and others had been searching for a diagnosis for a while.

4.4.2. Answers

In this sample, there were an average of 2.0 replies per question post, with a range of 0 to 16. The replies that addressed the original question poster provided information, advice, opinion, emotional support, and personal experience (See Table 4.4). They also requested more information from the question poster.

Information

The online community provided information on several topics, including diagnosis and cause, tests and testing, potential seriousness or risk, prognosis, management and treatment, and resources. More specifically, answers provided information on how a diagnosis is made, common symptoms associated with particular diagnoses, and common causes of abnormal laboratory test results, symptoms, or both. In addition, information on tests and testing was offered, such as the reliability and accuracy of testing methods, reliability of different laboratory values (e.g., TSH), different options for tests, whether tests are invasive and any required preparations (e.g., fasting), and generally what laboratory results mean. Some answers also included information on potential seriousness or risk and prognosis. Furthermore, the community provided information on management and treatment, including general treatment approach for a given condition (e.g., *"…doctors typically just monitor it, no real treatment needed."*), goals of treatment (e.g., management, cure), explaining or comparing options, treatment safety and risk, and new treatment options. Finally, answers offered social support and informational resources (e.g., pointing to websites or other OHC posts).

Advice

Answers also provided advice related to medical professionals, treating health concerns, further testing, and more information. Many reply posts suggested that question posters discuss their questions, and information provided by the community, with their physician. They also sometimes recommended that the question poster see a specialist, get a second opinion, or get a new doctor all together. In addition, the community provided advice and suggestions on treating health concerns, including whether or not treatment is needed, specific types of medication and dosages to try, changes in medication or dosage, suggestions for how to proceed with treatment (e.g., timing), and diet and supplementation recommendations. Some answerers also recommended additional tests that they feel the question poster should consider. Finally, many answers suggested that the question poster get more information, including by using search engines, going to specific sites that they felt were particularly helpful, and asking lots of questions of their physician.

Opinion

In addition, community members provided first and second opinions on topics, including primary concern, interpreting test results, possible diagnosis and cause, seriousness or risk, prognosis, and management and treatment. In cases where people had comorbidities or multiple pieces of information that conflicted, some answers provided opinions on the priority; for example, one community member said, *"You're focusing too much on the test results and not enough on how you are feeling."* The community also provided interpretations of laboratory results, often including their opinion on possible or likely diagnosis and cause or prognosis given their interpretation of the results (and symptoms and history, when provided). Finally, answers provided opinions on management and treatment such as whether they think a proposed treatment is appropriate, treatment (often, medication) or specific dosage they feel would be better, and the best way to make treatment decisions for a given issue (e.g., certain laboratory value).

Emotional Support

Replies from the community also provided emotional support through empathizing, encouraging, offering well wishes and congratulations, reassuring, showing concern or caring, and by indicating that the question poster is not alone – others have felt or experienced the same. Many of these were responding to posts where there was language indicative of distress (*as discussed above*) or another emotion (e.g., cautious excitement); therefore, whether it was bad news (e.g., tests are positive for a certain condition) or good (e.g., tests indicate the poster is pregnant), most responded in an emotionally supportive way (e.g., *"Don't give up!"*). In addition, even if the question poster did not appear to explicitly request emotional support, answers would often still provide it.

Personal Experience

Answers provided personal experiences in order to offer reassurance, or another type of emotional support, as well as to provide information, opinions, or advice. They tended to use their experience to support a claim or recommendation. For example, one community member wrote, *"I didn't hear a heartbeat until I was 10 weeks [pregnant]. So, try not to worry too much."* While another answer provided the following support for their suggestion that the problem may be pulmonary, *"I just had four days of intense fatigue and being short of breath. It wasn't until the chest ache and coughing kicked in that I realized it was my asthma flaring."*

More Information

Finally, community members often asked follow-up questions and requested that the question poster provide more or updated information. Such replies suggest that, given the information provided, they could not help or would be able to help more with additional information.

Table 4.4. Categories of answers to copying and pasting question posts, and representative quotations.

Providing	**Representative quotation**
Information	
Diagnosis and Cause	"There are many possible causes. Fatty liver, alcohol related liver disease, problems with the bile ducts are among the common causes for these elevations."
Tests and Testing	"In addition to fluctuations in actual VL [viral load], different methods of testing can produce different counts. Hence the sensitivity threshold at which they can measure."
Potential seriousness or risk	"This condition does not have any serious sequela."
Prognosis	"The disease at this point is generally incurable."
Management and Treatment	"Cortisone creams are often prescribed for the patches of red, dry skin but will also leave you at risk for UV [ultraviolet] exposure in those areas for the rest of your life."
Resources	"… see parathyroid.com for more information on this..."
Advice	
Medical professional	"Follow-up with your personal physician is essential." "Get a new, decent doctor who understands the difference between IBS [irritable bowel syndrome] and post-gallbladder problems."
Treating health concerns	"Take the Statin. It reduces the chance of having a heart attack even in people with normal cholesterol. And your LDL [low-density lipoprotein cholesterol] is high…"
Further testing	"I'd push for hormonal testing – cortisol and deficiencies."
More information	"Arm yourself with as much information as possible and make an informed decision."
Opinion (First or Second)	
Primary concern	"I would think your experience of dealing with Narcolepsy, which is awful by the way, should be the primary concern here."
Interpreting test results	"The low PTH [parathyroid hormone] suggests that the hypercalcemia [high level of calcium in blood] initially discovered was 'non-parathyroid' origin but if it were a malignancy the high calcium level would typically continue to rise."
Possible or likely diagnosis and cause	"You have positive antibodies (autoimmune thyroid disease) – most likely this is early Hashimoto's."
Prognosis	"I think you're going to beat it, yes I do, and I haven't seen anyone relapse yet who has taken the triple therapy."

Risk or seriousness	"Personally, I would feel better if your CRP [C-Reactive Protein] were also in the first quartile of risk (low risk <1.0). Facts are you have a high LDL [low-density lipoprotein] cholesterol and a level of CRP that is above the lowest risk group."
Management and Treatment	"I think vitamin D treatment is fine as long as hypercalcemia [high level of calcium in blood] is monitored closely."
Emotional support	"It just makes me sooooo angry when doctors act like that. I know if it were them feeling bad, they would take the medicine!"
Personal experience	"I have Geno 1A and 1B and two doctors insisted on Intron [treatment]. But, again, it's probably personal perspective."

Sufficient answers

The replies determined to be "sufficient answers," based on the reply from the original question poster, suggested that the question poster felt somewhat reassured or relieved, perceived themselves to have an improved understanding, or that they had or were going to take a recommended action. The largest number of "sufficient answers" were in reply to thyroid- and liver-related questions; however, "sufficient answers" were identified in threads related to infectious diseases, pregnancy, autoimmune disorders, cancer, and unknown condition. "Sufficient answers" more commonly provided opinion and emotional support, and more specifically tests and testing information, as well as concern or caring and encouragement emotional support.

4.5. Discussion

The results of this study provide evidence that it is feasible to identify and characterize the nature of patients' questions related to laboratory results, and to characterize the nature of the answers to these questions. Specifically, they revealed (1) a typology of patient confusion when viewing and trying to use laboratory results, (2) patients' social support needs, (3) the contexts of questions, as well as (4) the type of support that patients may gain, and find ‘satisfactory,’ from peers in OHCs. Similar categories have emerged from studies in the human-computer interaction and patient portal literature, beyond laboratory results and outside of peer-to-peer settings, suggesting that our findings are robust. However, my study had several unique aspects – including, a “target-rich” source of *actual* patient information and knowledge needs across multiple types of health conditions, and the classification of answers, which few studies have previously done – that resulted in a more thorough typology and novel findings. While these results are preliminary, they suggest potential opportunities to improve technologies that offer patients access to their medical records to better meet patients’ needs at the point of viewing their clinical data.

First, we found a typology of patient confusion about their laboratory results, which includes topics such as management and treatment. Although others have identified similar categories, their typologies were not as comprehensive. For example, when analyzing secure messages sent via a portal, Sun et al., found similar categories of questions aimed at patients’ healthcare teams, but we identified categories, such as risk, that they did not.[315] We were likely able to more comprehensively identify types of patient questions because of our rich dataset, which uniquely situates this study to add to the current understanding of the types of patient questions related to their clinical data. For example, compared to Sun et al.’s study,[315] we may have identified more clinical topics, because many patients seek information online first.[20,35] In fact, Wright et al. reported that patients were much more likely to search the internet after viewing their problem list through a patient portal, rather than contacting their healthcare provider.[316] As the results of this study suggest, after searching online, some of these individuals may believe that there is no need to, or may choose not to, follow-up with their physician.

Second, we observed that patients had social support needs, such as informational, that they tried to meet through the OHC. Other studies have reported similar categories; for example, Sillence et al. analyzed advice solicitation in an online breast cancer support group, and identified five patterns, (1) requesting advice, (2) requesting opinion or information, (3) disclosing a problem(s), (4) announcing a plan of action, and (5) asking "anyone in the same boat?"[317] Despite small differences, the overlap, as well as the fact that we identified our categories across a number of conditions, indicates robustness, and that our results may be relevant beyond this study setting and population.

Third, while other studies have peripherally reported situational factors, it emerged as a central theme in this study. For example, Powell et al. reported motivations for online information seeking, including perceived barriers to traditional information sources, as well as to seek reassurance, a second opinion, and a greater understanding.[318] In addition, this study also found that most online health information seeking was associated with consultations, either in preparation for or to find additional information afterwards.[318] In the context of our study, there appears to be some differences in the types of questions asked based on situational factors. Chapter 5 explores this further through an in-depth analysis of patient support needs in different contexts, specifically at different points in medical care.

Finally, while there is literature characterizing "best answers" on question and answer websites,[e.g.,319] to the best of my knowledge, our attempt to examine peer answers that patients perceive to be satisfactory in an online health community is novel. The results of this pilot suggest that answers perceived to be "sufficient" by patients more often included opinion and emotional support, and they usually provided more specific information on tests and testing, as well as concern or caring and encouragement emotional support. This may be because these elements were better aligned with what question posters were requesting. In terms of the emotional support, it may also be that when answers showed concern or caring or offered encouragement, it elicited more positive responses from the question poster, regardless of whether it actually helped them gain a better understanding of their situations. Future work should seek a more complete picture of the types of answers that patients find helpful and the underlying reasons.

4.5.1. Design Implications

These results provide preliminary evidence of opportunities to improve the design of technologies providing patients access to their medical records, including patient portals and miPHRs. In terms of content, as discussed above, patients often search online first and may not follow-up with their healthcare provider; therefore, it is crucial to provide more of the information and knowledge that patients need at the point of viewing their laboratory test results. This could reduce the information work – the time and effort often inherent in seeking medical information in the vast internet – and, at the same time, ensure that they are consuming, and making decisions based on, accurate information carefully curated by medical professionals. One way to provide more of the information patients want and need may be better understanding differences in needs based on situational factors, which could offer an opportunity to provide more personalized content through technologies, based on elements that are often available (e.g., appointment date). This would enable these technologies to better support both the short-term work such as visit preparation to ensure productive interactions with healthcare providers and the longer-term work of becoming an expert chronic disease patient (i.e., learning).[110] In terms of features, since patients tend to seek these social supports in online communities, it suggests that they may be lacking in their interactions with the formal healthcare system (whether in-person or through technologies), which could present opportunities for additional patient portal features or connected technologies. For example, supporting patients' desire for personal stories from others "in the same boat," by allowing them to opt-in to a social feature that enables finding similar patients or more fluid groupings based on similar information needs, could be beneficial.

4.5.2. Limitations

There are several limitations to this research. First, the emphasis was to comprehensively identify relevant themes and categories emerging from this rich dataset; therefore, posts were not double coded. Future studies should include more quantitative analysis, and validation of qualitative findings. Second, while it is possible to identify posts with indicators that the original question poster perceived the answer to be helpful, there were a relatively large number of answer posts to which the original question poster did not reply. In addition, there may be other factors, independent of perceived usefulness of the answer, that affect how someone responds, including personality, culture, and level of emotional distress. Therefore, the results related to "sufficient answer"' should be interpreted with caution and warrant further investigation. Finally, in this pilot I focused on one type of clinical information and one OHC. There is support in the existing literature that these are crosscutting categories; however, the extent to which these results extend beyond this study setting is unclear.

Despite these limitations, this study provides direct evidence of patients' comprehension issues related to their laboratory data. The results also highlight the types of supports they need, and the types that they gain, and deem 'satisfactory,' through online health communities. This knowledge directly informs how technologies can better provide social supports for patients as they view their medical records. Finally, this study will inform future research, including collaborating with stakeholders (e.g., patients, health IT developers, administrators) to assess how this study, and follow-up studies, can be incorporated into the design and redesign processes to improve technologies that offer patients access to their medical records.

4.6. Conclusions

This pilot study provides evidence for the feasibility of (1) identifying OHC posts containing patients' laboratory results copied from their medical record and pasted into OHCs; (2) identifying question topics, patient support needs, and situational factors; and (3) characterizing what peer-patients are providing and requesting in response. An extension of this work, presented in Chapter 5, will unpack patient support needs related to their laboratory test results based on context. In addition, the results presented in this paper provide a foundation for future quantitative studies involving computational methods.

Ultimately, this line of research may lead to improving the design of technologies such as patient portals, and the way that we present clinical data to patients. Such improvements may, eventually, lead to more patients being engaged in their healthcare and, as a result, improved health status and reduced costs.

CHAPTER 5. Unpacking the Use of Laboratory Test Results in an Online Health Community throughout the Medical Care Trajectory

5.1. Motivation and Summary

Chapter 4 presented a typology of patient confusion related to their clinical data, and specifically their laboratory test results, as well as the types of support the online health community (OHC) provides. It also highlighted that patients are trying to understand and use their data at different points in their medical care (e.g., diagnosis, treatment). In this study, I sought to build on that research to gain a more in-depth understanding of patient support needs in different contexts.

To do this, I again analyzed posts to an OHC that contained a patient's laboratory test results with the goal of better understanding how to support patients as they individually and collaboratively make sense of their data throughout the medical care process. I found that patients seek help on the OHC to understand and use their laboratory test results at multiple points in the medical care trajectory – the general path patients navigate when receiving care for a health concern. Specifically, in the diagnosis phase, patients tend to be focused on comprehending their data, to be receiving emotionally charged results and, of course, to be engaging the OHC in naming their medical issues. In the treatment phase, patients are often using their laboratory test results to ask more focused questions to identify treatment options, to seek treatment guidance from peers, and to predict the likely course of their disease. Throughout both phases, individuals are highly engaged in the medical process and put in substantial effort to proactively prepare for their care and interactions with doctors. They enlist the OHC in these efforts for many reasons such as a lack of confidence in their doctor. I discuss how gaps in the provision of healthcare services lead to the significant work involved in managing the complex and dynamic interplay between OHCs and the healthcare system. I offer design recommendations for technologies that provide patients with access to their medical records to fills some of these gaps and to reduce the burden on patients.

5.2. Introduction

Laboratory tests involve taking biological samples, including blood, urine, and tissue, and testing them for signs that the body is not working optimally. The results of these tests are crucial pieces of information in medical work that are typically used in conjunction with other information in the patient's medical record, including other types of tests (e.g., imaging studies), the patient's self-description of how they are feeling (i.e., symptoms), their social and medical history, and the doctor's physical exam. Laboratory test results are particularly valued by doctors, because they are viewed as the objective indicators of a patient's health status.[320] They are used throughout the medical care trajectory – the general path patients navigate when interacting with the formal healthcare system from diagnosis to treatment to recovery to recurrence. These data provide evidence for or against potential diagnoses, offer insights into how a patient is responding to treatment, and generally provide information on the patient's health status. Research suggests that providing patients with access to their own medical records, including their laboratory test results, has numerous benefits such as increased patient engagement and improved health outcomes (e.g., improved blood pressure control).[143,269]

Today, patients have greater access to their medical records than ever before. Policies such as the 2009 U.S. HITECH Act[27] and the 2016 21st Century Cures Act[33] have not only resulted in increased electronic health record (EHR) adoption by healthcare organizations, but have also included mechanisms for more easily sharing these medical records with patients.[27,33] Laboratory test results are one of the portions of their electronic medical record that patients most often view.[171,181,187,188] However, the extant literature indicates that patients often have difficulties understanding these data and that they are a common source of patient questions.[312,315,321] This is likely because they require both significant domain knowledge and health literacy and numeracy to interpret.[322(p62),323] As a result, patients often seek support when trying to understand and use their laboratory test results.[321]

Recently, online health communities (OHCs) have emerged as a popular virtual space for patients to seek health-related, and often condition-specific, social supports[266] from primarily peer-patients.[324,325] These communities can be standalone social websites or they can be found within broader platforms such as Reddit and Facebook.[81,326–328] There is a significant body of literature on patients' use of OHCs, including for seeking and receiving social supports from patients similar to them, particularly informational, emotional, and instrumental supports.[324,326,327,329–331] These studies typically characterize OHCs as peer-to-peer support outside of the healthcare system. With notable exceptions such as an interview study by Bussey and Sillence, which explored how patients integrate online health information into their interactions with doctors,[332] few studies have investigated how patient online support seeking fits into their healthcare experiences.

In this study, I sought to gain a broad understanding of the nature of patient questions related to their laboratory test results in different contexts through a qualitative analysis of posts containing these medical data on an OHC. I found that patients bring their laboratory test results to the OHC to understand and use these data at multiple points in the medical care trajectory. In both the diagnosis and treatment stages of care, patients are deeply engaged in the medical process, trying to proactively plan for their care and for their interactions with medical professionals. In the former stage, though, patients are more likely to be trying to make sense of the data themselves, to be emotionally fraught and, of course, to be focused on engaging peers in collaboratively identifying the cause of their health issues. In the latter stage, patients tend to use their laboratory test results to ask more focused questions meant to gather their treatment options, decide between known options, plan for changes in their treatment regimen, and to dynamically assess the likely course of their disease.

I discuss how the OHC has become one of the spaces where patients do the work necessary to address serious gaps in the provision of healthcare services – temporal, anticipation, and information gaps – that exist at different points in their medical care trajectories. These gaps create significant work for patients. Some of this work may be productive such as proactive learning and planning for one’s care. However, it can also be problematic, especially when there are strong emotions tied to the test results. Based on our findings, I recommend changes to the design of technologies that offer patients access to their medical records, to better support patients at the point of viewing these data. I also argue for long-overdue structural changes in healthcare to help patients thrive in their role as partners in their care. Thus, my contribution is two-fold; I contribute (1) empirical knowledge on patient support needs related to their medical records at different points in their care and (2) design recommendations for collaborative technologies mediating patient-doctor interactions.

5.3. Background and Related Work

This study builds upon previous work on patient engagement with their medical records, online health communities, and the medical care trajectory.

5.3.1. Medical Records

There is a considerable evidence base on patient engagement with their medical records – the data and information documenting medical care – particularly personal health information management (PHIM) in chronic disease care and through technologies. As mentioned in Section 1.1.2, PHIM "refers to activities that support consumers' access, integration, organization, and use of their personal health information."[114] Specifically with laboratory test results, Giardina et al. found that patients try to leverage their results to identify potential diagnoses and next steps.[321]

These activities may be done with paper records;[66,115,333] however, today, a number of technologies exist to help patients access and manage their medical records, with patient portals being the most widely used. Patient portals are a web- and application-based technology offered by healthcare organizations to provide patients with read-only access to their medical records and often have additional features to engage patients in their healthcare, such as secure messaging. As previously mentioned, according to the 2020 Health Information National Trends Survey (HINTS), 39.5% of U.S. adults had used a patient portal in the last year.[58] The most common uses of portals include viewing test results, communicating with medical teams, and requesting medication refills.[116]

Many barriers to portal use have been identified, including difficulty understanding the information provided[67,69] and too much medical data without enough personalized, actionable information.[35] Laboratory test results can be especially difficult for patients to interpret and are common sources of questions. For instance, one study found that many patients, especially those with lower health literacy and numeracy, had difficulties identifying out-of-range test values, which is critical to interpreting laboratory test results.[312] Other studies have reported that patients will ask their doctor, friends, and family, as well as consult online sources, for help making sense of their results such as decoding medical jargon.[315,321]

There is some existing research on how to improve the delivery of laboratory test results for patients, which largely focuses on visualization.[334–336] For example, Zikmund-Fisher et al. presented hypothetical laboratory test results to a “demographically diverse Internet panel” and found that graphics can help patients more accurately judge the risk involved with abnormal test results.[334] This line of research is critical to improving technologies such as patient portals, but largely relies on hypothetical scenarios where patients may be less invested than when they are viewing their own results. It also focuses on the individual's interaction with these data, with less emphasis on how patients engage others in leveraging laboratory test results to improve their care. Thus, it is critical to study patient support seeking related to these data as needs arise.

5.3.2. Online Health Communities

One place patients turn to when they require health-related social supports is OHCs. Overall, research on OHCs has tended to focus on the peer support sought and provided within these communities,[324,326,327,329–331] with fewer studies considering that support in the larger context of patient care. However, there are notable exceptions that have explored the integration of online health information into medical decision making[332] and patients' perceptions of doctors' reception of online information, including from OHCs.[332,337] Furthermore, other studies have looked at support sought and provided in OHCs at various points in patients' condition-specific care journeys, such as cancer and diabetes.[105,326]

Even though viewing medical records has become an increasingly common patient experience, both for those with and without a chronic condition, few studies have examined patient online support seeking related to the data that is generated in clinical interactions and shared on social sites. Among the existing evidence, one study focused on questions related to laboratory tests for the diagnosis and treatment of diabetes,[338] while another analyzed questions and threaded replies related to laboratory test results across conditions (study described in Chapter 4).[142] They both used an inductive qualitative content analysis approach to identify types of questions, including questions related to the laboratory tests (e.g., accuracy of the test), the numbers, their diagnosis, and their treatment.[142,338] In addition, and as discussed in Chapter 4, I found that patients were seeking and received a number of different types of social supports related to their results, including emotional and informational.[142] However, less is known about when, how, and why patients bring their personal health information, and specifically data from their medical records, to OHCs throughout the broader patient care experience.

5.3.3. Medical Care Trajectory

This broader patient care experience is what I refer to as the medical care trajectory. This concept is related to but distinct from the term illness care trajectory. Illness care trajectory was coined by Strauss, Fagerhaugh, Suczek, and Wiener to describe "the total organization of work" performed over the course of a patient's disease "plus the impact on those involved with that work and its organization."[108(p8)] More recent research has referred to healthcare trajectory.[339,340] Regardless, the concept has been widely used in HCI and CSCW research as a framework to understand the experience of living with and caring for a chronic disease and the complex dynamics of the many types of work done by multiple actors over time. This research tends to be condition-specific, because care trajectories differ based on the illness[108(p8)] and even between individuals with the same condition.[105–107] The extant literature has considered the illness trajectories or aspects of these trajectories of prevalent and well-defined diseases such as diabetes,[105,341,342] enigmatic chronic diseases such as endometriosis,[107] and stigmatized conditions such as infertility.[106,107,343] The trajectories of certain chronic disease treatments such as bone marrow transplants have also been studied.[339,340,344] This research has focused both on the individual patient and healthcare provider perspectives,[106,107,340,342–344] on collaboration between patient and doctor,[107,344] and on collaboration outside of the healthcare context such as spouse or peer-patients.[105,339,345]

Understanding the work being done and by whom is fundamental to the concept of illness care trajectories. As discussed in Section 1.1.2, many different types of visible and invisible patient work have been identified in the literature[108(pp194-195)] throughout illness trajectories,[105–107] including illness work (e.g., work related to diagnosis, treatment, crisis management), infrastructuring work (e.g., sharing medical records between providers), everyday life work (e.g., cooking, caring for children), biographical work (e.g., reshaping one's identity in the context of an illness), and articulation work (e.g., coordinating tasks).[109,111] Additionally, data and information work are required to perform all of these types of work.[112,113] For instance, Pichon et al. discovered that the illness, everyday life, articulation, and biographical work involved in the enigmatic chronic condition context is intensified due to the complex and uncertain nature of this type of disease.[107] In addition, in their study of online and offline help seeking among diabetes patients, Huh and Ackerman identified a new type of patient work that they call "illness trajectory alignment work," which is the effort patients put into comparing the different illness trajectories shared by other patients in order to "derive personal meanings."[105] Meanwhile, Büyüktür and Ackerman found misalignments in the flow of information to patients throughout the bone marrow transplant trajectory.[344]

In this study, I build upon this literature through a patient work lens and the unique view of exploring how patients take their medical record data, specifically laboratory test results, out of the healthcare context and bring it into the OHC to seek help in understanding and using these data and then how these primarily peer-to-peer virtual interactions may influence their future interactions within the formal healthcare system. As opposed to condition-centric studies, there is a universality to medical records, and the challenges patients face when trying to understand and use these data, that transcends specific health issues. This approach is supported by prior research that has found similarities in online support seeking activities across conditions and, in particular, related to the types of questions patients have about laboratory test results.[142,332]

Taking this view highlights the standard process, referred to as the hypothetico-deductive approach,[346] that doctors follow when collecting the data for the diagnosis and treatment of patients that forms the foundation of many patient-doctor interactions.[322(pp60-62)] Although this approach focuses on the doctor's efforts to generate and refine hypotheses as to what may be the cause of abnormal test results and symptoms, patient work remains central to this process. In fact, through this study, I show that patients seem to emulate aspects of this approach in the OHC. Thus, while I recognize the considerable value of the existing literature looking at individualized care trajectories, our approach highlights the shared experiences of being a patient and, ultimately, motivates us to view patient work in the context of the medical care trajectory (see detailed overview of laboratory test results in this context in Section 5.5.1).

5.4. Methods

The overall goal of this study was to better understand the nature of patients' questions related to their medical data, and specifically their laboratory test results, in different contexts. Towards this end, I qualitatively analyzed questions posted to an online health community that contained a patient's laboratory data, building on the work done in the pilot study described in Chapter 4. Studying patients' questions on OHCs provides unique insights into our focus in this Chapter. It sheds light on the interplay between support seeking in OHCs and interactions with the formal healthcare system throughout the medical care trajectory, that may otherwise be difficult to study since, at least in some cases, patients may not immediately come back into the healthcare system after seeking support online.[332] The broad understanding of how people make sense of and leverage laboratory test results that I gained through this research will provide a foundation for future in-depth interviews.

In this Chapter, as with Chapter 4, I use the singular they/their throughout, as gender identity is usually not discernable in posts even where biological sex can be inferred (e.g., the question is posted to the Ovarian Cancer Help Forum).

5.4.1. Data and Data Analysis

The Online Health Community

Our study site was a popular OHC with over one million unique users and over 400 forums covering a wide range of conditions that may be diagnosed or monitored using laboratory test results. These forums usually focus on a particular health condition or type of condition, such as diabetes, thyroid disorders, and infertility, but may also focus on broader health-related topics such as healthy recipes. It is primarily patients or caregivers (e.g., parents) communicating through these forums; however, there are some healthcare providers (e.g., nurses, doctors) that may respond to questions.

Data Curation

For this study, I leveraged a previously curated dataset of over 50,000 original posts (i.e., first post in a thread, often containing questions) with indicators that they may contain laboratory test results. The dataset was generated using a similar process to that described in Chapter 4.3.2 – an iterative approach that combined keyword search and natural language processing (NLP) methods. Briefly, keyword searches were first conducted using terms such as “lab test results.” Then, unique features of posts containing laboratory test results were identified, such as numbers followed by units (e.g., 10 u/mL), to use in the NLP methods. This approach resulted in a set of posts with increased likelihood that they include the individual’s laboratory test results regardless of condition and without relying on keywords, since it is challenging to ensure that all relevant terms are included in a keyword-only search.

Data Analysis

The goal of our analysis was to get an in-depth understanding of patients’ questions related to their laboratory test results and the context in which they were asked. Manually reviewing over 50,000 posts was not feasible, so I took a random sample of 1,000 of the potentially relevant posts for analysis.

We used the categories identified through the pilot study described in Section 4.3.3 as a starting point. To review that process, about 150 relevant posts (e.g., those that actually contained an individual's laboratory test results) were independently analyzed by a research assistant and myself using an inductive qualitative content analysis approach.[287] During this iterative review, the content analysis team met weekly to discuss coding and agree upon the codes and their definitions. No new categories emerged in the last approximately 50 posts reviewed, suggesting theoretical saturation had been reached.[314]

For the analysis in this Chapter, I further refined this codebook based on the data, goals, and discussions with a content expert. The final codebook had two main categories: Question Topics and Situational Factors. Broadly, in posts containing laboratory test results, questions tend to be about the Cause or Diagnosis of the patient's medical issues or be about the Management and Treatment of their condition, which are two key stages of the medical care trajectory. Within each of these stages, patients may have more specific question topics, such as understanding the data (their laboratory test results) and identifying treatment options, respectively. These categories are presented in more details in the results (Section 5.5.2 and Section 5.5.3). The Situational Factors category refers to the timing of their question posts – either before they have had a medical visit (and discussed their test results with their doctor) such as when they are waiting for their doctor to return their call or after a visit such as when they are seeking a second opinion.

A research assistant and I first used the final codebook to independently code about 140 relevant posts (in the sample of 1,000) using NVivo v1.4.1 to measure interrater agreement. The agreement was greater than 80% across codes (Range: 82%-98%). We discussed differences in coding and resolved any ambiguities. I then coded the remaining 179 relevant posts in the sample to understand the range of patient experiences in the sample and to ensure no important categories were missed. In total, in the random sample of 1,000 posts, 321 posts were relevant, and analyzed using the final codebook.

5.4.2. Ethics and Privacy Protection

While the analyzed online health forum posts are anonymous and publicly available and, thus, considered non-human subject research by the researchers' Institutional Review Board, I took extra steps to protect the privacy of OHC users, as existing research suggests that people may still include personal details in their online posts.[347] In addition to not naming the forum, I have also removed any idiosyncrasies from posts (e.g., corrected any major grammatical mistakes) and tested each post in a search engine. If the search returned any results that pointed to the original OHC post, I paraphrase the idea rather than directly quote.

5.4.3. Limitations

This study has several limitations. First, although our research aim focuses on patient questions related to their medical data, as Chapter 4 showed, the threaded replies could provide additional insights into patients' support needs and the types of support that they find particularly useful at different points in the medical care trajectory. This should be the focus of future research. Second, OHC users are likely a technologically advantaged population and may differ substantially from non-users. To the best of our knowledge, there is not currently evidence of a difference in patient questions related to their medical data between OHC users and non-users, but I cannot rule out this possibility. Third, descriptions of healthcare interactions are one-sided, offering insights into patients' perspectives, but missing the doctor side of the narrative. I feel it is important to amplify our participants' voices, especially given the power dynamics in healthcare that typically favor doctors and may serve to minimize the patient voice;[9,10] however, I acknowledge that doctors usually have legitimate reasons for their medical actions and valid perspectives. Finally, although this study includes multiple forums and health conditions, it focused on a single website. Future research should include additional online sites to better capture the breadth of patient experiences.

5.5. Results

5.5.1. Laboratory Test Results in the Medical Care Trajectory

The Medical Care Trajectory

Figure 5.1 summarizes the medical care trajectory – the general path patients navigate when interacting with the formal healthcare system – with embedded care cycles,[66] which highlight the short periods of healthcare interaction (orange bands) surrounded by longer periods where patients have more responsibility for managing their health (ovals). It is within the latter periods that patients interact with the OHC. At any stage of the medical care trajectory, laboratory tests may be ordered by doctors to offer an objective snapshot of a patient's health status.

As Figure 5.1 shows, in the *cause and diagnosis* stage, the goal is identifying the cause for, and particularly the underlying disease behind (i.e., diagnosis), one's health issues. This is one of the first steps in the medical care trajectory, both when people experience symptoms and when they get routine bloodwork and discover an abnormal level. At this stage, patients may be getting several new and different tests that could offer clues into the underlying problem. In some cases, after receiving normal laboratory test results, patients may exit the medical care trajectory as medical follow-up is determined to be unnecessary (by the patient or the doctor). Once a diagnosis is established, in most cases, a treatment plan will be developed, marking the beginning of the *management and treatment* stage. In this stage, it is more likely that patients will get regular laboratory tests meant to monitor their health status and inform treatment decisions. In some cases, treatment will resolve the issue and these patients will no longer require regular care, offering another potential exit from the care cycles and medical care trajectory.

This figure is, of course, a simplified representation; in reality, the periods between visits may vary based on where a patient is in the trajectory and the health issues the patient is experiencing. For instance, it may take several healthcare visits with different specialists and different medical tests over long periods of time before a patient has a diagnosis. Patients may also receive a diagnosis and start treatment, only to find the treatment does not alleviate their health issues, which can sometimes bring them back to the cause and diagnosis stage. Finally, patients may be managing multiple chronic conditions at once resulting in a more complicated and likely extended trajectory.

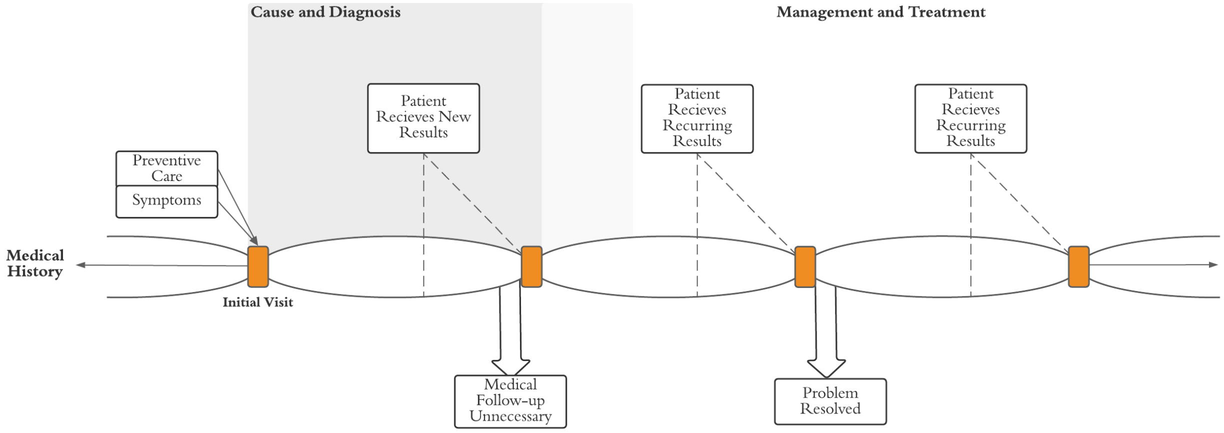

Figure 5.1. Simplified medical care trajectory with embedded care cycles. The orange bands represent healthcare visits, and the ovals represent periods between interactions with the formal healthcare system. It is in these periods that patients interact with the online health community.

Conditions and Types of Laboratory Tests in the Online Health Forum

In our coded sample (N=321 posts), patients, or occasionally a family member, posted questions containing laboratory test results to 50 different forums in the OHC. Table 5.1 provides an overview of the seven forums with 10 or more posts and includes the number of question posts per forum, common laboratory tests in posts to that forum, and the typical format of the test results. The forums with the most question posts are unsurprising considering that these conditions are often diagnosed and monitored through laboratory testing.

Table 5.1. Summary of the analyzed sample (N=321) – the forums to which questions were posted, the number of question posts per forum, common tests in these question posts, and the typical results format.

Forum	Number of Posts	Common Laboratory Tests	Typical Results Format
Thyroid Disorders Help	95	• Thyroid function tests (e.g., TSH)	• Value + Normal range*
Hepatitis C Help	44	• Diagnostic tests • Liver function tests (e.g., ALT) • Viral load test • Complete blood cell count	• Reactive/Positive or Non-reactive/Negative • Value + Normal range • Value • Value + Normal range
Thyroid Cancer/nodules & Hyperthyroidism Help	31	• Thyroid function tests (e.g., TSH) • Thyroglobulin (tumor marker test) • Biopsy	• Value + Normal range • Value + Normal range • Observations + Conclusions
Herpes Help	16	• Diagnostic tests	• Value + Positive, Equivocal, Negative ranges
Hepatitis B Help	13	• Diagnostic tests • Liver function tests (e.g., ALT) • Viral load test	• Reactive/Positive or Non-reactive/Negative • Value + Normal range • Value
Heart Disease Help	11	• Heart scan • Cardio CRP • Homocysteine	• Value + Level of plaque • Value + Average risk • Value + Normal result
HIV Prevention Help	11	• HIV Diagnostic tests (e.g., Oral Kwik HIV test, HIV PCR test) • Diagnostics tests for other sexually transmitted infections (e.g., Herpes)	• Positive/Negative • Positive/Negative

*The normal range is also sometimes referred to as the reference range. If one's result falls outside of that range, it is considered abnormal, and may be indicative of a problem (although not always).

Drawing on the concept of patient work,$^{108(pp194\text{-}195)}$ I found that patients bringing their laboratory test results to the OHC were seeking assistance in their pre- and post-healthcare visit work at different points in the medical care trajectory. Of course, due to the cyclical nature of care cycles, post-visit work can blend into pre-visit work, and compound patient support needs. In the following sub-sections, I report my results on how patients are using their laboratory test results in the process of asking questions on the OHC in the cause and diagnosis and the management and treatment stages of the medical care trajectory.

5.5.2. Understanding and Using Laboratory Test Results in the Cause and Diagnosis Stage

In this stage of the medical care trajectory, patient work on the OHC occurs both in preparation for and following an appointment with a medical professional in order to understand laboratory test results that are received through telephone, mail, or online; to plan their next steps in their medical care based on these results; and to identify the cause(s) of their symptoms and abnormal laboratory test results.

Understanding the Data

In some of these OHC posts, individuals are asking for the community's help to make sense of the laboratory reports themselves, which can include both numeric and non-numeric data. This often happens in the diagnosis stage of the medical care trajectory when they are more likely to be getting new and different types of laboratory tests and may need more support to understand what the unfamiliar data mean.

<u>Filling specific information gaps</u>: Patients are sometimes trying to fill a specific information or knowledge gap related to their laboratory test results on the OHC, including trying to interpret a single result without all the information (often normal ranges or cut-off values) and making sense of specific phrases. They may have done some independent reasoning or research first, or tried to seek help through other avenues, often making several attempts to contact medical professionals, but eventually they turn to the OHC for support. For instance, a patient posted to the Fertility/Infertility/IVF Help forum: *"I went to [healthcare organization] for blood test yesterday. Today I was curious and called. The result*

is 'Beta HCG [test to detect pregnancy] 16' What does that mean? I emailed my doctor, no reply. Called the fertility center, nurse is busy…I am crazy right now." Unfortunately, this patient appears to be missing the information necessary to interpret their test results – cut-off values. In addition, these test results seem to be emotionally charged. Given that they are receiving care from a fertility center, a pregnancy diagnosis is likely the desired outcome and they have probably faced a long, tough journey to get to this point. They will likely have a follow-up appointment soon, but they want answers now. When they are unable to get immediate answers from a medical professional after multiple attempts, they turn to the OHC to help them to understand what these results mean to their journey to becoming a parent.

Another patient posted their biopsy results, which included an explicit diagnosis of chronic hepatitis, to the Hepatitis C Help forum and stated, *"I received my report on Thursday and it has taken days to absorb it. There is no grade or stage on it, and I was extremely upset and confused about it. I have called the pathologist with no success… (D*** doctor got the results last Tuesday and never called me or returned my call)."* Despite the apparent distress and frustration, this patient has been constructive, doing their own research to try to overcome knowledge gaps and to decode the report. In the end, they share the fruits of their labor stating their understanding of the report, and then they implicitly ask for help deciphering two terms, *"p.s. the only phrases I am still confused about are 'lymphoid aggregates' and 'triaditis'…"* This post illustrates the considerable work patients sometimes put into filling knowledge gaps to understand the laboratory test results that they receive.

Unfortunately, and as this quote also demonstrates, the lack of prompt follow-up from doctors can negatively affect the patient-doctor relationship.

Interpreting laboratory test data as a whole: People also ask broader questions about all their laboratory test results or all the abnormal results. For example, one OHC user posted all the results of their hepatitis B test and liver function tests to the Hepatitis B Help forum and simply wrote, *"Can you please help me and explain the results of my test."* Similarly, in the following question posted to the Undiagnosed Symptoms Help forum, a parent is asking about their daughter who had a liver transplant one year ago and also has Epstein-Barr virus. The daughter appears to have gotten multiple liver function tests since the transplant and is likely being monitored to ensure that the new liver is functioning properly. However, since the parent posts to the forum focused on undiagnosed symptoms, it seems that they may believe that something else is going on as well. The parent writes, *"I'm concerned about some of her labs; well, really, I don't understand them…"* They then present the results that they find confusing and concerning, *"RBC-low Hemoglobin-low Hematocrit-low MCV-low MCH-low Eosinophil-low Lymphocyte 2.2 x 1000? Anisocytosis-slight Microcytosis-moderate Platelet Morphology-normal.*" Interestingly, for most of the tests, the parent does not include the numbers – either because they do not have them or because they do not feel that they are important – but only a qualitative description (e.g., "low," "normal"). The parent ends the post by broadly asking: *"What do all of these [results] mean?"* In both examples, the patients seem to have gotten their test results outside of a healthcare visit, but there is no indication of why they chose to bring these results to the OHC instead of seeking answers through other channels (e.g., their doctor). Regardless, these quotes are representative of the support patients often need to gain a holistic understanding of multiple laboratory test results.

Planning Next Steps in Medical Care

Some people do not ask questions about the data themselves, but instead seem to want to leverage their laboratory test results to plan the next steps in their medical care.

Determining whether a healthcare visit is necessary and how urgently: Sometimes patients post their test results on the OHC to seek help in determining whether they need to see a doctor and how quickly based on these data. For instance, one patient explained on the Liver Disorders Help forum that they had some laboratory tests, including liver panel, urine analysis, and cholesterol testing, done after experiencing uncomfortable symptoms such as nausea and other digestive issues. They then presented all their laboratory test results and asked, *"Is there anything serious, do I need to see a doctor?"* Of note, this patient does not indicate whether they are still experiencing symptoms but, instead, appears to be basing their decision on the objective data – their laboratory test results. It also seems like they do not have a doctor and may have had the tests run on their own. While this may not be the most common pathway to laboratory testing, in these cases, patients are then also on their own in making the decision about whether follow-up is necessary.

In another example, a patient who had several rounds of thyroid functioning tests over a six-year period brought their laboratory test results to the Thyroid Disorders Help forum. Early on in this period they were briefly treated for hyperthyroidism before deciding to discontinue the medication rather than cut the dose in half as their doctor had advised. They then explained that more recently they had been experiencing uncomfortable symptoms, *"very tired, lacked energy, brain fog, dizziness. Somewhat depressed. I am missing a third of my eyebrow and my leg hair barely grows. I also seem too hot a lot. Moody to put it mildly. Can't lose weight no matter what I try."* When a relative with hypothyroidism suggested that it could be a thyroid issue, they spoke with their doctor, who ordered another two rounds of thyroid functioning tests. After posting these results the patient stated, *"She [the doctor] faxes my lab work directly to me. She and I are not believers in follow up visits unless something is wrong."* Thus, while this patient seems to believe that they may have hypothyroidism, as with the last example, the individual appears to primarily be basing their decision to schedule an appointment on their laboratory test results. Overall, these examples suggest that patients may weigh their laboratory test data more heavily than how they are feeling in some cases.

In addition, even when patients know that their results are abnormal and require follow-up with a doctor, they may be uncertain about how urgently they need to seek medical attention. For instance, in the following post to the Undiagnosed Symptoms Help forum, a patient explains, *"I've had a steady increase of SGOT and SGPT levels from my blood tests [tests to assess liver functioning]."* They then present the values to illustrate their point, *"A week ago it was SGOT-141, SGPT-130… I've had another blood test today and the SGOT-110 with SGPT-218."* The individual concludes by asking, *"Is this serious enough to seek medical help immediately? The reason I am asking is that I have a flight to catch tonight, so will this wait 2-3 days or is this an emergency situation?"* While this individual does not include reference ranges, making it difficult for the OHC to interpret their results, they seem confident that their levels are elevated and require medical care. However, as is the case for most people, this individual must balance their healthcare needs with other aspects of their life. This person appears to be willing to prioritize their health if needed, but they are turning to the OHC to decide whether this is necessary.

Determining what additional information to gather: Patients also wonder what additional diagnostic tests they can or should request, as a concrete next step to determine the cause of their abnormal laboratory test results and symptoms. In these cases, the patient typically includes their test results, a description of how they are feeling and, sometimes, a belief about their diagnosis. For instance, one patient posted on the Thyroid Disorders Help forum: *"My TSH [thyroid stimulating hormone, thyroid functioning test] level has gone from 0.53 to 15.6 over the last year with increasingly higher adjustments to my medication. I just don't know what to do… I have all the classic symptoms. Are there any other tests that can be done to figure out what is causing this to happen?…"* The patient is at their wits end and desperate to find what is causing the abnormal test results and symptoms (presumably in order to find a way to improve their health situation). As with others posting their laboratory test results, this state of mind brings them to the OHC to seek support in identifying additional tests that might offer insights into their health issues. Interestingly, in this case, the patient does not directly mention their doctor's role, other than referencing the medication adjustments, possibly suggesting that their doctor has not been helpful in or supportive of their desire to find the root cause of the problem.

In another example from the Thyroid Cancer/Nodules & Hyperthyroidism Help forum, the patient writes:

> *"… I recently had my thyroid checked. TSH 1.069 (0.450-4.500) Free T3 3.3 (2.3-4.2) Free T4 1.5 (0.61-1.76). They are all in the normal range, but I feel SO hyper [hyperthyroidism], and have most of the 'usual' symptoms. My question is, do you think I should have the antibodies test? Would it really make a difference? Say I have high antibodies, but with the other normal labs, could I still feel so bad?..."*

Unlike the previous example, this individual has a particular test in mind; however, they are uncertain whether the test will provide valuable information given their current test results. Trying to understand what information a test provides (and what it cannot) is a relatively common question among OHC users and can affect patients' plans for their next steps.

Planning communication for an upcoming medical visit: Patients may also be gathering information to plan their communication with their doctor and seek to draw on the extensive patient expertise [107,348,349] in the OHC to try to get the information and care that they need. For example, the following was posted to the Thyroid Cancer/Nodules & Hyperthyroidism Help forum: *"My latest lab results show my Thyroglobulin, Quantitative at 54.5 (reference range is 0.5-55.0 ng/mL). Since it's still within the reference range (barely!) should I be concerned? I have multiple thyroid nodules that, as of last December, were supposedly benign."* In this example, the patient is pointing out that their thyroglobulin test results, which are most often used as a "tumor marker test,"[350] are at the upper end of the reference range. They are most likely worried that their nodules may now be malignant. They then explain that they have an upcoming appointment with a specialist, an endocrinologist, and fear that their doctor may just dismiss the result as “normal.” And this is not rare. Some patients even use war imagery when describing their interactions with doctors, such as *“[OHC user’s] answers are really informative and always provide weapons when talking to doctors.”* Although it is impossible to know, this mistrust may be based on past healthcare experiences. Bringing their results to the OHC to get input from peers may give patients the confidence to push back on the doctor’s opinion, if necessary, in order to advocate for themselves.

In other cases, patients seem to want to prepare questions so that they can get the most out of the time they have with their doctor. For instance, in the following question posted to the Thyroid Disorders Help forum, a parent of an ill 12-year-old girl states that they *“have been to the doctor several times,”* presents their daughter’s symptoms, including throat and nose pain, *“a low-grade fever,”* and *“extreme exhaustion,”* and the results of their thyroid functioning tests: *“TSH-6.4 T4 Free-0.81 T3-152 Peroxidase-303.”* The parent concludes the post with, *“We are going to the Endocrinologist [a specialist] on Monday – what do I ask?”* This post illustrates that some patients recognize that they may not know what they do not know and seek help from the community in having the most productive healthcare visit possible.

Hypothesis-driven Efforts to Identify the Cause of Health Issues

Most patients posting their laboratory test results on the OHC in the cause and diagnosis stage want answers as to what is causing their symptoms, abnormal laboratory tests, or both. Many individuals posting to the OHC already have an idea of potential causes and are checking or verifying these hypotheses with the online community. As mentioned earlier, generating hypotheses is a major part of the hypothetico-deductive approach[346] that doctors typically follow when diagnosing patients. For patients, these educated guesses may come from their personal research, a friend or family member, or their doctor. When asking their question to the OHC, they include the evidence that they believe that the community may need to evaluate the hypothesis.

<u>Missing pieces – Solving the puzzle with only the objective data</u>: Sometimes patients focus exclusively on the objective indicators of their health status, their test results, using it as the primary evidence by which to assess their existing hypotheses and sometimes to also gather additional ideas of what are the possible causes of their health issues. For example, in the below quote from a post to the Liver Disorders Help forum, the person does not state whether they are experiencing symptoms or what symptoms they are experiencing. They focus on their numbers. They start with their abnormal results, and quickly concentrate on one in particular – the low sodium level. This patient clearly did some research before they came to the online community: "*I have read that low sodium level can be caused by a thyroid issue, but my TSH came back at 1.37ulU/ml (normal range 0.40-4.00). I've also read that low sodium can be the result of liver disease, but my liver enzymes all came back normal.*" In other words, this person found information that they believed could point to the cause of their low sodium level, but their test results did not support the two research-driven hypotheses – (i) thyroid issues and (ii) liver disease – so now they need the community's help in assessing the likelihood that each of these could still be the cause (despite the data). They also present a third hypothesis that appears to be based on a personal belief, "… *I've suspected that I may*

have celiac disease for some time now. Can a gluten allergy affect sodium levels?" They conclude the post by saying that they have an appointment with a specialist (gastroenterologist) in two weeks. Ultimately, they seem to want the community's help in assessing their hypotheses on the cause of their abnormal results and in gathering information as they await their appointment with the specialist.

In another example, a patient posts on the Thyroid Disorders Help forum:

> *"I just had thyroid tests done. My readings are T4-1.2; Triiodothyronine, Free Serum-2.7; Thyroid Peroxidase (TPO)-18; Antithyroglobulin Ab <20. I had Graves' Disease [an autoimmune condition that leads to an overactive thyroid gland (hyperthyroidism)]… but recovered with Tapizol. Obviously, I am concerned that it has returned... My only insurance is for hospitalization, so I had the tests run on my own."*

This patient is likely experiencing symptoms, motivating the laboratory test, but they chose not to share these with the community. Instead, as with the previous example, they focus exclusively on the numerical data. In this case, though, they came to the OHC because of a lack of access to medical expertise caused by insufficient insurance coverage. As with the decision about whether to schedule a follow-up appointment, these examples also show that patients sometimes seem to become hyper-focused on their medical data, possibly at the expense of other pertinent information such as how they are feeling.

<u>Presenting all the pieces to solve the puzzle</u>: Other patients, though, include multiple types of information, such as symptoms, personal information such as age, and medical

professionals' opinions, along with the laboratory test data, as evidence when asking OHC members to help them verify their hypotheses. For instance, a patient posted their symptoms, key demographics (age and sex), and laboratory test results to the Thyroid Disorders Help forum. They explain that *"another doctor online"* told them that they have hyperthyroidism: *"He said my TSH is too low and T4 is too high."* The patient ends the post asking, *"Can you tell me what you think?"* In this case, the individual posts the details of their medical case, including their laboratory test results on the OHC to get a second opinion, and to gain access to more medical expertise.

In another example, the person posting to the Infectious Disease Help forum states their symptoms and mentions their normal test results: *"I've been sick for a while, it started with mild chronic gastritis… odd rashes, fatigue, bloating, stomach/liver pains. Ulcers, h. Pylori, celiac all ruled out. Colonoscopy was clean, gastric emptying test normal, no allergies, no food intolerances."* Then they go on to explain the timeline of their symptoms, which started with an international trip, and discuss some of their medical history. They explain that they have seen multiple types of specialists – one did not provide any answers and the other two offered a potential cause: *"Since I was getting nowhere with a gastroenterologist, I've seen a tropical disease specialist and hematologist. Both suggested that I might be having an autoimmune response to a chronic infection or post-infectious response."* The patient then presents the abnormal objective indicators of health – their laboratory test data – that include an indication of whether the result is high or low, as well as some interpretation. For instance, they write, *"…RBC [Red Blood Cell]-4.02 (normal: 4.2 - 5.4) LOW; MCH [Mean*

Corpuscular Hemoglobin]-32.6 (normal: 27 - 31) HIGH; Ferretin-8 (normal: 20 - 360) LOW; Iron-10 (normal 9 - 31) NORMAL; Transferrin-3.72 (normal: 2.13 - 3.6) HIGH; Transferrin saturation-11% (normal 20 - 55%) LOW; (Interpretation: Iron Deficiency)..." They end the post by asking about whether their abnormal test results, along with their symptoms, indicate specific conditions: *"does it sound like it's an Autoimmune Disorder? Maybe Hemolytic Anemia? Chronic Inflammation? Chronic infection?"* Like many patients posting their laboratory test results in the OHC, after dealing with symptoms and searching for answers for years, this person has a good deal of information accumulated – on their own subjective experience, objective indicators of their health status, and the opinions of medical professionals – but still does not have definitive answers. Patients in this situation are hoping that the OHC can help them make sense of all this information.

Co-creating new hypotheses with the OHC: Some patients do not currently seem to have a hypothesis for what is causing their health issues; these individuals often appear lost, posting a more open question(s) on the OHC meant to generate new hypotheses. For instance, one patient posted on the Thyroid Disorders Help forum:

> *"High TSH [thyroid stimulating hormone] normal T3 and T4, Can anyone help me, I am a 33 year-old male, and last year I had a blood test and my TSH was 18.00 (0.27-4.20) F3 4.76 (3.13-6.76) and T4 16.28 (12-22). After taking thyroxine for 6 months my TSH went down to 10.50 and my T4 went to 36. I had a high pulse and hands were shaking so I stopped taking it. I have seen two endocrinologists and they both say it is strange and they don't know what it is that I have..."*

While this patient was diagnosed with and began treatment for a thyroid problem, they discontinued the treatment due to their reaction to the medication. It is unclear whether they stopped taking the medication on their own or under the direction of their doctor. Regardless, they now seem to be back to square one. Like other patients posting their laboratory test results to the OHC, they have seen multiple specialists and have not been able to get satisfactory answers from them about what is causing their symptoms. Patients in this situation have seemingly hit a dead end within the healthcare system, and with medical experts, prompting them to look for new ideas and perspectives elsewhere (i.e., the OHC).

Another patient posted to the Thyroid Disorders Help forum, explaining their medical history and current situation – they are 31 years old and were diagnosed with hypothyroidism 15 years ago. Their symptoms had been kept under control with medication since then. Within the past year, though, they had a sudden change in their health status, resulting in distressing and extremely uncomfortable symptoms (e.g., frequent hot flashes). Their primary care physician ran some laboratory tests and found that both their thyroid and estrogen levels were abnormal. Their doctor prescribed medication to address the symptoms, expressed concern about their laboratory test results, referred them to a specialist, and suggested that they follow-up with this specialist immediately. The patient writes about this frustrating follow-up visit:

> *"… all she said was to redo my blood work as the lab may have screwed up and get a new prescription for thyroid pills as they could have been no good and come back… When asked about my vision, she said to see an eye specialist. That's it, no more*

> *tests, nothing. I at least expected maybe a MRI, CT scan, something to ease my worry. So, I am at my wits end, I am moody, gaining weight, can't see normally and so bloody tired…"*

They end the post by requesting *"any ideas"* from the community that might explain their symptoms and alarming test results. As this example shows, misalignments in expectations and attitudes between patients and doctors can bring patients to the OHC in search of support. In cases such as these, patients may feel like they have not been heard or that their doctor has not adequately addressed their concerns, leading the patient to do their own work in the OHC, which will then likely be used to advocate for themselves within the healthcare system.

This section highlighted the data, illness, and anticipation (e.g., planning) work related to their laboratory test results in which patients engage on the OHC during the cause and diagnosis phase of the medical care trajectory. Overall, in this stage, question posts tend to be emotionally charged and include broader questions. Patients bring their results to the OHC for a number of reasons, including knowledge gaps, uncertainty about next steps in their medical care, lack of trust or confidence in their doctor, and for fresh perspectives on their medical case.

5.5.3. Using Laboratory Test Results in the Management and Treatment Stage

In addition to identifying causes and diagnoses, people posting their laboratory test results to the online community also use that data as a key indicator of their health status to understand and plan for the management and treatment of their health condition, as well as dynamically assess the likely course of their disease throughout this stage.

Identifying Treatment Options

In some cases, individuals are asking open questions meant to understand their treatment or self-management options. For example, one patient writes to the Hepatitis Social Help forum: *"Extremely High ALT AST [liver function tests]? HELP, ALT (SGPT) 2226 and AST (SGOT) 1091. What treatments are available?"* This individual chose to provide very little information. They do not include reference ranges. They do not state whether they have already spoken to their doctor or not or whether they are aware that these results may suggest liver damage. What is clear is that the patient is concerned about their laboratory test results and is asking the OHC for help proactively gathering information on their treatment options. Presumably they will eventually need to follow-up with a doctor to access treatment.

Similarly, in a post to the Congestive Heart Failure Help forum, a patient describes getting blood tests during a hospital stay and receiving a report that showed that their homocysteine level was high. High levels of the homocysteine amino acid in the blood can increase one's risk for blood clots, heart attack, and stroke. However, according to the patient's account, the doctor only communicated that the levels should decrease over time and did not mention the patient's increased risk for those serious conditions. The patient later learned about the risks associated with the laboratory result through an online search and was concerned. Since they no longer have the same access to medical expertise that they had in the hospital, they turned to the OHC, ending the post with a request for help, *"If anyone can guide me and advise me on what I need to do [to lower risk], it will be very helpful for me."* As this example illustrates, when patients discover important information after a healthcare interaction, especially a hospital visit, it can result in significant effort to address their subsequent information needs.

Choosing between Treatment Options at the Start of Treatment

Some patients seem to know their treatment options and ask more specific questions aimed at making treatment decisions – whether these are standard treatment options provided by a medical professional or the decision to go against their doctor's recommendation. For example, in one post to the Thyroid Disorders Help forum, the patient has just been diagnosed with Graves' Disease. They explain that they have been given the three typical treatment options for this condition (likely during a visit with their doctor) – antithyroid medication to control the overactive thyroid, surgery to remove the thyroid, or radioiodine therapy (RAI) to shrink and eventually destroy the thyroid gland. Their doctor does not think that they are the best candidate for the medication option, and they agree. Thus, they are deciding between the surgery and RAI options. In the majority of the post, they explain their concerns with each option, specifically highlighting the risks, and what is most important to them – the health and safety of their 18-month-old baby. They ask the OHC for help, writing, *"This is all so very overwhelming! What is your opinion of what I should do, and why?"* In this case, the patient tacks on their test results at the end noting: *"I'm not sure what it all means but figured it to be pertinent information."* As with others in this situation, they will presumably use this information to help them to weigh their options and to, ultimately, make a decision that will likely be discussed with their doctor at their next appointment. In addition to different opinions and reasonings on the options, though, some people seem to want to hear personal experiences with different treatments. For example, one patient posted to the Hepatitis C Help Forum, and said that their doctor had given them the choice between two treatment options, and ask the community, *"Anyone of you tried both [treatments], if so, what is your story on the difference."*

Patients may also be contemplating going against their doctor's treatment recommendation by refusing a prescribed medication or canceling an upcoming procedure. For instance, in a post to the Heart Disease Help forum, a patient who has high cholesterol has come to the OHC after a visit with their doctor. They explain that their doctor has recommended that they manage their high cholesterol with medication (*"a statin"*). However, they would prefer to take a "wait and see" approach, maintaining their healthy lifestyle and monitoring for signs of increased risk: *"I'd prefer to have a heart scan every two years to monitor plaque and take the statin if there is any evidence of plaque."* So, they ask the community, *"If my heart scan shows no plaque at 48 years old, if my Cardio CRP [C-reactive protein] is average, and my homocysteine [amino acid level] is normal – do I need a statin?"* This patient has a strong preference for how their condition is managed. Indeed, statins are very effective and considered relatively safe, but they do come with their own risks, including for side effects such as mental cloudiness and digestive issues.[351] While the benefits of statins are generally considered to far outweigh these risks, the patient is the one who will need to bear the burden of any negative effects of the medication. Self-management requires sustained effort to maintain a healthy lifestyle and may not always be as effective as medication; however, this patient feels that it is the best option for him and appears to be seeking validation for this choice from the OHC.

In another example of choosing whether to treat a medical concern now or wait, a person explains their situation in the Ovarian Cancer Help forum. They have had two blood tests to screen for ovarian cancer, which revealed that the level had increased over the course of about a year. Based on these results, their doctor appears to have recommended getting a hysterectomy (a procedure to remove a woman's uterus). They decide to take this option, scheduling the procedure but, as the date approaches, they are clearly feeling conflicted. They explain, *"A cyst was removed. Another cyst is back. I am lost, confused. I don't have any symptoms, no complications whatsoever. No family history of cancer. I can't even talk about it to my family. All kinds of thoughts are going through my mind, negative thoughts. I don't know if I should have the surgery or not."* They bring this decision to the OHC asking, *"Should I have a hysterectomy?"* While the patient also states that they trust their doctor, it does not seem sufficient in this case to reduce the conflict they feel surrounding this decision. They need help and the anonymity of the online community may provide them with the outlet they need to voice their fears and get new perspectives on this very difficult decision.

Planning for Adjustments in Treatment

In some cases where patients are undergoing longer-term treatment, individuals may believe that their symptoms or laboratory test results indicate that a change in their medication dosage is necessary. They are checking with the community to see what others think they should do and, in many cases, to assess their risks. In situations where the patient is asking if they should increase their dosage, it is likely that they would have to discuss this with their doctor and get a new prescription. On the other hand, in cases like the following quote from the Thyroid Disorders Help forum, where the patient is asking if they should discontinue or reduce their dosage, it is possible that they may act on their own (e.g., cut a pill in half). However, this intention is rarely explicitly stated. In this example, the patient has been taking medication for hypothyroidism for six months, but recently ran out of the medication. They had bloodwork done after they had been off the medication for a couple of days and found that the results were normal. After presenting the numbers, they ask, *"Does that mean I should stop the medication, or should I continue on the same dosage? Or should I reduce the dosage? Is there any chance of me being hyperthyroid if I continue on the same dosage?"* It is unclear whether they have discussed these questions with their doctor or what they plan to do with the community-provided information (e.g., discontinue medication, make a medical appointment), but they are clearly trying to proactively manage their health through active engagement with their laboratory test results and the OHC.

Patients also post questions to gather information on what the OHC believes should be their treatment plan based on their laboratory test results and symptoms with the explicit intention of bringing this information to their doctor to negotiate their treatment, especially when they perceive limits in their doctor's expertise. For example, in their post to the Thyroid Disorders Help forum, a patient states that they were *"diagnosed with* *hypothyroidism 1 year ago,"* provides their relevant medication history, current symptoms, and most recent laboratory test results. They then ask the community, *"What should my Armour thyroid dose be?… Should I also be on Cytomel? Dose to start?... Please provide what information I would need to share with my doctor for any changes/revisions in my current medication."* This patient also explained, *"My doctor is very easy to work with, but endocrinology is not his specialty."* Overall, this post highlights that many patients recognize the, largely peer-patient, expertise on the OHC and want to leverage that expertise to influence their care and better manage their condition.

Understanding the Likely Course of Disease throughout the Treatment Phase

Some patients bring their laboratory test results to the OHC to try to determine their prognosis both prior to starting treatment and during treatment, illustrating that this is a dynamic assessment often centered on their numbers. For instance, a patient posting their laboratory test results to the Hepatitis B Help forum had many questions, including: *"How much time do I have left? Is it 1-5 years, still 20-30 years, or even 40-50+ with proper treatment?... Can I be cured? Can I stop the disease process until I die from… old age with proper treatment?..."* In cases such as these, patients seem to want to know what their laboratory test results imply about how they might respond to treatment, even before they seem to know the specific treatment that they will receive.

After a patient starts treatment, they may have a better idea of their prognosis (for better or worse) as care becomes focused on how they are responding to the treatment. For example, in the below quote from the Hepatitis C Help forum, a patient writes:

> *"… Second week blood work very discouraging, or at least that's the impression I got from my doctor. WBC-3.74 RBC-10.8 Hemoglobin-32.5… I got the impression that he didn't think I could tolerate the treatment, next visit would decide that (it would only be 8 weeks)… He said My counts were 'dropping like a rock,' decreased ribavirin from 1000 to 800 mg. Is this 'normal'?…"*

Unlike when patients are planning for adjustments in their treatment, here, patients often seem to have far less influence over treatment decisions. If laboratory test results are not "good," the doctor may discontinue their treatment for their own safety, which may significantly affect their prognosis. In this example, the individual is deeply concerned that they may be forced to terminate their treatment early, which would reduce the odds that the hepatitis virus will be cleared (i.e., cured). As with other examples I have presented, they also seem to have some communication issues with their doctor that they are trying to compensate for on the OHC: *"I asked questions, but I did not understand what deciding factor determines continuing treatment."* Later in the post, they also proactively ask the community for questions to bring to their next doctor's appointment. Between filling in the gaps from the previous appointment and gathering ideas for questions for their upcoming appointment, they may be trying to improve their communication with their doctor. If this is the case, such interactions on OHCs have the potential to not only improve the patient's understanding of their own health, but also improve the patient-doctor relationship.

This section highlighted that, in the management and treatment stage of the medical care trajectory, questions related to their laboratory test results tend to be more focused, often occurring after a patient has had at least some discussion of the results with a doctor. Still, patients are doing significant information, illness, and anticipation work on the OHC in this phase. I found that they may turn to the OHC at this point for numerous reasons, including because they are specifically seeking patient experiences with treatment, they are trying to make sense of conflicting information, or they want validation in a preference for a treatment option not recommended by their doctor.

5.6. Discussion

Patient work, including data, information, illness, and anticipation work, to understand and use their laboratory test results on the OHC occurs at multiple points in their medical care trajectory and throughout care cycles. It tends to be concentrated around points of medical decisions (e.g., whether to schedule a follow-up appointment, diagnosis, initiating treatment), with patients posting on the OHC seeming to want, or feel that they need, to be active participants in the medical process. I found that this work can be productive and empowering for patients, but it can also be stressful and burdensome. Our data also show that, for many patients, the OHC is just one part of their support seeking efforts, which may also include reaching out to healthcare professionals, family, and friends, as well as utilizing other online resources. In other words, I found that patients seem to be using their laboratory test results to fuel what Young and Miller referred to as "ecosystems of support."[328]

Although previous research on questions posted on social sites related to laboratory test results have identified similar types of questions,[142,338] here, our analysis uniquely emphasizes several gaps in the provision of healthcare services that can lead to the aforementioned patient work on the OHC to understand and use their laboratory test results: (1) temporal gap, (2) anticipation gap, and (3) information gaps. In the following sections, I discuss how the OHC has become an important space for patient work to address these gaps in healthcare service design, but also highlight how integrating this information back into their medical care, including the work required to negotiate that care with their provider, will likely also require considerable effort and is not well-supported by the current design of OHCs. Ultimately, I argue that having access to medical data can help to engage patients in their healthcare, but it is imperative that patients have access to sufficient supports. While the OHC provides one place to seek help, the design of the technological ecosystem to support patients as they view and try to leverage their medical data could be improved to fill the gaps in healthcare service design and to reduce the consequent patient work.

5.6.1. Temporal Gap and the Need for Emotion-aware, Real-time Support

One of the key gaps that seems to lead to patients seeking support in OHCs, especially in the cause and diagnosis stage of the medical care trajectory when patients may be getting many different types of tests, is a pattern that likely became even more common in the last decade as more and more patients adopt technologies that facilitate access to their medical record outside of healthcare visits.[58] Patients now have access to more of their medical data, faster than ever before, which is in-line with what the literature says patients and caregivers want,[352] as well as larger movements toward patient empowerment and patient-centered care.[4,353] However, doctors may have an even more difficult time keeping up and providing patients with the information that they need to understand and use this medical data.[321,354,355] Indeed, one study found that fewer than 40% of patients received a note or interpretation from their doctors along with their results.[321] Meaning that patients often must either wait for their next visit to discuss the results with their doctor or put in the effort to try to contact a medical professional outside of a visit, seek support outside of the formal healthcare system, or both. In situations where the stakes, and correspondingly the emotions tied to the results, are high, a lack of timely support can be problematic. In other situations, though, this gap can be productive, giving patients the time to proactively prepare for an upcoming appointment.

Lack of Timely Support Outside of a Visit

Our analysis revealed that, whether because there are strong feelings tied to the results (e.g., fear, hope) or they are experiencing distressing symptoms, some patients want or need support immediately, but are unable to see a doctor right away or have been unable to reach a medical professional, often despite multiple attempts usually via phone. Secure emailing (also known as secure messaging) is commonly offered by healthcare organizations and could help to address this problem. However, not all doctors offer this service and, among those who do, response times can be highly variable.[208] In other words, some patients have urgent support needs that cannot always be met by the overextended healthcare system with its overscheduled doctors and their limited availability,[145–147] even with technologies that attempt to facilitate patient-doctor communication. As others have emphasized, this points to one of the key benefits of OHCs: they are open and available 24 hours a day, 7 days a week, 365 days a year.[356,357] In this setting patients have the time and space to learn through discussions of their data[358] and for collaborative sensemaking and problem solving.[81,328] This can, at least partially, fill this gap in healthcare service design, with our study showing that patients do try to use the OHC in this way. Unfortunately, patients may not get immediate support through the asynchronous OHC either.

Proactively Preparing for an Upcoming Visit

Patients also come to the OHC when they receive results outside of the healthcare context to crowdsource their appointment preparations both to arm themselves with information so that they can advocate for themselves and to try to improve communication with their doctor. Our results support extant research that suggests that patients often use or plan to use the information obtained in the OHC to negotiate their care with their doctor.[332] Past research has found that doctors can be skeptical of information obtained through OHCs, which can also lead patients to feel like they cannot reveal the source of the information.[332,337] However, there is growing recognition of the potential of engaging patients in agenda-setting in preparation for their upcoming appointment,[359] as well as studies testing the effectiveness of providing patients with suggested questions to ask their doctors.[360,361]

Design Recommendations

Our results suggest that the support offered through technologies connected to the healthcare system could be improved with personalization based on patients' level of concern. One concrete step towards this capability would be to proactively incorporate emotional state metrics into the EHR – for example, when a doctor orders a laboratory test, they could explicitly ask the patient how they are feeling about the test and record the response in the EHR. For those with stronger emotions tied to the results, a prompt could be given to the healthcare team to be especially sensitive in the delivery of the results (e.g., perhaps calling them to explain the data), enabling prioritization of human efforts. In addition, a real-time chat option could also be offered with the release of laboratory test results. An artificial intelligence (AI)-powered tool could handle common questions, with an option to connect with a healthcare professional for more complicated support needs or if a patient shows signs of being distressed. Patient-facing AI chat-bots have been used to aid in screening for a particular disease and in diagnosing patients based largely on their symptoms.[362,363] Recent research has also begun to explore how to improve patient trust in such tools, particularly when helping patients to understand the results of diagnostic tests,[364] but more research is needed.

These proposed changes to the technologies supporting healthcare service delivery could eliminate some unnecessary patient work, by providing synchronous support for two-way communication at the point of viewing laboratory test results. However, as our results show, the collaborative work done in OHCs has the potential to be very productive, empowering patients, supporting their autonomy, and giving them the confidence to be active participants in their care. Thus, I am not arguing to eliminate OHCs, but to rethink the design of technologies that offer patients access to their medical data to better support the growing role that patients are playing in their care, in addition to leveraging the strengths of

OHCs in support of patients. An ideal solution may be for OHCs to partner with healthcare organizations. For instance, patient questions to the OHC, along with relevant questions asked through secure messaging, could be used to power the previously discussed AI tool, potentially also in conjunction with offline sources to mitigate the risk of bias. In addition to having the option to chat with a healthcare professional, patients could be given the option to connect with peer-patients on the OHC especially in cases where patients may particularly benefit from patient expertise (e.g., newly diagnosed with a chronic condition). When the patient finally does have a healthcare visit, OHCs could better support the integration of information back into the healthcare system by facilitating patient synthesis of what they learned from peer patients and providing suggestions for productively communicating this information with their doctor. This type of workflow is becoming more feasible through standards (i.e., FHIR[281]) and Policy such as the 21st Century Cures Act[33], which presents new opportunities for an ecosystem of smartphone apps where health data flow to better support a more patient-driven healthcare system.

5.6.2. Anticipation Gap and Guiding Patients in their Planning and Expectation Management

While some patients are using the temporal gap to proactively prepare for an upcoming appointment, our results also suggest that there is often a lack of support for patients trying to plan their care, which has been referred to as anticipation work in the literature. Anticipation work is a crucial aspect of the articulation work[108,365(p151)] that makes collaboration possible, including patient-doctor collaborative work. It has been described as "practices that cultivate and channel expectations of the future."[366] Clarke explains in a chapter on the topic in the book Boundary Objects and Beyond: Working with Leigh Star, "Anticipation work includes but is not limited to gathering information, abducting, simplifying, guessing, deciding, planning, acting…."[367(p104)] For instance, print shop workers anticipate when their next task will come,[368] and intensive care unit nurses expect when they will receive laboratory test results.[369] This type of work is often invisible and can be "very costly labor in terms of sustained anxiety and hypervigilance."[367(p104)]

In the medical context, the patient-doctor collaborative relationship is complex, with each having their unique perspectives, knowledge, and routines. Although patients are traditionally viewed as passive recipients of healthcare and the work that they do is often not recognized,[108(p191)] in this study, I found that patients were actively engaged in this work. They had their unique expectations for their healthcare (e.g., "after I see the specialist, I will have answers") and they tried to plan for what they thought should come next. Ultimately, the anticipation gap is caused by the lack of support for this anticipation work, as well as for patients' agency in their care. Patients sought to fill the gap through collaborative work on the OHC, particularly centering on key decisions at different points in the medical care trajectory: determining if medical follow-up is needed and how urgently, making new testing decisions, and making treatment decisions. While doing this work collaboratively with OHCs can be productive, I contend that better supporting patients' anticipation work at the point of viewing their laboratory test results is also important, particularly at medical care trajectory exit points (e.g., deciding whether to schedule a follow-up visit, determining whether to discontinue a medication on one's own), where the decisions may take patients away from the formal healthcare system and have potentially serious consequences.

Design Recommendations

To address this gap, technologies that offer patients access to their medical data could automatically provide some guidance with laboratory test results. This is likely technically feasible for many tests and may be helpful in steering patients in their anticipation work throughout the medical care trajectory and, thus, enable smoother collaborative work with doctors. For example, in the cause and diagnosis stage, if one or more values is outside of the reference range, this could be brought to the patient's attention, as opposed to patients having to look through all their results to try to identify any potential problems, and a suggestion could be made to contact their doctor about scheduling a follow-up appointment. If the results are within the reference range, however, the system could prompt patients to think about whether they are still experiencing symptoms. Our results suggest that sometimes patients seem to become hyper-focused on the "objective" data, especially when making decisions about medical follow-up after receiving laboratory test results. This problem has also been discussed in the quantified self literature.[370,371] However, in our study, patients may be trying to emulate doctors; research suggests that patients perceive doctors to put significant weight on these "objective" indicators of health.[107] Unfortunately, putting too much emphasis on laboratory test results is a "major misconception among clinicians."[320] Providing a cue to help patients bring how they are physically feeling back into their decision making could reinforce the importance of their subjective experience. In both cases where patients receive normal and abnormal results, information could also be presented on potential follow-up tests based on one's results and what additional diagnostic information those tests might provide (and what they cannot), as well as their costs and potential risks, helping to set and manage expectations up-front to promote a positive patient-doctor interaction.

In the management and treatment stage, for those making initial preference sensitive treatment decisions, there is evidence that decision aids, which provide information on the risks and benefits of treatment options and help patients make decisions that align with their values and preferences, can lead to patients feeling more confident in their decisions and can improve patient-doctor communication.[372] Integrating these aids into patient portals, for example, could provide a mechanism for guiding subsequent communication – the patient completes the decision aid at home, a report is generated for their doctor, the patient and doctor review the report together at the next healthcare visit to facilitate shared decision making. This structured process could help align patient and doctor expectations and planning.

5.6.3. Information Gap and Using ICTs to Address Structural Issues in Healthcare

Our analysis revealed two main information gaps that can result in patient support seeking on the OHC: seemingly ineffective patient-doctor communication during healthcare visits and insufficient access to medical expertise.

Ineffective Patient-doctor Communication

Patients sometimes appear to bring their laboratory test results to the OHC due to communication issues during healthcare visits such as communication breakdowns in question answering (either the doctor did not answer the question, or the patient did not understand the answer). Previous research has highlighted the struggles with effective patient-doctor communication, including the tendency for doctors to interrupt patients.[373] There are also well-known issues with patient health literacy, which has been defined as, "capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions," that may create barriers to patients understanding of information shared in visits.[73] In addition, research suggests that patients often only retain a fraction of what their doctor communicates, especially when receiving difficult news.[344] Thus, there are likely multiple factors leading to this problem and the patient work to fill information gaps on the OHC.

There are two key roles the OHC may be playing that could positively affect patients' healthcare experiences and interactions with their doctors: supporting patient learning and helping patients develop or refine their illness story. First, our results show that many patients come to the OHC as a part of their learning process. Existing research suggests that there are benefits to becoming an expert patient in terms of patient autonomy and empowerment, as well as patient-doctor communication.[107] As our results show, patients may come to the OHC to vet ideas and to learn more so that they can advocate for themselves.

This process could help to fill information and communication gaps that may, ultimately, result in improved healthcare interactions.

Second, beyond filling information gaps, one of the key roles the OHC may play is in helping some patients, especially those in the diagnosis stage, develop their illness story – the narrative people cultivate to tell the story of their medical journey.[374] The development of "an efficient, coherent narrative" can be critical to effective doctor-patient communication.[373(p223)] This story often involves integrating medical data, their health history, their personal description of how they are feeling, personal details that could affect their health (e.g., going through stressful life events such as divorce), and information and advice that they have gathered thus far from other people, such as doctors and family members, as well as through personal research (e.g., doing a Google search). In our study, the narrative presented to the online community was often, by the patient's own admission, somewhat scattered, whether due to them experiencing symptoms affecting their cognition (e.g., "brain fog") or being overwhelmed by what is going on or just uncertainty about what is important to include. Previous research has shown that peer patients may ask questions to obtain more information in the course of answering questions.[142] These questions could also serve to help patients refine the narrative they share with their doctor.

Insufficient Access to Medical Expertise

Patients may also come to the OHC in search of expertise beyond that of their doctor, even when there seems to be good patient-doctor communication. In particular, patients report that their doctors are out of ideas or do not specialize in their condition; that they want access to more expertise, including being particularly interested in learning from the lived experiences of other patients, so that they can be sure that they are receiving the best care possible; and that they are currently experiencing barriers to accessing healthcare (e.g., geographically isolated, limited insurance coverage). The OHC also provides patients with access to more expertise, which they may use in their future healthcare interactions in several ways such as to propose potential new hypotheses to investigate.

Design Recommendations

There are individual-level design recommendations that could address this gap; for instance, recording and storing healthcare interactions so patients are able to review them at their convenience, which is a feature patients have requested be added to patient portals[352] and better supporting patient learning and illness story development in both technologies such as patient portals and OHCs. However, it also points to more structural issues in healthcare, including power structures, financial incentives for healthcare organizations to maximize the number of patients seen, healthcare access and, likely, disparities in health, all of which can be reinforced by the technological infrastructure in healthcare. While OHCs may provide one avenue to push against these structural issues by providing practical peer-to-peer support that can empower patients with the information and confidence that they need to advocate for themselves, they are also not accessible to everyone, with research suggesting that online health support seekers tend to be younger and have higher incomes and levels of education.[120] Thus, here, I echo the recommendations of Veinot et al. and “leveling up”[375] in an effort to address the structural issues at play. For example, shared agenda setting[359] and just-in-time prompts in electronic health records to clinicians to ensure that they covered all of the patient's priority items could target the power dynamics that can make it difficult for patients to get their questions answered.[309,376(pp127-129)]

5.7. Conclusions

This exploratory study investigates patient support seeking throughout the medical care trajectory and embedded care cycles. It contributes to the existing literature by identifying the significant gaps in healthcare service design – temporal, anticipation, and information – and the consequent patient work related to medical records, and specifically laboratory test results, that is currently being done in the OHC at different points in the medical care trajectory. Based on my results, I recommend changes to the patient-facing technological infrastructure available for viewing medical data to better support and empower patients. Improving support for collaboration, information exchange, and learning through these technologies is critical to achieving this. Future research should seek to better understand support needs and practices related to medical records among less technologically advantaged populations, as well as assess the effectiveness of interventions that seek to address structural causes of the identified gaps.

CHAPTER 6. Discussion and Conclusion

These four studies provide insights into how to improve the design of health interface technologies to better support patient work using the example of technologies for sharing clinical data with patients, including patient portals and miPHRs. I found that while these technologies may reduce the burden of accessing one's clinical data, the prevailing designs do not seem to adequately support other important types of patient work. In particular, patients have many different support needs related to their clinical data and must often put in significant effort to: (1) understand and use their clinical data both when trying to identify the cause of their health issues and, after, when treatment becomes the focus, and (2) address gaps in the provision of healthcare services and the prevailing designs of these technologies. This effort includes illness, anticipation, data, and information work related to their medical records. I found that patients and caregivers want these technologies to better support these types of work, as well as enable easier interactions with the healthcare system (e.g., support infrastructuring work[111]) through offering more data and information related to their health and medical care, particularly contextualized and actionable information, improving existing features such as video visits by making them reviewable, and offering new functionalities such as opportunities for integrated peer-to-peer support. The proposed health app ecosystem discussed in Chapter 3 has the potential to meet some of these patient needs but is in a nascent stage with very few options for leveraging automatically imported clinical data to help patients manage their personal health and the health of their families. In addition, I found that it may be very difficult for patients to discover apps with this feature, highlighting the work patients must often do to find the "right" technological tools for them in the massive health app marketspace. Based on these results, I provide recommendations for designing health interface technologies that better support patients and patient work along three themes: Designing for True Patient Empowerment, Designing for Ecosystems, and Expanding the View of Human-centered Design.

6.1. Designing for True Patient Empowerment

Patient portals have been promoted as a way to empower patients in their collaborations with healthcare providers through access to their clinical data,[377,378] and they do provide access, but they instead often seem to reinforce traditional power dynamics in healthcare. For instance, Chapter 2 surfaced that patients typically have little say in how they ask questions through portals (i.e., pre-defined drop-down menu) and which member of their healthcare team answers these questions. One of the reasons for this may be that portals are often considered a feature of EHR systems rather than a critical patient-facing technology in and of themselves; for example, "… KP HealthConnect added an online feature, MyHealthManager. This feature allows members to obtain secure online access to their health records, including test results, immunization records, active medications, medical problem list, and care plans."[379] This EHR-centric view is analogous to the provider-centric, paternalistic model that healthcare systems have been trying to move away from for decades, a view that fails to identify and prioritize the needs, values, and preferences of patients. Indeed, one two-year prospective, sociotechnical study of the implementation of a new patient portal found that, over time, the organization discovered that they could not fully meet the needs of both patients and providers, which invariably resulted in changes to the original plan that meant the portal would be less likely to fully meet patients' needs.[380] This is also an issue at the Policy level. For instance, in the years after the HITECH Act was passed, many participating organizations were primarily focused on achieving meaningful use as defined by the Meaningful Use criteria.[303] However, through a study of four safety net health systems, Ackerman et al. reported that, despite organizational decisions that resulted in reaching the Meaningful Use targets, some organizations discovered that patient use was fairly low, and they then had to try to redefine what "meaningful use" meant for their patient populations,[381] suggesting that the standardized definition may not be appropriate for all contexts. Overall, a fundamental shift in how EHR vendors, healthcare organizations, healthcare providers, and policymakers view technologies such as patient portals to one that aligns with the patient-centered care approach may be required.

The prevailing view of patients as partners in their health respects patient autonomy and enables care based on their values and preferences. However, it also requires significant patient effort. For example, and as highlighted in Chapter 5, putting in the work to make sense of their laboratory test results prior to a healthcare visit so that they can advocate for themselves in their interaction with their healthcare provider. I argue that *true patient empowerment is providing the supports patients need to thrive in this role and legitimizing and formalizing patient expertise by reimagining the patient-provider interface*. This may include health interface technology design changes such as providing more contextualized information, advice, and decision support (e.g., based on where they are in the medical care trajectory); offering opportunities to interact with AI-powered bots, medical professionals, and peer-patients synchronously online when social supports are needed; encouraging patients to take the lead in some cases (e.g., set the visit agenda[359]); and offering patients, especially expert patients, meaningful opportunities to co-author their medical record (e.g., having a patient's visit note field or allowing them to co-author the clinician's note). Furthermore, and in addition to technological design, more off- and online educational opportunities to improve computer and health literacy are needed.

Such features would enable the creation of new boundary negotiating artifacts[153] and boundary objects.[149] Based on existing research, this could not only empower patients and support their health learning, but also challenge healthcare providers to better understand their patients' needs and perspectives, as well as facilitate collaborative sensemaking and decision making.[157,159] However, existing research on patient-generated data also suggests that it can create tensions in the patient-provider relationship.[e.g.,8] Thus, more multi-stakeholder research is needed to understand perceptions and feasibility of such solutions.

The envisioned interoperable app ecosystem may also be a step in the right direction offering patients more convenience, control, and flexibility but, as Chapter 3 showed, this has yet to come to fruition. Thus, in addition to improving existing health interface technologies now, this also suggests that it may be an optimal time for technology designers to consider the second recommendation theme, designing for ecosystems in support of patient work.

6.2. Designing for Ecosystems

Chapter 3 investigated the ecosystem of patient-oriented health technologies that is emerging around computable clinical data, in particular, the integrated mobile health app ecosystem. There is little research and guidance on designing, implementing, and evaluating third-party apps with this capability.[382,383] In the U.S., the 21st Century Cures Act and miPHRs such as Apple Health Records likely address some of the barriers that have been previously described in other contexts, including regulatory and heterogeneity in clinical data across sources (e.g., differences in terminologies).[e.g.,382] However, some issues remain, including variation in the completeness of records between users,[e.g.,382] as not all healthcare organizations currently enable their patients to download their medical record onto their smartphone. There is an urgent need to understand patient, and especially user, perceptions of the ability to import clinical data into these apps and whether and how it is meeting their needs and expectations. While the few apps with this capability are likely conducting internal user studies, more widely published and independent research is essential to guide future app development. An ecosystem-based marketing plan (e.g., cross-promoting apps with this feature) and the development of a formal evaluation framework that takes into consideration the interconnected nature of these apps may also be useful.

In addition, Chapter 4 and Chapter 5 highlighted the ecosystem of human support[328] in which patients share clinical data on- and offline in an effort to engage others in their health care, including healthcare providers, family and friends, and people in online health communities. This suggests that these ecosystems may be most effective if they are able to seamlessly interact, which means facilitating coherent, narrative-based integration of multiple data sources (possibly with slight differences depending on the audience) and designing for easy sharing across multiple modes (e.g., printed vs. email) and platforms (e.g., online health community). In terms of coherent integration of data and information from multiple sources, including clinical data, and narrative-based sharing there is some existing evidence for how this may be better supported through technologies for the case of self-tracking data. For example, Epstein et al. found that the app that they designed using human-centered methods was too structured, with participants wanting more control over their narrative.[232] With that said, more research is needed about how to facilitate meaningful sharing of clinical data with different members of a patient's support system and to stimulate different types of engagement (e.g., problem-solving vs. sharing an update). In addition, offering different options for patients to share their clinical data and narrative with different members of their support system is critical to facilitating the information seeking and social sensemaking processes that I observed in my research.

Finally, the patient portal literature suggests that one of the primary factors affecting portal engagement is health status. In general, healthier patients are adopting and using portals at lower rates.[87,187,190,202,207,245,256,384–388] Since the portal approach tends to be largely centered on clinical encounters and information, if one is relatively healthy and only visiting their physician for an annual exam, there may be little incentive to use this technology. In fact, almost all the 'triggers of use' are related to a healthcare need or service.[174,206,389] This could also be an issue with the clinical data-driven health app ecosystem. However, unlike the current design of patient portals, there may be more flexibility to create a personalized micro-health app ecosystem that supports health work rather than just some aspects of illness work,[390] where clinical data including data elements to trigger preventative care reminders are a part of a more holistic picture of the patient's health and wellbeing. This could capitalize on the 70% of U.S. adults report that they track at least one health indicator[70] by incorporating self-monitored measures of health (e.g., data from wearable fitness trackers). Mobile iPHRs such as Apple Health are trying to achieve this through integrating data from different sources, but more research is needed to determine whether and to what extent this integration is currently meeting users needs and how it could be improved.

6.3. Expanding the View of Human-centered Design in Healthcare

Patient work is often invisible or, at least, undervalued, so it is perhaps unsurprising that it is often not adequately supported in the designs of health interface technologies. Those designing or redesigning patient-facing health interface technologies need to have a deep understanding of the various types of work that patients do, but this can be difficult. Previous research has noted that disadvantaged patients are rarely included in user-centered design processes,[e.g.,391] and a recent paper found that healthcare organizations and EHR vendors tend to take a superficial approach to including patients in the design process, relying largely on patient and caregiver representatives on advisory panels, who may only represent a privileged segment of the patient population.[392] While this is likely a convenient method that is resource sensitive, these representatives are also likely to be particularly vocal, health literate, and empowered patients. This is not enough. So, what can be done to include other, more difficult-to-reach segments of the patient population?

It may be time to expand our view of human-centered design, beyond the traditional methods such as interviews and card sorting activities. Chapter 2 suggests that, for mature technologies such as patient portals, a systematic literature review could provide initial insights into patient and caregiver perspectives on what is missing from or not adequately supported by a technology. For technologies or aspects of technologies with fewer existing studies, Chapter 4 and Chapter 5 show the potential of other empirical methods for gaining empathy and an initial understanding of a wide range of patient experiences, including those of under-insured individuals; existing studies have also showed the potential of this approach.[e.g.,81] In both cases, the initial understanding may then provide the foundation for more focused, in-depth interviews or other more traditional methods. Using such exploratory methods first, can point to specific patient populations on which to focus or point to specific problems to target. Although there is some evidence from public health informatics studies,[393,394] more research assessing the feasibility of using computational methods to try to scale-up this approach is needed.

6.4. Conclusion

Health interface technologies, which are technologies that enable digital data, information, and knowledge sharing to support patient work and patient-provider collaborative work, have the potential to empower patients in their partnership with healthcare providers to maintain and improve their health. However, and despite supportive policy, technology advances, and cultural changes, currently, the potential of many of these technologies has not yet been realized and adoption and use are somewhat lower than expected. This dissertation research includes four patient-centered studies focused on health interface technologies for sharing clinical data with patients and enabling patients to leverage that data, including patient portals and mobile personal health record apps. I found that while some patient work is supported by the prevailing design of these tools, such as accessing their clinical data, many other types of work are not adequately supported, including aspects of illness work, anticipation work, data and information work, learning, and infrastructuring work.

These studies offer insights into designing health interface technologies to better support patient work. First, I recommend designing for true patient empowerment, which likely requires changing attitudes and practices around patient-facing health interface technology development and building and legitimizing patient expertise. Second, I also recommend designing for ecosystems – both the integrated health app ecosystem and how clinical data may more effectively be leveraged in human support systems. Third, I suggest that the methodologies used in this research, systematic literature review and social media analyses, may offer a way to get an initial, human-centered understanding of a range of patient perspectives, which could then be used to target the use of the traditional, more resource-intensive human-centered design methodologies. Finally, more research is urgently needed in many areas, including multi-stakeholder perspectives of potential design solutions for technologies to truly support patient empowerment, to determine the feasibility and usefulness of scaling up social media insights for use in a human-centered design approach, to understand patient perceptions of sharing clinical data with third-party health apps and how the design of miPHRs could be improved to support holistic health monitoring, and to develop and test an evaluation framework for interconnected applications capable of sharing clinical data.

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