

# Navigating the Healthcare Service “Black Box”: Individual Competence and Fragmented System

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CSCW research has investigated how people at workplace and organizational settings gain knowledge required for work, but less is known regarding how “organizational outsiders” obtain knowledge about organizations and organizational landscapes that provide a service. Gaining knowledge about service landscapes is particularly difficult because they are often complex, non-transparent, and fragmented. We address this gap through an interview study of 19 U.S. parents regarding how they navigated health services for their young children, and how they gained competence in navigation practices. We describe a similar process all participants went through including four inherently iterative stages: seeking and integrating knowledge, decision-making, encountering breakdowns, and repairing and reflecting. We further elucidate what constitutes navigational competence, or the creation of resources about how to navigate, for our participants. We discuss how our study could advance understanding of navigation practices, and the importance for HCI design to support these complex yet essential navigation practices and the accumulation of navigational competence.

CCS Concepts: • **Human-centered computing** → **HCI design and evaluation methods**; Empirical studies in collaborative and social computing

## KEYWORDS

Healthcare system, health consumers, health services, caregiver, parents, navigation practice, navigational competence, organizational knowledge, organizational outsider, health informatics

## ACM Reference format:

Xinning Gui, Yunan Chen, and Kathleen H. Pine. 2018. Navigating the Healthcare Service “Black Box”: Individual Competence and Fragmented System. In *Proceedings of the ACM on Human-Computer Interaction*, Vol. 2, CSCW, Article 61(November 2018). ACM, New York, NY. 28 pages. <https://doi.org/10.1145/3274330>.

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## 1 INTRODUCTION

*Every three months, I just know I’m going to lose a few days of my life.* [35]

The quote above represents the deep struggles facing many patients and caregivers nowadays. In this example, Aaron Carroll, an ulcerative colitis sufferer, had to devote multiple

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2573-0142/2018/11 – 61 \$15.00  
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<https://doi.org/10.1145/3274330>

days to the heavy workload of managing the healthcare system as a patient—making phone calls, connecting his doctor and his pharmacy to refill medications, and managing missing lab tests—in order to *navigate* the complex healthcare service system. In many countries, including the U.S., healthcare service delivery involves a series of separate care settings—sometimes referred to as “silos” [29]. These care settings are often within different organizations, operated under different budgetary regimes, and under different levels of governmental jurisdiction [29]. At the micro-level, patients often receive services from a number of different providers including physicians, nurses, medical assistants, pharmacists, and insurance providers in different departments and organizations (e.g., emergency department, home care agency, skilled nursing facility, pharmacy, insurance company) [11], and each often has its own legal, financial, and regulatory systems [14] and does not coordinate with one another well [11]. The siloed, fragmented healthcare system presents intense challenges for patients and patient caregivers—yet, individuals must find their way through to achieve desired outcomes [29].

Although it is common to refer to a “healthcare system,” from the perspective of patients and caregivers this is a misnomer. Individuals are forced to take on the role of connecting and patching fragmented healthcare organizations. This requires them to *know* how organizations work on their own and with each other, and to be able to apply such *knowledge* of organizations to plan, negotiate, and make decisions as they navigate through the healthcare journey. It is particularly challenging for patients and caregivers, who are often consumers and outsiders of the healthcare organizations, to gain such knowledge since the complex healthcare service provision landscape is often opaque to them [29]. Much research has been conducted on topics falling under the umbrella “health literacy,” which focuses on a person’s ability to access, understand, appraise, and apply health information [10]. Little is known regarding how individual health consumers gain knowledge and skills that specifically relates to how particular organizations and organizational groupings work and “how patients maneuver their way through the trajectory of large and complicated health systems” [51]. To fill this gap, we address the following research questions: 1) How do patients and caregivers navigate the complex healthcare system to acquire essential health services? 2) How do they gain navigational competence?

To answer these research questions, we conducted a qualitative interview study of 19 parents navigating the U.S. healthcare service system on behalf of their young children. We chose this population since it bears multiple significances: as parents of young children, individuals face radical changes in their lives and they must navigate a variety of health service sectors during pregnancy and antepartum, as children transition to the pediatric service system. It is a type of everyday negotiation that many people are accustomed to, yet it is extremely complex, involving numerous service providers with different management structures, resources, and consumer interfaces. In addition, parents of young children experience a transitional status change from being the ones who receive healthcare services to the primary caregivers for their children. Thus, the study of this population has profound implications for both caregivers and patients. We conducted 17 narrative interviews with 19 parents (two interviews with father-mother dyads) who had diverse demographic backgrounds to understand how they obtained health services for their young children, and how they gained knowledge and skills that we call **navigational competence** in seeking

health services. We use navigational competence as a working definition to denote a set of integrated capabilities consisting of knowledge and skills for individual healthcare consumers to go through complex service provision systems effectively.

Drawing on a practice theory lens [49], we use practice as the level of analysis. A practice theory lens allows us to examine how people navigate complex services from the perspective of participants themselves, while preserving the complexity and specificity of these practices. An emic approach allows us to unpack self-reported experiences, encounters, and strategies at the micro-level of individual experience through which each individual patient encountered the service landscape and cultivated competence. Our findings suggest that our participants are deeply challenged by interorganizational breakdowns, opaqueness, complexity, and fragmentation of U.S. healthcare system. We document their practices of navigation in obtaining health services for their young children, particularly how they had to frequently go beyond the official procedures and recommendations in order to create a functioning micro service system. In engaging bottom-up navigation practices, participants experienced a common process in becoming more knowledgeable about the health system and gaining adeptness at navigating health services. Building upon these findings about breakdowns and situated navigation practices, we highlight how interorganizational knowledge and coordination became a substantial component of navigational competence.

Our study makes multiple contributions to CSCW and healthcare research: First, we document and present detailed practices of how organizational outsiders navigate a complex system composed of diverse organizations and gain navigational competence, which provide empirical insights that complements the existing CSCW research takes on an organizational insider’s view to examine how team members or employees coordinate (e.g. [16,39,52,67]) with each other and acquire and use organizational knowledge (e.g., [1,50,64]). Second, we describe a common process through which participants gained navigational competence and created functioning micro healthcare service systems, which has important value for developing a theoretical understanding of individual service consumers’ navigation practices and competence. Third, we derive implications for HCI design to support individual healthcare consumers to acquire essential services amidst a complex service provision landscape and build up navigational competence.

### 3 RELATED WORK

In this section, we discuss practice theory as our analytic lens. We then review multiple strands of relevant literature for healthcare navigation. First, literature on patient navigation as an intervention to mitigate health disparities, including the current status of patient navigation programs and related HCI research. Second, literature on coordination. Coordination and navigation are related concepts because navigation often involves individuals connecting and coordinating different organizations, thus, we review literature on health and coordination and describe how coordination research informs the current research on navigation practices. Third, to situate our working definition of navigational competence, we draw together a set of seemingly related concepts including “patient competence,” “health literacy,” and “patient expertise,” and leverage these related streams of research to describe current thinking on what constitutes competence as maneuvering healthcare and how this competence is gained. We further describe research on

organizational knowledge in CSCW to underpin understandings of how healthcare consumers gain knowledge about the complex healthcare system.

### 3.1 Unpacking the Social through the Practice Lens

Rooted in the extensive sociological and philosophical debates around the agency/structure relationship, the practice lens has garnered much scholarly attention as a means through which to explore the constitution of social life, as well as the complex interplay between individual agency and social structure. In this paper, we found the practice lens to be a pertinent theoretical angle because of the scope of our academic inquiry consisting of patients' interactions with the larger service systems, as well as our core interest in understanding how patients as social agents know situations, make decisions, and carry out actions in their relationship with the structure of service systems comprised of medical policies, routines, norms, and dispositions.

The practice lens has already been valued and advocated by HCI and CSCW researchers. For example, Kuutti and Bannon called for practice-oriented research programs in HCI [37]. Wulf et al. discussed the values and considerations of engaging with practices with designing innovative technologies [78]. In this paper, when applying the practice lens, we draw from the interpretation and articulation of practice theory in organization science [49], because the service systems are primarily organizational and because CSCW's longstanding overlapping interest with organizational studies.

Organization researchers Feldman and Orlikowski noted that practice theory entails a key set of theorizing moves including highlighting situated actions as consequential in the production of social life, rejecting dualisms, and stressing mutual constitution [21]. They outlined how practice theory could inform three application areas that are highly relevant to our study: how strategizing is relational and enacted, how to reformulate notions of knowledge, and how to rethink institutions from the practice lens [21]. Further, the practice lens can help interpret technology use in practice [49]. Technology structures are not static and fixed, but routinely enacted through everyday situated activities [51]. This perspective is relevant to the current research since people use a variety of information technologies as part of navigating healthcare services and building navigation competence, but they do not use them in static ways—navigation practice and information technology are dynamically emergent in use.

The current work also draws inspiration from information practice research to understand how our participants find, use, evaluate, and share information through their navigation practices. Information scientist Reijo Savolainen stressed that the basic characteristic of information practice research is to emphasize “the role of the contextual factors of information seeking, use, and sharing” [58]. The framing of information literacy could move beyond the idea of a reified and decontextualized set of skills, and be understood as a critical information practice [40]. Contextual factors such as access to and trust in information [41], as well as the dynamics of interdependencies between individual information workers [46], should not be taken lightly in information practice research.

### 3.2 Patient Navigation

In the medical field, there has been increased interest over the past decades in “patient navigation.” Patient navigation is defined as “...the assistance offered to underserved populations in ‘navigating’ through the complex health-care system to overcome barriers in accessing quality care and treatment” [23]. Patient navigation was introduced more than two decades ago in response to health disparities in cancer care [54]. It is conducted by professional patient navigators who serve as liaisons to help individuals obtain needed services in the health care labyrinth [62,74]. However, the role of patient navigators is often not well-defined, and the key responsibilities and qualifications of patient navigators, e.g. licensure, training, and practice setting, vary significantly [53,76]. These differences lead to a variety of stances on who can be formally considered a professional “patient navigator,” what the duties of this job are, and what the needed qualifications for the job are. For instance, patient navigators might be individuals who have lived through the same cancer [25], oncology nurses [18], or licensed social workers [13]. They may be employed by healthcare organizations or directly hired by patients [79]. A patient navigator's duties may range from providing transportation and appointment scheduling to providing emotional support [53].

Currently the established patient navigation programs and academic research on patient navigation have primarily targeted patient populations at higher risk (e.g., vulnerable and underserved populations due to culture, language, or socio-economic status) of not receiving adequate care services, and have focused on these vulnerable populations for a limited range of conditions. Patient navigator services are available in some geographic areas and care settings for patients with cancer and certain chronic diseases such as diabetes, asthma, and depression [30,31,52–54,56]. Thus, in reality, most individuals do not have access to professional navigators. Previous HCI and CSCW research has focused on cancer navigation practices through the role of professional cancer navigators [30,31]. In contrast to research on “patient navigation” that focuses on professional patient navigators providing support to individuals, our research adopts the individual consumers’ perspective of navigating the healthcare system as unpaid, untrained, and usually unprepared navigation workers.

### 3.3 Coordination Work in Health Domain

HCI and CSCW research has focused extensively on the study of coordination, defined as “...the act of managing interdependencies between activities performed to achieve a goal” [43]. Coordination involves “...the allocation, planning and integration of the tasks of individual group members or groups” [6] and can refer to activities within organizations (e.g., a workplace, home, or a particular organizational setting) or to mutual activities between organizations (e.g., [9,19,20,26,33,48,59]).

In the realm of healthcare, previous CSCW and health informatics research has focused primarily on coordination activities between patients, family members, and organizational insiders such as physicians and nurses in clinical settings (e.g., [4,39,72]). Previous studies have examined how patients and their caregivers collaborate and coordinate to manage chronic conditions in inpatient settings [5,12,13,16]. However, service providers in clinical settings are only part of the health service delivery system, and they are tied to organizations. Little research examines informal caregivers’ navigation practices, which go significantly

beyond patient-provider communication in clinical settings, or the practices that people must engage prior to and after entering clinical settings.

Our study builds on previous research on caregiver and patients' coordination activities, but we take the perspective of the consumer navigating a broad and complex array of healthcare service providers rather than focusing on simple, discrete interactions based in the clinic. The case of parents navigating on behalf of children is particularly rich because, in contrast to caregivers who can collaborate with patients directly, new parents need to navigate the system without clear input of patients (babies) such as verbal articulation of their health conditions. Where the focus in previous research has been squarely on clinical settings and chronic disease management, our study examines not only new parents' navigation practices in clinical settings, but also every day, mundane activities related to identifying, seeking, and obtaining healthcare services and resources for their baby's health.

### **3.4 Related Concepts: Patient Competence, Health Literacy, and Patient Expertise**

The term patient competence refers to patients' capacity to make decisions about treatment which the provisions of informed consent are designed to protect [36,44]. The term has a long history in law and medical ethics. Physicians are required by law to obtain the informed consent of a patient before initiating any treatment [7]. Patient competence is a prerequisite for valid informed consent. It mainly concerns legal and ethical implications, especially in terms of how to evaluate and determine individual patient competence and how to achieve the balance between preserving patients autonomy and providing needed medical care (e.g., [7,36,44,70]). Therefore, the concept of patient competence focuses on patients' capacity to make treatment-related decisions and the legal and ethical implications of these decisions. In contrast, the concept "navigational competence," as we define it, covers a broader set of skills and knowledge that individuals bring to bear as they maneuver complex service provision systems effectively.

Another related concept is health literacy. Nutbeam [47] reviewed past research and described two distinct conceptual meanings for health literacy: one is health literacy as a risk factor, which focuses on lack of literacy skills (numeracy and language skills) as a clinical risk factor for health. The other conceptualization is health literacy as asset, which focuses on health literacy as development of skills that enable individuals to exert greater control over their health and the factors that shape health. It is this second view that is relevant to our research. However, both conceptualizations have deep roots in educational research on literacy, emphasizing health literacy as an outcome to health and patient education [47], which is different from the perspective of individual agency we want to emphasize by focusing on practices and competence in practices. In addition, definitions of health literacy [63] and operational means for measuring health literacy [47] focus on a person's ability to access, understand, appraise, and apply health information, not on competence and knowledgeable ability about how to get desired services in a complex health service system.

An additional body of research attends to patient expertise. Patient expertise refers to "experiential knowledge" that patients have gained "...from personally managing the day-to-day experience of illness" [27]. Patient expertise emphasizes patients' self-management of illness on personal aspects of health [15], which is different from our study's focus on health

service navigation which extends beyond self-management of personal health into practices and knowledge about multiple aspects of acquiring needed services for oneself or another.

### 3.5 Organizational Knowledge in CSCW

In CSCW and organizational research fields, organizational knowledge refers to the capability “...members of an organization have developed to draw distinctions in the process of carrying out their work, in particular concrete contexts, by enacting sets of generalizations whose application depends on historically evolved collective understandings” [71]. Individuals working in organizations often face challenges in conducting collaborative work. Organizational knowledge, as a significant organizational resource [3], plays a critical role in teams’ performance and organizations’ capacity of problem solving and innovation [64]. There has been a substantial body of CSCW research on the creation, acquisition, and management of organizational knowledge in collaborative settings, as researchers have explored mechanisms of generation, usage, storage, sharing, and reusing (e.g., [1,50,64]) organizational knowledge, and how to design systems to support these mechanisms (e.g., [2,65]). However, this research is primarily concerned with how organizational insiders (e.g. employees) gain and use organizational knowledge for better cooperative work within one organizations. How organizational outsiders obtain knowledge about organizations and organizational landscapes involved in providing a service is understudied. In this paper, we use organizational knowledge to denote the knowledge about how organizations work.

In summary, while patient navigation programs and research focus on professional navigators’ role in supporting certain patient populations to receive adequate care service, our research focuses on individual health consumers’ perspective of navigating the healthcare system. Different from previous research on patient-provider interactions in clinical settings and chronic disease management, our research examines interactions between individual health consumers and healthcare service providers amidst a larger healthcare service provision landscape. Existing concepts including patient competence, health literacy, and patient expertise, while related, are insufficient to describe our study’s focus on health service navigation. Compared to previous CSCW research on organizational knowledge that focus on organizational insiders, our study shifts the focus to organizational outsiders’ knowledge about how organizations work.

## 4. METHODS

### 4.1 Data Collection

From 2016 to 2017, the first author conducted 17 narrative interviews [24,32] with 19 participants (two interviews conducted with father-mother dyads) who had diverse demographic backgrounds. The narrative interview “...encourages and stimulates an interviewee...to tell a story about some significant event in their life and social context” [32] (p.59). We chose the narrative interview method because people’s experiences of navigating health services are deeply embedded in situated life events and people naturally use narrative to describe these events and their means for managing them. Narrative interviewing follows an unstructured approach that allows participants to tell a narrative of their experiences and elicits a naturalistic rendering of the participants’ perspectives that are

more valid than what can be provided by structured and semi-structured interviews [32]. Narratives tend to be detailed with a focus on personal experience including events, actions, contexts, outcomes, motivations, and so on. Thus, a narrative interview “...reconstructs actions and context in the most adequate way [32] (p.58)” and “...reveals place, time, motivation, and the actor’s symbolic system of orientation [32] (p.58).”

We recruited participants through direct contacts and snowball sampling. To diversify our participants, we screened interview candidates based on their ethnicity, educational background, occupation, location, socioeconomic status, length of stay in U.S., and their children’s health condition(s). Our final participants include parents of children who are generally healthy and face no extraordinary circumstances, parents of children with chronic health conditions, and parents of children with rare diseases. Participants aged from 28 to 39, including those who are new to the U.S., e.g. international students and new immigrants, and those who are more familiar with the healthcare system such as people born and raised in the U.S. Our sample of parents had children aged between one month to two years. The sample is ethnically diverse, including people from Asian, African American, and White ethnic backgrounds. Their occupations included stay-at-home parent, student, teacher, engineer, manager, university staff, professor, and small business owner. Because of the language capabilities of the research team, all participants were able to speak at least conversational English or Mandarin Chinese. Among the 17 interviews, nine interviews were conducted in English, and eight interviews were conducted in Mandarin Chinese.

Before conducting interviews, we asked whom in the family was primarily responsible for navigating the healthcare system for the young children to help them decide whom should be interviewed. When two parents shared the responsibility roughly equally, the interview was conducted with the parental dyad (each of the dyads was a heterosexual father-mother dyad, which is why we refer to “father-mother dyads” in the remainder of the paper). When one parent clearly identified as performing the majority of navigational work, we interviewed this person. In the end, we conducted 17 interviews with 19 participants, including one father, two couples, and 14 mothers.

Following the narrative interview method, the first author used the question “When was your first time navigating the healthcare system for your baby?” as “a generative narrative question” [57] to invite participants to share their personal experiences and elicit their perceptions of what constitutes the healthcare system in U.S. During the interview process, the first author listened attentively to the participants, exerted no interruptions, and only probed with questions including “is there anything else you want to say,” “how did it begin,” and “what happened before/after/then?” [24,32]. The interviews lasted from 1 to 2.5 hours. When possible, we conducted face-to-face interviews. Skype interviews were conducted when the participants lived too far away to meet in person. Nine interviews were conducted face-to-face, and the remaining eight interviews were via Skype. All interviews were audio recorded with participants’ permission. Each interview produced a rich description of the participant’s lived experience of navigating the healthcare service landscape on behalf of their children. Some participants also shared artifacts that they created to help them navigate health services, such as lists comparing OBs and pediatricians, and lists of bills. All participants received compensation for their participation in our study. IRB approval was obtained prior to the beginning of data collection.



## 4.2 Data Analysis

We followed Schütze’s six steps [32,60] to analyze our narrative data in an inductive approach to identify individuals’ trajectories. “Trajectory” is a term coined by Strauss et al. [66] “to refer not only to the physiological unfolding of a patient’s disease but to the total organization of work done over that course, plus the impact on those involved with that work and its organization” (p.8), which reflects “the complicated relationship between the development of an illness and the various types of work done to ‘manage’ that illness “ [57]. Schütze later developed “trajectory” as a basic concept for analyzing narrative interview data [57,60], which refers to a biographical process of “the ordering of events for each individual” [32]. The first step is transcribing detailed and high-quality transcriptions. The first author transcribed the interviews by herself, which helped her immerse herself within the data and re-experience each participant’s emotions [24,32]. For interviews conducted in Mandarin Chinese, the first author, as a native Chinese speaker, translated them into English. For the second step, the first author disaggregated long chunks of talk into segments of narratives, and separated the text into indexical and non-indexical materials. Indexical statements refer to “who did what, when, where and why,” while non-indexical statements go beyond events and express values, judgements and any other form of generalized “life wisdom” [32]. Non-indexical statements include two types: descriptive, and argumentative. Descriptions refer to “how events are felt and experienced, to the values and opinions attached to them, and to the usual and the ordinary” [32]. Argumentation refers to “the legitimization of what is not taken for granted in the story, and to reflections in terms of general theories and concepts about the events” [32]. In the third step, the first author used of all the indexical components of the text to analyze the ordering events (“trajectories”) for each participant. In the fourth step, the first author analyzed each participant’s self-understanding about their trajectory by examining the non-indexical components such as opinions, concepts, and reflections. In the fifth step, the first author compared the trajectories between different participants, in search of similarities and differences. The last step was to construct a theoretical model which established similarities to recognize collective trajectories. During the whole process, three researchers had regular meetings to discuss the analysis. Next, we will present the collective trajectories we identified. To protect our participants’ identities, we use P1, P2, etc. to denote different study participants.

## 5. FINDINGS

Our participants found the U.S. healthcare system opaque and complex. They experienced a common process which we summarized as consisting of four stages: seeking and integrating knowledge, decision making, encountering navigational breakdowns, and repairing and reflecting. As they persisted in seeking desired healthcare services for their babies, our participants continuously accumulated navigational competence as they encountered breakdowns. Breakdowns served as a trigger for participants, and resulted in expanded knowledge of how processes in healthcare delivery worked, why processes worked in specific ways, and what they personally could do to grow their own micro healthcare service systems. Next, we present the process of navigation, and illustrate it using two distinct cases.

### 5.1 Healthcare System as a Black Box

All participants stated that they started navigating the healthcare system for their babies when they were planning to become pregnant or knew they were pregnant. Participants saw no real distinction between the antepartum and postpartum period, instead relating that navigation began while the fetus' health was still deeply entangled with the mother: during pregnancy. All participants (n=19) reported that they could not fully understand the internal workings of the healthcare system, and felt that mechanisms and processes were extremely complex. We use the classic metaphor of the "black box" (e.g., [38,68,77]) to capture the lived experiences of participants encountering the healthcare system because the inner mechanisms of the health system took inputs from participants (health needs, money, and other resources) and produced outputs (health services), but the inner processes were not transparent. Participants felt they were dealing with a number of unknown variables, and were often surprised and taken off guard by unexpected requirements and breakdowns. They generally felt lost as to how the healthcare procedures related to them succeeded or failed. For instance, P10, a PhD student born and raised in U.S., explained:

*I had to go to (the) student health (center) to get the pregnancy confirmed. And that's when they gave me a referral...because of the student insurance, they require a referral for everything...The doctor gave me the referral, and I found another doctor at XX medical center...I did follow the steps, they had like, if you do this, whatever it was paperwork and stuff. And then they still messed up my insurance, and I still had to call the insurance, because they sent me a bill...They fixed it eventually. But yeah, I still don't know what or who caused the mess-up.*

For P10, since she followed the procedures and sent the referral, ideally there should not be a bill. Even though she contacted the insurance company and got the mess-up fixed, no one explained to her what issues caused the 'mess-up,' who was responsible for fixing the issue, or what they did to fix it. P10 was left not knowing what she could do to prevent similar issues in the future.

Similarly, P12, a teacher who had lived and worked in New Jersey for six years, found the healthcare system difficult to understand. One incident she described relates to understanding and managing bills:

*I have been very confused during the whole process...I am still receiving bill(s). However, I don't really understand what those items are, because these items are usually listed only using abbreviations or acronyms. Sometimes...I could make a guess. But most times, I just can't make sense of those abbreviations and acronyms. Also, the bills contain too little useful information...Sometimes, the hospital...sent my samples to some outside labs to analyze and didn't notify me. Then when I received bills, I was totally puzzled...I don't know whether and how the hospital and insurance company communicate. It seems that the hospital sends bills to the insurance company, and the insurance company calculates then list the bills on its website. But sometimes the hospital directly mailed me bills. Most of the time, it's like I downloaded bills from the insurance company and paid. I'm not even sure whether there are overlaps between bills mailed by the hospital and bills on the insurance website.*

P12 was extremely puzzled about how the hospital and insurance company handled her bills, especially when numerous bills started to arrive. To avoid paying a same bill twice, P12 started carefully managing bills from the hospital and insurance company. She categorized

the bills into different folders and named each bill with labels such as “fully covered,” “not paid,” “over paid,” and “new not paid” to avoid missing or paying a bill twice.

The health services black box departs from classic examples of black boxes. This is because despite the opacity of the processes contained in the box, our participants are often required to engage with health services organizations at multiple points to get what they need—yet they do so with little available information and no formal training in how the organizations work. For example, P15, an engineer from Seattle, expressed her confusion regarding how different sectors of healthcare system might disconnect or connect with each other, and lamented that as an individual consumer she bore the responsibility to navigate health services almost entirely alone:

*I don't know how the whole healthcare system operates. It's not transparent at all. Everything relies on one's own effort to search, to understand...Every time my OB ordered blood tests, I needed to drive to another clinic to draw the blood. I feel very confused about this. Why cannot those related facilities be in a same building? I don't know what organizes them together. I mean, there must be some kind of network, or system, but I just don't know...Even now, I can only say I kind of understand the OB/GYN and pediatricians related services, but everything else is still unclear to me.*

Our participants identified a range of issues that they must manage in navigating the healthcare service. These issues related to clinicians, clinics, hospitals, insurance, billing, referrals, medications, diagnoses, treatments, and many others. Participants felt that specific healthcare organizations, and the healthcare system as a whole, are opaque and difficult to understand. Participants reported lacking an understanding of how health services worked, how different elements connected to one another, or how errors occurred and how they could be corrected and avoided in the future. Perceiving the lack of transparency and complex nature of the healthcare system, as P15 so clearly expressed, patients must seek information and get what they need on their own. Participants felt as if they were grappling in the dark as they struggled to navigate through a non-transparent set of complex processes.

The emotional ramifications of this work are very real: participants reported a wide range of overwhelming negative feelings such as confusion, frustration, distress, anger, and loss of control. They also had to exert a large amount of time and energy attempting to obtain and manage health services for their children.

## **5.2 Building Up Navigational Competence and Creating a Functioning Micro Healthcare Service System**

Gaining a full understanding of the health service landscape can be incredibly difficult. Yet, over time all of our participants reported becoming more adept at understanding and navigating the black box of healthcare services. In this section, we describe knowledge and skills participants gained that enabled them to navigate health services for their young children. Because different participants had their own unique life circumstances, including location, health needs, and financial factors, their service provision landscapes and specific experiences of encounters with service providers varied.

Despite their different circumstances, all of our participants experienced a common process in becoming more knowledgeable about the health system and gaining adeptness at navigating health services for their young children. The process that we constructed based on

diverse participant accounts involves multiple stages, and is inherently iterative in the sense that each of the stages is typically revisited multiple times. First, individuals seek and combine information from various sources including their own pre-existing knowledge to make decisions regarding what services they need and which providers to choose. Each of our participants described putting a large amount of effort into seeking information and making informed decisions related to selecting insurance, selecting clinicians, evaluating clinician diagnoses and treatment options, and so forth. However, despite the large amounts of information seeking and integration that went into decision making, participants all reported breakdowns of various types that they encountered while using health services. When they encountered breakdowns, they exerted their agency to figure out how to repair the breakdowns and reflect on what should have been done or what lessons they could learn for the future. Breakdowns prompted gains in knowledgeability and competence about how to navigate, which in turn informed future service use.

Next, we present two “typical” cases, that share insights common to all interviews in the study, to demonstrate the process through which participants gained competence to navigate health services.

### 5.2.1 Case 1: Dealing with Insurance

Our first case is an episode where P4 had to put much effort into figuring out how to coordinate a hospital, the Human Resources (HR) office of her employer, medical labs, and an insurance company. Similar to most of our participants, this was just one of the many stressful incidents she encountered in getting desired health services for her child.

At the time of interview, P4 was 39 years old with a seven-month old baby. She received a Master’s degree in Economics in Japan. She moved from Japan to the U.S. seven years ago, where she worked in a company in New York City as a business development manager, and married an ophthalmologist who was born and raised in the U.S. Although her husband worked in the healthcare field, his professional knowledge was not helpful for P4. Navigating the healthcare system was still a significant challenge for P4.

#### Seeking and Integrating Knowledge

P4 encountered insurance difficulties prior to planning for pregnancy, such as choosing doctors who were not in-network and having reimbursement mistakenly denied by the insurance company. From these past experiences, she possessed pre-existing knowledge regarding how to deal with insurance in the U.S. She said: *“Ever since I came to the U.S., I knew that the healthcare system, especially the insurance, is a very tricky part. Because of the past experiences, I know whom I should call when there’s an issue and how to explain the cases.”*

She told us that the first time she started navigating insurance services related to her child was actually one year before she started trying to conceive. Because of her past difficult experiences with insurance companies, she felt that understanding and choosing an insurance plan was the most important thing she could do to prepare for having a baby. She wanted to know which obstetricians (OBs) her insurance would cover, what hospitals particular OBs were affiliated with, whether her insurance would cover certain hospitals, which insurance plan would be ideal for the pregnancy (in case she needed to plan a switch from her current plan), what pregnancy-related tests (e.g. ultrasound, amniocentesis) different plans would cover, and so forth. Meanwhile, she posted on online forums asking for

new moms’ recommendations of OBs in her local area. She combined these recommendations with personal research on other factors such as the reputation of OB’s affiliated hospitals and OB’s educational background and compiled a list of potential OBs. She then compared her list with insurance companies’ coverage of OBs.

As an ophthalmologist, her husband was “*very sensitive to the insurance issues*” and “*didn’t want any problems of that kind.*” However, he could not offer useful suggestions to P4, because his medical knowledge was highly specialized, and he had limited knowledge regarding things such as insurance and billing.

To understand the couple’s complex insurance policy and make informed choices, P4 spent much effort seeking information. She sought information from various sources, including the HR office in her company, the insurance company, and online information in peer message boards. She typically approached the HR office in her company with questions first, but the information provided by the HR staff was too basic for her to make decisions and focused on issues such as copays, not the specific information she needed.

To gain more detailed information, P4 called the insurance company many times, which was time-consuming and not informative. It took around “ten minutes” to reach a real customer service representative every time she called. Despite the wait, P4 described how the customer service representatives gave standardized, shallow answers that did not adequately answer her questions and spoke in vague generalities beginning with the phrase “it’s our policy” rather than providing detailed, relevant answers to her questions. P4 felt frustrated and even expressed a suspicion that such frustrating service was perhaps by design: “*I think they intentionally design the customer service system in this way, so the customers will just give up.*”

P4 then started searching online extensively and posted questions on online forums to gain as much knowledge as possible about which insurance carrier and plan would be ideal for pregnancy, childbirth, and pediatric care. After finally figuring out the optimal plan provided by her employer’s insurance provider, she started considering whether to continue partaking in the insurance through her company and only changing the specific plan, or switching to her husband’s insurance. To make an informed decision, she asked her husband about his plan, and used the online benefit guide and quotation system for his insurance so she could compare both insurances based on a range of factors.

### **Decision Making**

After spending “*half a year*” figuring out these “*complex*” things and integrating pre-existing knowledge with new knowledge, P4 was finally confident that she was ready to make the best decision. P4 decided to continue partaking in insurance through her company, but she changed to another plan within the same insurance company because the plan covered more of the providers on her list of preferred OBs, had more coverage for pregnancy-related expenses than her previous plan, and was cheaper than the dependent insurance plan of similar coverage scope offered through her husband’s workplace.

### **Encountering Navigational Breakdowns**

Even though P4 tried her best to make an informed decision regarding insurance, she still encountered multiple breakdowns related to insurance service. We only describe two breakdowns here. The first breakdown related to the insurance company’s refusal of

coverage. When her OB was planning to order a genetic test for her, P4 called the insurance company to check whether the test would be covered by the insurance company (something she knew to do based on her pre-existing knowledge). The insurance company confirmed that it would be covered. She felt reassured and did the test. However, a breakdown still happened when the company later refused to cover it:

*When I received the bill provided by the insurance company, I found that it's full-price. It's very expensive. They didn't cover it at all. I was shocked. I contacted the insurance company. I asked them, "it's like this, you told me that it would be covered, so I accepted the test. I only did it after confirming with you. Why didn't you cover it?" The insurance company said, "because your OB or the lab didn't contact us to ask for pre-authorization. Your OB's billing office should've asked for that from us first.... It's not your fault, but your OB's billing office or the lab missed one step..." You see, the insurance company was so evil. They could've just told me that I should ask my OB to request a pre-authorization."*

Understandably, P4 felt extremely upset when confronted with this surprise bill despite taking action to ensure the test would be covered. P4 was not sure how she could verify the insurance company's explanation for the bill. Moreover, even if the explanation was valid, the insurance company did not provide sufficient actionable information in response to her initial inquiries that would have allowed P4 to take a different path or anticipate the expense.

Another major breakdown occurred when P4's employer notified her that they decided to change to another insurance provider. P4 was forced to revisit her process of extensive information seeking and comparison of plans once again. Even worse, the employer decided to officially switch to the new insurance on June 1, when P4's estimated due date was June 3. P4 experienced a lot of stress and worry regarding the temporal implications of her delivery since she knew full well that the due date was "*just an estimate.*" P4 spent a lot of time worrying about what would happen if she went to the hospital "*on May 31*" and delivered "*on June 1,*" and had a number of nagging questions about the change to insurance, including: "*Which insurance company will pay for me? How am I going to explain this to the hospital? How should I ask the hospital to separate each day's bills for me? What if I don't receive my new insurance ID number and other details before going to the hospital?*"

P4 was literate in pregnancy information and aware that her due date was simply a guess. She was also aware that inducing delivery early could have negative implications for herself and her baby. Despite this knowledge, P4 was at a loss about how to ensure she would get the insurance coverage she needed amidst her company's change.

### **Repairing and Reflecting**

P4 had to repair the breakdowns described above by herself. To fix the first breakdown, she first tried to appeal the company's decision not to cover her test, which failed. Then she joined an online mommy's group, seeking advice from those moms:

*There were quite a few moms younger (in the group than 35 years. Some of them did the test too, because they were concerned about baby's health. Of course, insurance companies didn't cover the tests ...They shared how they negotiated with the lab. They told me, "you can directly call the lab to bargain, then the expense will be reduced from about \$2000 to around \$200...." Some moms even told me that they negotiated more aggressively and only paid \$150....I got such information through such private communication in mommy's group. It's not like you can easily get this kind of information by searching online, and some people may not tell you so frankly.*

P4 followed the advice. She called the lab and explained the situation, which resulted in positive movement: *“I called the lab. The lab is in California. ...Maybe because this lab is rich and they had witnessed so many similar cases, they didn’t care anymore. So they said, “OK, it’s our fault. We should’ve communicated with your insurance company first...” Then they waived the bill for me. They waived the full amount!”*

P4 reflected on the experience. She told us that she gained skills and knowledge about how to manage health tests and procedures: *“you have to take care of all the procedures in advance. Before doing any examination or test, even if it’s a simple blood test or urine test, always call the insurance company, ask as many details as possible.”* P4 reported that she had developed a new process since this specific breakdown occurred. From then on, she always calls the insurance beforehand and asks about specific procedures that have been recommended or ordered. She asks whether the insurance company covers specific laboratory tests, what the procedures for reimbursement are, and so forth.

To fix the second breakdown, P4 acted proactively and contacted the insurance company, the HR office, and the hospital. She reported calling the insurance company *“almost everyday”* to ask them to provide her ID number and other essential information. She also brokered contact between her employer and the insurance company, saying *“I also pushed the HR office to push the insurance company. The HR office helped this time. They kept requesting the insurance company.”* This was successful: *“at the last week of May, the HR office got all the information I needed.”* P4 then *“immediately called the hospital, explained the situation, asked which insurance I should use and provide when staying in the hospital.”*

P4 reflected on the experience, and drew two lessons. The first one was *“You need to manage the timing issues carefully, because pregnancy is very time-sensitive.... You have to connect these institutions by yourself, proactively!”* The second one was *“You should seek help from whoever may help you, like the HR office.”* As part of learning to “seek help,” P4 had to identify sources of help, and obtain crucial information like which departments to contact at her work and at the hospital, how to actually get into contact with them, (e.g. key phone numbers and extensions), and who are the key people she should speak with. P4 gained working knowledge of her micro health service system, comprised of her HR, insurance, clinician, lab, and so forth, and learned who, what, when, where, and how to contact each of these entities. Crucially, P4 not only gained knowledge about her current micro-service system, she also gained capacity to identify and create other health micro-service systems in the future.

While P4 managed to deal with these breakdowns and simultaneously gain skills and knowledge that will help her prevent or address future breakdowns, these gains were not without cost. P4 continuously suffered from severe worries about the breakdowns, and performed intense labor, such as daily phone calls. Even after the breakdowns were repaired successfully and multiple months had passed, she still occasionally relived past frustrations about the fact that she had to take care of so many procedures with so much effort completely alone: *“I am so mad that I pay money for insurance, I pay money to hospitals. Then everything falls on my shoulders. I have to guide them to sort out things.... I was quite experienced. I still had to spent so much time to fight ....”*

### 5.2.2 Case 2: Treating a Baby's Acid Reflux

At the time of interview, P8 was a PhD student in California, born and raised in the U.S. Her baby was close to two years old. Similar to other study participants, she encountered many challenges in finding and receiving desired healthcare services during both the antepartum and postpartum periods. Below, we present one episode related to treating her baby's infant acid reflux, a common condition in babies.

#### Seeking and Integrating Knowledge

When her baby Emma (pseudonym) was about two and a half months old, Emma started screaming and crying a lot. P8 searched online. Based on the information she gained by searching, she suspected that something must be wrong. She talked to her parents and friends, as she thought they had experiences of raising kids and must know what was going on. However, her parents and friends did not offer any useful advice or understand how severe the situation was: *"...my parents were like, 'oh, you know, it's a baby. Yeah, they cry.' and I was like, 'No, you don't understand, she's screaming constantly, something is wrong'."*

P8 took her baby to the pediatrician. The pediatrician diagnosed Emma with infant acid reflux, a condition occurring when the stomach contents reflux or back up into the esophagus and/or mouth. Because the pediatrician and P8 shared a similar value of not using pharmaceutical solutions as *"the first line of defense, unless it's like something that's very serious,"* they decided P8 should do an elimination diet to try eliminating food that *"could possibly be causing reflux,"* since P8 was breastfeeding. The elimination diet, it was hoped, would allow them to identify and eliminate the food(s) responsible for Emma's reflux (possibly because she was allergic to them). Based on the pediatrician's advice, P8 stopped eating a number of foods that might be problematic for the acid reflux and allergies. However, Emma did not get better. P8 started searching online, reading books, and integrating her and the pediatrician's pre-existing knowledge regarding herbal medicine to make a plan of using herbal remedies. P8 tried different types of herbal medicine. Unfortunately, none of them worked well.

#### Decision Making

After the alternative medicine failed, the pediatrician suggested using Prilosec, a pharmaceutical medicine administered in liquid form, to treat the baby's reflux. P8 decided to try the treatment because both she and her baby had been suffering a lot. The medicine turned out to be helpful:

*And at that point it's just there's something called Prilosec, which is on the adult market, and there is essentially a baby version. After not sleeping and listening to your child cry for like twelve to sixteen hours a day, and I'm not exaggerating. Like screaming not just like crying, but like screaming in horrible pain and doing that for months, we were like OK, let's try the medicine... We tried everything that you could do, and so we tried the medicine, and it didn't make it go away, but it helps. And that was nice.*

#### Encountering Navigational Breakdowns

Even though P8 found a knowledgeable and helpful pediatrician, chose an expensive insurance, and found an effective medicine, she still encountered breakdowns in receiving



desired healthcare services. Although things went smoothly with the pediatrician, P8 encountered problems with the pharmacy and insurance company.

P8 said that getting Prilosec was “perfectly easy” the first time: the pediatrician sent the transcription to the pharmacy and they just went there and picked it up. Problems arose the second time P8 needed to get the prescription filled when she was about to leave for a week to visit her parents for a holiday in another state. P8 wanted to get a refill in advance to prepare for the upcoming trip. However, when she attempted to do the refill, the pharmacist told her that the insurance company rejected to cover the cost because of “policy constraints” which stated that a patient could only get one refill “every 30 days.” Worse still, because the insurance’s rejection, the pharmacist did not prepare the medicine. However, the pharmacist did not notify P8 of the issue until P8 went in at the scheduled time to pick up the medicine:

*... He (the pharmacist)'s like, “oh the insurance rejected us, so we didn't make it”. And I was like “well, why didn't you call me and tell me that, because we have to leave in the morning and...it was like 6pm or something, like the insurance company is not doing anything now.” ... He's like “people usually call and check to make sure it's ready beforehand”. And I was like “you told me it would be ready, and so I came” ...*

Since they needed to leave the next morning and the medicine was urgently needed, P8 was forced to pay for Prilosec out of pocket, which “was well over one hundred dollars.”

Three weeks later, P8 accidentally spilled her baby’s medicine. The remaining medicine could only last for one week. Because she paid out of pocket for the last prescription, it had been more than 30 days since last time the insurance covered the prescription. Thus, she felt relieved. She believed that according to the insurance policy, the insurance would cover the medicine this time. Because of the negative experience with the previous pharmacy (which did not notify her of the insurance’s decision in a timely manner), to avoid potential issues, P8 asked the pediatrician to write another prescription. Then she went to a different pharmacy to fill the prescription. However, she still ran into problems:

*The pharmacist was like “oh OK, well, the compounding pharmacist isn't in until Monday. Can you wait until then?” ...The compounding pharmacist came in ... (and provided the medicine). ...so we got it and it's in this really weird bottle, and then they were like “oh your insurance didn't cover it”, and I was like “This is strange.” I said, “First of all, being in this bottle is weird and then the insurance not covering is weird, because they should have, as they covered it before... I had the same prescriptions filled at R (the previous pharmacy), and they were just rude, so I came to you guys.”*

### **Repairing and Reflecting**

To repair the first breakdown, P8 called the insurance company the next day:

*And then I called the insurance company the next business day. We were already on the road. And the insurance company said, “oh well, you know you only cover it once every thirty days.” And I was like “OK, so what happens if I have to leave, how does that work”, and they're like “well, it's just the policy” and I said “well can you please make an exception for this? You know how am I supposed to afford to give my daughter this medicine which was well over one hundred dollars for it. You know if I have to travel and I have to buy some in advance or like.” “well then you should have your prescription transferred to where you're going”. And I was like “OK thanks buddy”.*

Although her efforts in communicating with the insurance company failed to resolve the issues, P8 reflected on the experience and shared the lessons she learnt with us: always check beforehand with the pharmacy before going in for the pick-up, check with the insurance company in advance, manage the timing and geographic issues in advance when planning travel, and ask the doctors to send new prescriptions to another location beforehand.

To repair the second breakdown, P8 decided to find out why the insurance did not cover the medication anymore. She suspected that the pharmacists made the medication without knowing the insurance would not cover it: “It was just lags in communication between pharmacy and insurance company.” To understand the reasons why the insurance did not cover it and avoid running into similar issues in the future, she urged the pharmacist to call the insurance in front of her, and initiated communication among herself, the pharmacists, and the insurance company: “*They (pharmacists) were very cooperative....So they called the insurance again...then they actually, even though we’re on the scene like me and pharmacists were in the same building and we’re right next to each other, they had to call me and do a three way call to talk about it. Anyway, it was just weird. Very very strange...*”

**Table 1: The Comparison of Case 1 and Case 2**

|  | P4  | P8  |
|--|---|---|
| <b>Dealing with multiple organizations</b> | OB, Hospital, HR office, medical lab, insurance company, pharmacy   | Pediatrician, insurance company, pharmacy   |
| <b>Breakdowns (relational)</b>             | Insurance company vs. OB and lab vs. P4<br>Insurance company vs. P4 and Hospital (temporality)  | Insurance policy and pharmacy vs. P8’s travel plan (temporality and location)<br>Insurance vs. pharmacy vs. P8  |
| <b>Pre-existing knowledge</b>              | A lot about the healthcare system; a husband who was a healthcare provider  | About treatment; little about insurance   |
| <b>Gained Competence</b>                   | Know-what and know-why: <ul style="list-style-type: none"> <li>• Knowledge about some specific plans and insurance choices</li> <li>• Expenses are negotiable</li> <li>• Some tests may need preauthorization</li> </ul> Know-how: <ul style="list-style-type: none"> <li>• Always double check with organizations and ask for as many details as possible</li> <li>• Take care of all the procedures proactively</li> <li>• Manage the timing issue carefully</li> <li>• Seek help from others (e.g., HR)</li> <li>• Negotiate with providers</li> </ul> | Know-what and know-why: <ul style="list-style-type: none"> <li>• Insurance companies differentiate commercially available and customized medications.</li> <li>• Prescription can be transferred to another state</li> </ul> Know-how: <ul style="list-style-type: none"> <li>• Always double check with organizations</li> <li>• Manage the timing and geographic issues in advance</li> </ul> |

Through the effortful three-way conversation, the pharmacists and P8 were able to figure out the reason why the insurance did not cover the medicine this time: *“Well, it turned out that the pharmacy wasn’t aware that there was a premade version of this, that’s covered by insurance, and they made it completely from scratch, ...so they’re like “you know, we’re willing to throw it away, and order it for you, but that ’ s going to be several more days.” And at that point... “I don’t have several more days,” and so I paid for that one again. And it was even more expensive....”*

Thus, P8 learned that the insurance companies differentiate between commercially available and customized medications. She told us that since then, she always double checks with pharmacists about the form of a medications (commercially available or compounded).

Similar to our other participants, P8 managed to fix breakdowns and gained skills and knowledge through the process, while simultaneously suffering a from a large amount of stress and worry and taking a weighty financial loss. When *“not sleeping and listening to”* her baby *“cry for like twelve to sixteen hours a day,”* she still had to take care of breakdowns. When she shared the process during her interview, she cried and said, *“I’m crying because it was hard.”*

In summary, both cases brought to the fore the fragmentation and lack of transparency that characterizes the U.S. healthcare system. P4 and P8 were located in different states, but experienced similar navigational breakdowns despite conducting prior research. Both were damaged by breakdowns, and were forced to conduct extensive repair work to get what they needed for their infants. The breakdowns they experienced were primarily interorganizational. For example, organizations might have miscommunication or disregard each other’s decision. In the table 1, we compare the similarities and differences between the cases of P4 and P8 along several critical dimensions.

Notably, similar episodes happened to each and every participant in the study sample. Even when navigation was shared by two people (as a shared the responsibility of a couple), navigation was still incredibly fraught with frequent breakdowns, which induced stress and loss of time and money. For example, P1 and P2 expended a lot of effort to enroll in insurance in a timely manner and find a good medical daycare for their baby, who has Type 1 diabetes. P16 and P17 who were small business owners had to read academic articles to figure out how to treat their baby’s overlapping toes, because all the pediatricians they visited either did not notice the problem or simply told them *“it doesn’t matter.”* During these stressful processes, our participants’ navigational competence continuously increased, but this increased competence came at a steep cost since they also suffered from severe stress, worry, loss of productive time, and financial loss.

## 6. DISCUSSION

In this paper, we reported on how our participants navigate the complex, opaque, and fragmented healthcare service system in the U.S. We analyzed a common process shared by all of our participants which consists of four stages. The process is inherently iterative in the sense that each of the stages is typically revisited multiple times. We further illustrated the process using two distinct cases. We highlighted the challenges and struggles that our participants went through in their navigation practices. As breakdowns became frequent as

even mundane to our participants who navigated the healthcare service system, growing micro healthcare service system and cultivating navigational competence in a bottom-up fashion became urgent and essential. Through our study, we analyzed our interviewees' navigation practices as to how their recurrent, situated actions and their navigation competence co-constructed each other through their repeated, and often exhausting, encounters with the U.S. healthcare service system. Building on these findings, we discuss what constitutes navigation practice and competence.

### 6.1 Conceptualizing Navigation Practices

Our study uncovered the specific practices that individuals engage to maneuver the healthcare service provision landscape. Individual health consumers engaging in navigation are “groping in the dark” since tasks and elements are often impossible to know fully in advance and these tasks are situated with the specific context of their health conditions, geographic areas, and resources and constraints related to healthcare services. Even those participants who have pre-existing knowledge and skills and prepare carefully often encounter numerous navigational breakdowns, and have to seek solutions to repair breakdowns.

Navigation practices encompass multiple inter-related activities, including (but not limited to): seeking domain information, identifying key organizations and providers (e.g., OB, hospital, pharmacy, pediatrician, insurance company, employer), making choices from an array of options (e.g., P4 carefully reviewed and chose an optimal insurance plan), advocating for particular resources or courses of action (often in the face of adversity) (e.g., P8 advocated for receiving timely pharmaceutical service), transmitting information from one organization to another (e.g., P4 requested a new ID number from the insurance company on her own and passed it to the hospital), connecting organizations and providers who need to speak but are not connected (e.g., P8 initiated the phone call between the pharmacy and insurance company), negotiating with service providers (e.g., P4 negotiating with the medical lab for a cheaper, affordable price), and doing all of these things on an ongoing basis in the face of uncertainty and breakdowns. Thus, navigation practices include not only information practices where interviewees sought, analyzed, and shared information, but also coordination and negotiation with organizations just to make things work.

Navigation pertains to how individuals move from touchpoint (the contact points between the customer and the service providers [55]) to touchpoint to get what they need. It also pertains to how individuals connect and coordinate different service providers to create a functioning micro-service system that meets their needs through acquiring and transmitting information from one service provider to another. Previous research in CSCW has extensively studied how people coordinate actions *within and across* organizations to achieve work efficiency and effectiveness. This research on coordination in organizations focuses on coordination within the organizations or across the organizations, examining how *organizational insiders* use information technology to communicate and coordinate in physically co-located, virtually co-located, and distant groups and increasingly across organizations (e.g., [9,19,20,26,33]). Different from the coordination widely studied, navigation in this paper is about individual consumers as *organizational outsiders* who must learn about organizations, coordinate with multiple complex organizations on their own, and

fix breakdowns. Drawing on our empirical findings, we conceptualize **navigation practices** as *the means through which an organizational outsider who has a need(s) traverses a metaphorical “landscape” of elements, interacting with a variety of touchpoints in the process of acquiring a resource(s) or accomplishing a needed task(s) by patching different organizations to create a functioning micro-service system.*

As our findings revealed, navigation is often (and sometimes incredibly) time-consuming, labor-intensive, and uncertain, imposing emotional distress, financial loss, and time loss on individual health consumers. It is a form of *invisible work* that is seldom acknowledged or supported by service providers or ICT interfaces for service provision. Unlike the invisible patient work described in relation to self-managing health conditions [5,34,73], such as obtaining and managing information about current health status and resolving clinicians’ inconsistent recommendations, navigation is the invisible work that patients and caregivers have to conduct in order to obtain desired services from a large and complex health service delivery system. Nevertheless, both types of invisible work to some extent align with contemporary biopolitical rationales and neoliberalism that promote citizens’ self-responsibility [22,42], so much so that citizens can take care of their own health as long as they follow official procedures and recommendations defined and maintained by healthcare authorities and institutions. However, it is exactly those authoritative communication and coordination logics that failed our participants, yet formalized means of repair were missing. Against this backdrop, navigation is the invisible work that patients and caregivers are forced to do beyond official, authoritative procedures in order to receive seemingly passable services from a large and complex health service delivery system.

Intense navigation through a fragmented landscape of service providers is an everyday necessity in many domains besides healthcare. For example, parents of children with disabilities face a huge burden to acquire special education services [80]. Immigrants have to navigate complex application processes and the endless bureaucracy of government entities and the legal system to acquire and maintain legal status [8,61]. Thus, designing service systems, which are by and large embedded in ICTs, to facilitate navigation practices and reduce the burdens of navigation is an important issue for HCI and CSCW researchers to explore. More empirical studies are needed to generalize insights regarding the “overall structure of the multi-interface service system [55] and service consumers’ navigation practices, which can help HCI designers to design technologically embedded systems to support individual consumers. Our work also contributes to the ongoing discussions around ethics and values in the design and implementation of large socio-technical systems in relation to the humans they are meant to serve [12,75]. Our work demonstrates the need to investigate the practices and associated struggles of individuals to better diagnose urgent challenges and identify design opportunities facing these large and complex “black-box” service systems.

## 6.2 Navigational Competence

The involvement of patients has been widely noted as a determining factor for their overall health quality and health outcomes. For instance, some studies [15,16] have examined patient expertise—their experiential knowledge related to self-management of illness on personal aspects of health [15]), and believe it can help patients manage their health conditions.

Another rich research strand focuses on health literacy: a person's ability to access, understand, appraise, and apply health information [10,63]. Health literacy enables individuals to exert control over their own health. Both strands of research stress the importance of patients' knowledge, skills, learning and empowerment in the scope health management and care. In relation to these streams of research, our study points to one previously untouched area, the navigational aspect of knowledge and skills patients must have in order to effectively seek appropriate and timely health services in the larger healthcare service landscape. Taking the perspective of consumers, it becomes clear that competence is not narrowly related to health behaviors or adherence to treatment; it involves a broader organizational context where consumers must both gain acumen in managing health information and health conditions as well as ability to navigate a larger organizational landscape and create their own functioning micro-health service system. This is a type of patient skill that is often overlooked but is critical to successfully acquiring healthcare, and sometimes critical to staying alive or keeping a dependent alive.

In navigating the complex healthcare service landscape, participants gained competence through encountering and repairing inherent breakdowns in the fragmented systems they encountered. Navigational competence is a set of integrated capabilities consisting of knowledge and skills for individual healthcare consumers to go through complex service provision systems effectively. Our findings revealed different types of knowledge and skills that constitute navigational competence. For instance, for P4 and p8, navigational competence includes *technical knowledge and skills* to maneuver Internet and phone interfaces, and search and transfer information; *organizational knowledge* to know where, who and how to seek services, make requests, and manage an ongoing trajectory of organizational interactions; *domain knowledge* permitting an individual to understand the information they acquire from a service organization and ask for clarifications; *articulation knowledge and skills* to coordinate complex tasks together; and *social knowledge and skills* to advocate for oneself in the process of pursuing and receiving services and to seek for help from formal and informal social resources.

The organizational knowledge participants gained contains both explicit and tacit knowledge. The rich body of research on organizational knowledge has argued that the duality of explicitness and tacitness is an important dimension to examine the organization knowledge creation process [45]. Explicit knowledge refers to knowledge that is transmittable in formal and systematic language [45]. Tacit knowledge is highly personal, deeply rooted in action, commitment, and involvement in a specific context [45]. Previous research has mainly examined tacit and explicit organizational knowledge in corporate organizational settings, focusing on organizational insiders' creation and transmission of such knowledge. In our study, organizational knowledge gained by participants who are organizational outsiders manifested similar dimensions. For example, insurance policies that our participants referred to are official forms of explicit knowledge that is relatively easy for our participants to find out and learn. The fact that expense of lab test, in P4's case, can be negotiable and even waived, is tacit knowledge that is not readily accessible for organizational outsiders.

### 6.3 Accumulation of Navigational Competence

We have shown that participants gained navigational competence through their various interactions with the healthcare system. In an ideal scenario, people deal with the healthcare system in a smooth fashion, as designated by health authorities and institutions, without much necessity to understand how the healthcare system actually works. Their navigational competence would be limited to how to interact with the healthcare system as a unit. However, because of the fragmentation and complexity of the U.S. healthcare system, reality is much messier. Breakdowns to navigation are rampant for individual consumers, and inter-organizational disconnections and conflicts emerge frequently. Consumers in our sample had no choice but to buildup navigational competence due to these circumstances.

The accumulation of navigational competence is a spiral path consisting of numerous breakdown-reflection-repair loops: first, pre-existing knowledge and skills constitutes pre-existing navigational competence, which help individual consumers to interact with the healthcare system. To make better decisions and interactions, individuals often seek new information and knowledge, as our participants did, which increases their navigational competence. Second, during interactions with the healthcare system, breakdowns occur, triggering 1) additional information seeking, 2) attempts to rectify the problem, and 3) reflection about what could be done differently in the future to prevent the same breakdowns from occurring. As a result of information seeking, rectification attempts, and reflection about what they could do differently, individuals’ navigational competence increases again, as our participants’ trajectories show. Then, the increased navigational competence becomes the pre-existing competence for individual’s future navigation. Thus, the buildup of navigational competence is a continuous process.

Our participants learned knowledge and skills in various ways such as searching information online and asking for authoritative explanations and recommendations (e.g., in P4’s case, calling the insurance company explanations regarding insurance plans). In particular, participants acquired tacit knowledge through probing into organizations, negotiating with organizational insiders, learning from people in their offline and online social networks, and exploring different possibilities. For instance, in P4’s case, she gained such tacit knowledge only through asking in a large social media group and thus encountering people who had survived similar situations.

A large stream of CSCW research has focused on supporting organizational insiders’ knowledge acquisition and sharing in formal organizational settings (e.g., [2,65]). In addition, some researchers [15,16] have explored how to design systems facilitating patient expertise locating practices and sharing in everyday life to help patients who have similar health situations and contexts locate and share experiential knowledge they have gained through their own treatment experience about symptoms, treatments, side effects, prognosis, clinical terminology and so on [17]. However, little attention has been paid to how organizational outsiders gain and share tacit organizational knowledge. Because of the difficulty in accessing such tacit knowledge, it is worth exploring how to help service consumers share such knowledge.

## 6.4 Design Implications

Our work has several important implications for the design of healthcare systems and large socio-technical systems. First, the “black-boxness” of the healthcare system that all our interviewees struggled with points to the necessity of design interventions that could make the internal workings of both individual healthcare organizations and interconnections between organizations more transparent and support individuals to learn about how these organizations and organizational “tangles” work. While computational methods to improve transparency and accountability in online systems have been explored for many years in the HCI and CSCW community (e.g., [67,69]), the peculiar challenges in improving the transparency of healthcare systems lie in many service providers’ lack of digitalization and organizational inertia. More work needs to be done in improving service providers’ consumer-facing digital interfaces, providing powerful user interface for patients to understand the internal workings, as well as the interoperability between service providers’ digital systems.

Second, we point to the need to share of tacit knowledge (e.g., help individuals to find peers who have the needed tacit knowledge regarding navigation) and assistance to avoid or prepare for potential breakdowns (e.g., help individuals know what bills will arrive and how much money they may be for). This work thus augments an existing line of research that explores existing online platforms in supporting patients to meet, support each other, and share knowledge [73].

Third, our interviewees’ self-initiated (or, one may see it as forced) exploration of the healthcare system highlights design opportunities for both empowering patients and facilitating their exploration practice. Novel systems could be designed that help raise awareness of possible issues and breakdowns and recommend preemptive actions patients may take to prevent breakdowns. Social networking platforms can be designed to promote collective sensemaking and problem solving among patients facing similar health conditions.

Fourth, our findings about interviewees’ management of inter-organizational communication points to new design opportunities for socio-technical systems that could help individual service consumers and providers to both monitor and coordinate the communication between different service providers. One unique challenge is that our interviewees had to switch between multiple communication channels such as email and phone to contact different service providers, which is inefficient for wrangling inter-organizational communication. To overcome this challenge, a multi-party platform could be designed that mediate the inter-organizational communication so that patients and their service providers could use the same channel to exchange information and discuss issues.

## 7. LIMITATIONS AND FUTURE WORK

This work is a preliminary investigation and our first step to understanding individual service consumers’ navigation practices. With this focus, we selected study participants based on who was/were primarily responsible for navigating the healthcare system for the young children. We obtained such information by directly asking our potential participants upon contact. Therefore, our study excluded those partners who did not involve in navigating the healthcare system for their children. The imbalanced gender ratio in our final sample struck us as a possible indicator to the invisible work of caring for babies that is frequently carried



out by women [28]. However, our sample size is limited in reaching a definitive conclusion about this issue. We believe it will be fruitful to investigate this issue in future work using a comprehensive survey study from a feminist stance that could make a compelling point on the division of care labor in contemporary families. While this work is not focused primarily on a gendered analysis, we believe that the conceptualization of navigational practices and competence in this analysis has laid a solid ground for future investigations as to who engage in these practices, how they cultivate navigational competence similarly or differently, and the hidden tensions and values behind the gendered landscape of care work.

## 8. CONCLUSION

In this paper, we reported on 19 parents’ navigation practices and accumulation of navigational competence in coping with the healthcare system in the United States. We described a common process that participants undertook as they frequently encountered navigational breakdowns that were inherently interorganizational. By discussing navigational competence in depth, we hope to contribute to not only research on patient work/expertise/strategy/literacy in the domain of healthcare, but also deepen the understandings of the work that organizational outsiders have to perform in order to cope with complex, opaque, and fragmented service landscapes. There are urgent needs for more research on this topic in a variety of domains, as well as design activities that could support individuals’ navigation.

## ACKNOWLEDGMENTS

We are grateful to our study participants for their dedication. Many thanks to our anonymous reviewers for insightful feedback, and to Yubo Kou for his cogent comments. This work was partially supported by the National Science Foundation under grant HCC-1219197.

## REFERENCES

- [1] Mark S. Ackerman and Christine Halverson. 2004. Organizational Memory as Objects, Processes, and Trajectories: An Examination of Organizational Memory in Use. *Comput Support Coop. Work* 13, 2 (April 2004), 155–189. DOI:<https://doi.org/10.1023/B:COSU.0000045805.77534.2a>
- [2] Mark S. Ackerman and David W. McDonald. 1996. Answer Garden 2: Merging Organizational Memory with Collaborative Help. In *Proc. of CSCW 1996*, 97–105. DOI:<https://doi.org/10.1145/240080.240203>
- [3] Maryam Alavi and Dorothy E. Leidner. 2001. Review: Knowledge Management and Knowledge Management Systems: Conceptual Foundations and Research Issues. *MIS Q.* 25, 1 (March 2001), 107. DOI:<https://doi.org/10.2307/3250961>
- [4] Ofra Amir, Barbara J. Grosz, Krzysztof Z. Gajos, Sonja M. Swenson, and Lee M. Sanders. 2015. From Care Plans to Care Coordination: Opportunities for Computer Support of Teamwork in Complex Healthcare. In *Proc. of CHI 2015*, 1419–1428. DOI:<https://doi.org/10.1145/2702123.2702320>
- [5] Jessica S Ancker, Holly O Witteman, Baria Hafeez, Thierry Provencher, Mary Van de Graaf, and Esther Wei. 2015. The Invisible Work of Personal Health Information Management Among People With Multiple Chronic Conditions: Qualitative Interview Study Among Patients and Providers. *J. Med. Internet Res.* 17, 6 (June 2015), e137. DOI:<https://doi.org/10.2196/jmir.4381>
- [6] J.H. Erik Andriessen. 2012. *Working with Groupware: Understanding and Evaluating Collaboration Technology*. Springer Science & Business Media.
- [7] Paul S. Appelbaum. 2007. Assessment of Patients’ Competence to Consent to Treatment. *N. Engl. J. Med.* 357, 18 (November 2007), 1834–1840. DOI:<https://doi.org/10.1056/NEJMcp074045>
- [8] Sameer M Ashar, Edalina M Burciaga, Jennifer M Chacon, Susan Bibler Coutin, Alma Garza, and Stephen Lee. 2016. Navigating Liminal Legalities along Pathways to Citizenship: Immigrant Vulnerability and the Role of Mediating Institutions. *Legal Studies Research Paper Series*, 2016–5. Retrieved October 16, 2017 from <http://ssrn.com/abstract=2733860>

- [9] Victoria Bellotti and Sara Bly. 1996. Walking Away from the Desktop Computer: Distributed Collaboration and Mobility in a Product Design Team. In *Proc. of CSCW 1996*, 209–218. DOI:<https://doi.org/10.1145/240080.240256>
- [10] Nancy D. Berkman, Stacey L. Sheridan, Katrina E. Donahue, David J. Halpern, and Karen Crotty. 2011. Low Health Literacy and Health Outcomes: An Updated Systematic Review. *Ann. Intern. Med.* 155, 2 (July 2011), 97. DOI:<https://doi.org/10.7326/0003-4819-155-2-201107190-00005>
- [11] Thomas Bodenheimer. 2008. Coordinating Care — A Perilous Journey through the Health Care System. *N. Engl. J. Med.* 358, 10 (March 2008), 1064–1071. DOI:<https://doi.org/10.1056/NEJMhpr0706165>
- [12] danah boyd and Kate Crawford. 2012. CRITICAL QUESTIONS FOR BIG DATA: Provocations for a cultural, technological, and scholarly phenomenon. *Information, Commun. Soc.* 15, 5 (2012), 662–679.
- [13] Elizabeth A Calhoun, Elizabeth M Whitley, Angelina Esparza, Elizabeth Ness, Amanda Greene, Roland Garcia, and Patricia A Valverde. 2010. A national patient navigator training program. *Health Promot. Pract.* 11, 2 (March 2010), 205–15. DOI:<https://doi.org/10.1177/1524839908323521>
- [14] Deborah J. Cantrell. 2001. Justice for Interests of the Poor: The Problem of Navigating the System without Counsel. *Fordham Law Rev.* 70, (2001).
- [15] Andrea Civan-Hartzler, David W McDonald, Chris Powell, Meredith M Skeels, Marlee Mukai, and Wanda Pratt. 2010. Bringing the Field into Focus: User-centered Design of a Patient Expertise Locator. In *Proc. of CHI 2010 (CHI '10)*, 1675–1684. DOI:<https://doi.org/10.1145/1753326.1753577>
- [16] Andrea Civan, David W McDonald, Kenton T Unruh, and Wanda Pratt. 2009. Locating Patient Expertise in Everyday Life. In *Proc. of GROUP 2009*, 291–300.
- [17] Andrea Civan and Wanda Pratt. 2007. Threading together patient expertise. In *AMIA Annual Symposium Proceedings*, 140–144.
- [18] Rebecca Crane-Okada. 2013. Evaluation and Outcome Measures in Patient Navigation. *Semin. Oncol. Nurs.* 29, 2 (May 2013), 128–140. DOI:<https://doi.org/10.1016/j.soncn.2013.02.008>
- [19] Jonathon N. Cummings and Sara Kiesler. 2005. Collaborative Research Across Disciplinary and Organizational Boundaries. *Soc. Stud. Sci.* 35, 5 (October 2005), 703–722. DOI:<https://doi.org/10.1177/0306312705055535>
- [20] Paul Dourish and Victoria Bellotti. 1992. Awareness and Coordination in Shared Workspaces. In *proc. of CSCW 1992*, 107–114. DOI:<https://doi.org/10.1145/143457.143468>
- [21] Martha S. Feldman and Wanda J. Orlikowski. 2011. Theorizing Practice and Practicing Theory. *Organ. Sci.* 22, 5 (October 2011), 1240–1253. DOI:<https://doi.org/10.1287/orsc.1100.0612>
- [22] Michel Foucault. 2008. *The birth of biopolitics: lectures at the Collège de France, 1978-79*. Palgrave Macmillan.
- [23] Tisha Fowler, Caryn Steakley, A. Roland Garcia, Jennifer Kwok, and L. Michelle Bennett. 2006. Reducing Disparities in the Burden of Cancer: The Role of Patient Navigators. *PLoS Med.* 3, 7 (July 2006), e193. DOI:<https://doi.org/10.1371/journal.pmed.0030193>
- [24] Heather Fraser. 2004. Doing Narrative Research: Analysing Personal Stories Line by Line. *Qual. Soc. Work Res. Pract.* 3, 2 (June 2004), 179–201. DOI:<https://doi.org/10.1177/1473325004043383>
- [25] Janine Giese-Davis, Caroline Bliss-Isberg, Kristin Carson, Path Star, Jessica Donaghy, Matthew J. Cordova, Nita Stevens, Lynne Wittenberg, Connie Batten, and David Spiegel. 2006. The effect of peer counseling on quality of life following diagnosis of breast cancer: an observational study. *Psychooncology.* 15, 11 (November 2006), 1014–1022. DOI:<https://doi.org/10.1002/pon.1037>
- [26] Rebecca E. Grinter, James D. Herbsleb, and Dewayne E. Perry. 1999. The geography of coordination: dealing with distance in R&D work. In *Proc. of GROUP 1999*, 306–315. DOI:<https://doi.org/10.1145/320297.320333>
- [27] Andrea Hartzler and Wanda Pratt. 2011. Managing the Personal Side of Health: How Patient Expertise Differs from the Expertise of Clinicians. *J. Med. Internet Res.* 13, 3 (August 2011), e62. DOI:<https://doi.org/10.2196/jmir.1728>
- [28] Arlie Hochschild and Anne Machung. 2012. *The Second Shift: Working Families and the Revolution at Home*. Penguin Books.
- [29] Maria M. Hofmarcher, Howard Oxley, and Elena Rusticelli. 2007. *Improved Health System Performance through better Care Coordination*. OECD Publishing. DOI:<https://doi.org/10.1787/246446201766>
- [30] Maia Jacobs, James Clawson, and Elizabeth D. Mynatt. 2014. Cancer Navigation: Opportunities and Challenges for Facilitating the Breast Cancer Journey. In *Proc. of CSCW 2014*, 1467–1478. DOI:<https://doi.org/10.1145/2531602.2531645>
- [31] Maia L. Jacobs, James Clawson, and Elizabeth D. Mynatt. 2014. My Journey Compass: A Preliminary Investigation of a Mobile Tool for Cancer Patients. In *Proc. of CSCW 2014*, 663–672. DOI:<https://doi.org/10.1145/2556288.2557194>
- [32] Sandra Jovchelovitch and Martin W. Bauer. 2000. Narrative Interviewing. In *Qualitative Researching with Text, Image and Sound: A Practical Handbook for Social Research*, Paul Atkinson, Martin W Bauer and George Gaskell (eds.). SAGE Publications, 57–74.
- [33] Katherine C. Kellogg, Wanda J. Orlikowski, and JoAnne Yates. 2006. Life in the Trading Zone: Structuring Coordination Across Boundaries in Postbureaucratic Organizations. *Organ. Sci.* 17, 1 (February 2006), 22–44. DOI:<https://doi.org/10.1287/orsc.1050.0157>
- [34] Predrag Klasnja, Andrea Civan Hartzler, Kent T Unruh, and Wanda Pratt. 2010. Blowing in the Wind: Unanchored Patient Information Work during Cancer Care. In *Proc. of CHI 2010*, 193–202. DOI:<https://doi.org/10.1145/1753326.1753355>

- [35] Sarah Kliff. 2016. Unpaid, stressed, and confused: patients are the health care system’s free labor. *Vox*. Retrieved from <http://www.vox.com/2016/6/1/11712776/healthcare-footprint>
- [36] Jean S. Kutner, John E. Ruark, and Thomas A. Raffin. 1991. Defining Patient Competence for Medical Decision Making. *Chest* 100, 5 (November 1991), 1404–1409. DOI:<https://doi.org/10.1378/chest.100.5.1404>
- [37] Kari Kuutti, Liam J. Bannon, Kari Kuutti, and Liam J. Bannon. 2014. The turn to practice in HCI: Towards a research agenda. In *Proc. of CHI 2014*, 3543–3552. DOI:<https://doi.org/10.1145/2556288.2557111>
- [38] Bruno Latour. 1988. *Science in Action: How to Follow Scientists and Engineers Through Society*. Harvard University Press.
- [39] Soyoung Lee, Charlotte Tang, Sun Young Park, and Yunan Chen. 2012. Loosely Formed Patient Care Teams: Communication Challenges and Technology Design. In *Proc. of CSCW 2012*, 867–876. DOI:<https://doi.org/10.1145/2145204.2145334>
- [40] Annemaree Lloyd. 2010. Framing information literacy as information practice: site ontology and practice theory. *J. Doc.* 66, 2 (2010), 245–258.
- [41] Annemaree Lloyd, Ola Pilerot, and Frances Hultgren. 2017. The remaking of fractured landscapes: supporting refugees in transition (SpiRiT). *Inf. Res.* 22, 3 (2017), paper 764.
- [42] Deborah Lupton. 1995. *The imperative of health : public health and the regulated body*. Sage Publications.
- [43] Thomas W. Malone and Kevin Crowston. 1990. What is Coordination Theory and How Can It Help Design Codperative Work Systems? In *Proc. of CSCW 1990*, 357–370.
- [44] Haavi Morreim. 1983. Three concepts of patient competence. *Theor. Med.* 4, 3 (October 1983), 231–251. DOI:<https://doi.org/10.1007/BF00489207>
- [45] Ikujiro Nonaka. A Dynamic Theory of Organizational Knowledge Creation. *Organization Science* 5, 14–37. DOI:<https://doi.org/10.2307/2635068>
- [46] Anita Nordsteien and Katriina Byström. 2018. Transitions in workplace information practices and culture: The influence of newcomers on information use in healthcare. *J. Doc.* (2018).
- [47] Don Nutbeam. 2008. The evolving concept of health literacy. *Soc. Sci. Med.* 67, 12 (December 2008), 2072–2078. DOI:<https://doi.org/10.1016/j.socscimed.2008.09.050>
- [48] Gerardo A. Okhuysen and Beth A. Bechky. 2009. Coordination in Organizations: An Integrative Perspective. *Acad. Manag. Ann.* 3, 1 (January 2009), 463–502. DOI:<https://doi.org/10.1080/19416520903047533>
- [49] Wanda J. Orlikowski. 2008. Using Technology and Constituting Structures: A Practice Lens for Studying Technology in Organizations. In *Resources, Co-Evolution and Artifacts. Computer Supported Cooperative Work*, Mark S. Ackerman, Christine A. Halverson, Thomas Erickson and Wendy A. Kellogg (eds.). Springer, London, 256–305.
- [50] Julian E. Orr and Julian E. 1986. Narratives at work: story telling as cooperative diagnostic activity. In *Proc. of CSCW 1986*, 62–72. DOI:<https://doi.org/10.1145/637069.637077>
- [51] Michael K Paasche-Orlow and Michael S Wolf. The causal pathways linking health literacy to health outcomes. *Am. J. Health Behav.* 31 Suppl 1, S19–26. DOI:<https://doi.org/10.5555/ajhb.2007.31.supp.S19>
- [52] Victoria A. Parker, Jack A. Clark, Jennifer Leyson, Elizabeth Calhoun, Jennifer K. Carroll, Karen M. Freund, and Tracy A. Battaglia. 2010. Patient Navigation: Development of a Protocol for Describing What Navigators Do. *Health Serv. Res.* 45, 2 (April 2010), 514–531. DOI:<https://doi.org/10.1111/j.1475-6773.2009.01079.x>
- [53] Victoria A Parker and Christy Harris Lemak. 2011. Navigating patient navigation: crossing health services research and clinical boundaries. *Adv. Health Care Manag.* 11, (2011), 149–83.
- [54] Electra D. Paskett, J. Phil Harrop, and Kristen J. Wells. 2011. Patient navigation: An update on the state of the science. *CA. Cancer J. Clin.* 61, 4 (July 2011), 237–249. DOI:<https://doi.org/10.3322/caac.20111>
- [55] Lia Patrício, Raymond P. Fisk, João Falcão e Cunha, and Larry Constantine. 2011. Multilevel Service Design: From Customer Value Constellation to Service Experience Blueprinting. *J. Serv. Res.* 14, 2 (May 2011), 180–200. DOI:<https://doi.org/10.1177/1094670511401901>
- [56] Mark Rabiner and Amy Weiner. 2012. Health Care for Homeless and Unstably Housed: Overcoming Barriers. *Mt. Sinai J. Med. A J. Transl. Pers. Med.* 79, 5 (September 2012), 586–592. DOI:<https://doi.org/10.1002/msj.21339>
- [57] Gerhard Riemann and Fritz Schütze. 1991. “Trajectory” as a basic theoretical concept for analyzing suffering and disorderly social processes. In *Social organization and social process: Essays in honor of Anselm Strauss*, David R. Maines (ed.). Aldine de Gruyter, 333–357.
- [58] Reijo Savolainen. 2007. Information Behavior and Information Practice: Reviewing the “Umbrella Concepts” of Information-Seeking Studies. *Libr. Q.* 77, 2 (2007), 109–132.
- [59] Kjeld Schmidt and Carla Simonee. 1996. Coordination mechanisms: Towards a conceptual foundation of CSCW systems design. *Comput. Support. Coop. Work* 5, 2–3 (1996), 155–200. DOI:<https://doi.org/10.1007/BF00133655>
- [60] Fritz Schütze. 2008. *Biography Analysis on the Empirical Base of Autobiographical Narratives: How to Analyse Autobiographical Narrative Interviews*. EU Leonardo da Vinci Programme.
- [61] James R. Silkenat. 2013. Immigrants face numerous hurdles as they struggle to navigate the legal process. *ABA Journal*. Retrieved from [http://www.abajournal.com/magazine/article/immigrants\\_face\\_numerous\\_hurdles\\_as\\_they\\_struggle\\_to\\_navigate\\_the\\_legal\\_pro/](http://www.abajournal.com/magazine/article/immigrants_face_numerous_hurdles_as_they_struggle_to_navigate_the_legal_pro/)

- [62] S. Sofaer. 2009. Navigating poorly charted territory: patient dilemmas in health care “nonsystems”. *Med. Care Res. Rev.* 66, 1 suppl (February 2009), 75S–93S. DOI:<https://doi.org/10.1177/1077558708327945>
- [63] Kristine Sørensen, Stephan Van den Broucke, James Fullam, Gerardine Doyle, Jürgen Pelikan, Zofia Slonska, Helmut Brand, and (HLS-EU) Consortium Health Literacy Project European. 2012. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health* 12, 1 (December 2012), 80. DOI:<https://doi.org/10.1186/1471-2458-12-80>
- [64] Patricia Ruma Spence and Madhu Reddy. 2012. Beyond Expertise Seeking: A Field Study of the Informal Knowledge Practices of Healthcare IT Teams. *Comput. Support. Coop. Work* 21, 2–3 (June 2012), 283–315. DOI:<https://doi.org/10.1007/s10606-011-9135-1>
- [65] Alexander Stocker, Alexander Richter, Patrick Hoefler, and Klaus Tochtermann. 2012. Exploring Appropriation of Enterprise Wikis: *Comput. Support. Coop. Work* 21, 2–3 (June 2012), 317–356. DOI:<https://doi.org/10.1007/s10606-012-9159-1>
- [66] Anselm L. Strauss, Shizuko Fagerhaugh, Carolyn Wiener, and Barbara Suczek. 1985. *Social Organization of Medical Work*. The University of Chicago Press, Chicago; London.
- [67] H. Colleen Stuart, Laura Dabbish, Sara Kiesler, Peter Kinnaird, and Ruogu Kang. 2012. Social Transparency in Networked Information Exchange: A Framework and Research Question. In *Proc. of CSCW 2012*, 451–460.
- [68] Lucy A. Suchman. 1985. *Plans and Situated Actions: The Problem of Human-Machine Communication*. XEROX.
- [69] Bongwon Suh, Ed H. Chi, Aniket Kittur, and Bryan A. Pendleton. 2008. Lifting the Veil: Improving Accountability and Social Transparency in Wikipedia with WikiDashboard. In *Proc. of CHI 2008*, 1037–1040.
- [70] Allan M. Tepper and Amiram Elwork. 1984. Competence to consent to treatment as a psycholegal construct. *Law Hum. Behav.* 8, 3–4 (1984), 205–223. DOI:<https://doi.org/10.1007/BF01044693>
- [71] Haridimos Tsoukas and Efi Vladimirov. 2001. What is Organizational Knowledge? *J. Manag. Stud.* 38, 7 (November 2001), 973–993. DOI:<https://doi.org/10.1111/1467-6486.00268>
- [72] Kenton T. Unruh, Meredith Skeels, Andrea Civan-Hartzler, and Wanda Pratt. 2010. Transforming Clinic Environments into Information Workspaces for Patients. In *Proc. of CHI 2010*, 183. DOI:<https://doi.org/10.1145/1753326.1753354>
- [73] Kenton T Unruh and Wanda Pratt. 2008. The Invisible Work of Being a Patient and Implications for Health Care: “[the doctor is] my business partner in the most important business in my life, staying alive.” *Conf. Proc. Ethnogr. Prax. Ind. Conf.* 2008, 1 (November 2008), 40–50. DOI:<https://doi.org/10.1111/j.1559-8918.2008.tb00093.x>
- [74] Roberto B. Vargas, Gery W. Ryan, Catherine A. Jackson, Rian Rodriguez, and Harold P. Freeman. 2008. Characteristics of the original patient navigation programs to reduce disparities in the diagnosis and treatment of breast cancer. *Cancer* 113, 2 (July 2008), 426–433. DOI:<https://doi.org/10.1002/cncr.23547>
- [75] Michael Veale, Max Van Kleek, and Reuben Binns. 2018. Fairness and Accountability Design Needs for Algorithmic Support in High-Stakes Public Sector Decision-Making. In *Proc. of CHI 2018*, Paper 440.
- [76] Kristen J. Wells, Tracy A. Battaglia, Donald J. Dudley, Roland Garcia, Amanda Greene, Elizabeth Calhoun, Jeanne S. Mandelblatt, Electra D. Paskett, and Peter C. Raich. 2008. Patient navigation: State of the art or is it science? *Cancer* 113, 8 (October 2008), 1999–2010. DOI:<https://doi.org/10.1002/cncr.23815>
- [77] Norbert Wiener. 1961. *Cybernetics Or Control and Communication in the Animal and the Machine*. MIT Press.
- [78] Volker Wulf, Markus Rohde, Volkmar Pipek, and Gunnar Stevens. 2011. Engaging with Practices: Design Case Studies as a Research Framework in CSCW. In *Proc. of CSCW 2011*, 505–512.
- [79] ORNOA - Oncology Referral Network of America. Retrieved from <http://www.ornoa.com/>

Received April 2018; revised July 2018; accepted September 2018.