

Chapter 15

Designing for Lived Health: A Practice-Based Approach for Person-Centered Health Information Technologies

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15.1 Introduction

Health is almost always a deeply *personal* issue. As individuals, people struggle to maintain and enhance their health within their own “messiness”—their values, practices, and beliefs.

At the same time, a person’s health is always *social*. It is arranged against and in conjunction with medical practices and institutions. Health is also engaged often within a family and almost always within a community context (e.g., with a person’s lifeworld and set of social worlds).¹

Systems that incorporate both a deeply personal view of one’s health and at the same a nuanced understanding of its social contexts would be—in keeping with the arguments in the rest of this book—the most helpful and usable. Currently, a medicalized viewpoint limits system designs to narrowly prescribed forms of activity, almost always within the hierarchical relationship of doctor and “patient.” (Indeed, in US medicine, there is currently no vocabulary for “person” outside of “patient” and “consumer.”) While the Human-ComputerInteraction (HCI) and

¹In this paper we use “community” in the common usage to refer to a group of people living in the same place (e.g., Flint community) or having common characteristics (e.g., medical informatics community). We use the technical term “lifeworld” to talk about an individual’s view of their lives and social contexts. For a fuller discussion of the “lifeworld,” see Luckmann (1970), Shutz and Luckmann (1973), and Schutz (1967). We will use the term “social world” to talk about specific collectivities that form and encapsulate social contexts. For a fuller discussion of “social world,” see Strauss (1991, 1993).

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Computer-Supported Cooperative Work (CSCW) research communities have a more nuanced view of the “personal,” designs are arguably still limited in their adoption of social context.

This chapter examines what sets of social relations “person centered” has and might include, based on theoretical grounds and grounded in a field study in Flint, Michigan (a city in the American Midwest). We wish to ask how relationships among family, friends, caretakers, and community health workers can be reflected in healthcare designs. Below, we first examine the history of the “personal health record” (PHR) and find that the design of PHRs has swung toward an individualized view of the patient mirroring that of institutionally controlled electronic health records. It has become, over time, limited in its view of the “personal.” We then proceed to extend the PHR’s view of the “personal” based on recent social-theoretical frameworks and show that this extension is in line with recent HCI and CSCW personal health application designs.

We argue for a new approach to healthcare systems—oriented toward *lived health*—that supports the social richness of people’s practices. As a part of this wider design space, we call our socially enhanced vision for the PHR a “person-centered health technology” or PchIT. (We use the “PchIT” term primarily for expository clarity here; it can also be seen as a general extension of the personal health record or of personal health applications.) The chapter then demonstrates the analytical power of this extension by showing that it fits the findings from a study of people with chronic diseases in Flint.

We begin with a brief history of work in medical informatics that involves “personal” health information.

15.2 Framings of the *Personal* in PHRs

One place where conceptions of the “personal” have most prominently played a role in medical informatics is personal health records (PHRs), of growing interest to a wide range of academic disciplines. PHRs have optimistically been lauded by many as ushering in a new age of patient-empowered medicine. As Sittig (2001) writes, “Internet-based, personal health records have the potential to profoundly influence the delivery of health care in the twenty-first century.”

It has often been remarked upon, however, that “PHR” as a concept and technology includes a range of definitions and designs (Angst et al. 2006; Archer et al. 2011; Gearson 2007; Kaelber et al. 2008; Osterlund et al. 2011). Over its relatively brief history, the “P” in PHR has stood for personal, patient, parent, and patient controlled and patient held (Kim et al. 2011). The medical informatics literature has increasingly come to see PHRs as various arrangements of information, architectures, and tools focused on supporting the institutional role of the patient and the work practices of clinicians; yet, other less bounded interpretations of PHRs have been voiced. A widely cited report released by theMarkle Foundation, for

instance, broadly defines the PHR as “a single, *person-centered* system designed to track and support health activities across one’s entire life experience” (original emphasis, Markle 2003).

This section surveys how medical informatics has come to adopt a particular viewpoint toward the “personal.” In short, a set of institutional imperatives—including fixing a dysfunctional and fragmented healthcare system in the United States—have pushed toward conceptualizing the PHR as a unified data set for an individual that can be shared across organizational boundaries. In this way, the “P” in PHR has become more specifically framed around the medicalized role of the *patient*.

15.2.1 *PHRs: A History*

The personal health record is far from a new concept in that people have long maintained paper-based health records, be it a notation of births and deaths inscribed in a family bible or a list of medications hastily scribbled on the back of an envelope. Community health studies in the 1970s and 1980s focused on the use of paper health records in specific populations. This research—grounded in the theoretical discourse of medical anthropology and medical sociology—acknowledged that meanings of health varied widely among groups of people. This understanding of health provided the starting point for research on health records driven by social interests.

Kim et al. (2011) note that the first appearance to a PHR in an academic journal came in 1969, a brief allusion to a “personal record linkage.” Studies on the history of personal health records show that there was a steady number of references to PHRs in the medical informatics literature through the 1990s and a dramatic increase in PHR references around 2005. During this period of heightened attention, a number of publications engage specifically with the challenges of classification as researchers within medical informatics set themselves the daunting task of “defining” the PHR. (For a complete review of the PHR literature, see Jones et al. 2010, Kim et al. 2011, and Archer et al. 2011.)

In the 1990s, the “P” in the acronym of PHR held a number of interpretations. Kim et al. (2011) point out, for example, how the terms “*parent held* record” and “*patient-held* health records” were both introduced to the medical informatics literature in 1993. Many of these early descriptions of PHRs offer inclusive understandings of the personal. Such a viewpoint can be found in Iakovidis’ (1998) article on the adoption of electronic health records in Europe that heralds the emergence of personal health records. Iakovidis describes PHRs as a “new generation” of electronic healthcare records that would be connected to “virtual healthcare centers.” PHRs are positioned as tools for patient empowerment that will support people in taking a more active role in managing their health information and making decisions about personal health-related activities.

Although “patient” is referenced heavily in Iakovidis’ design narrative, several of his design specifications demonstrate a nuanced understanding of the personal that extends beyond a strictly biomedical framing.

The electronic healthcare record will not only be accessible to the patients but it will also incorporate their views and notes resulting from self-monitoring of chronic illness, to make dietary notes, monitor sport and exercise performance, behavioral activities and moods etc. We could see in the near future the development of personal health status monitoring and support systems at home that interact with personal health records and complete the picture in the continuity of care scenario. (Iakovidis 1998)

Iakovidis' vision of self-monitoring and data tracking, interoperable home health technologies, and emphasis on health and wellness can be seen in the current Health Information Technology (HIT) landscape of endless mobile health applications, biosensing technologies, and the popularity of the Quantified Self movement whose participants enthusiastically record, track, and share a variety of biometric data from sleep patterns to heart rate fluctuations. This early PHR vision is additionally compelling in that Iakovidis also suggests people will "incorporate their views and notes" on diet and health conditions. This wording implies that PHRs have the potential to extend beyond a strictly medical framing to include reflective activities that engage individuals in sensemaking.

Despite an early openness in the medical informatics community to explore alternative framings, the personal became increasingly conceptualized in a way that was synonymous with that of patient. In what Kim et al. (2011) describe as "a shift to patient centeredness," the conflation of the term personal with that of patient was directly linked to the development of EHR systems in the 1990s. In particular, the Institute of Medicine's 1991 report, *The Computer-Based Patient Record, an Essential Technology for Healthcare*, played an influential role in helping shape the boundaries of the electronic health records movement in the United States. This document includes directives for digitizing provider-controlled patient records (what would become known as EHRs) in order to lower the rate of medical errors (Gearson 2007). Although the report does not specifically mention personal health records, the concept of EHRs provided an intellectual template for PHRs that framed the personal in terms of an individual's interaction with various clinicians and relationship to professional medical work. An emphasis on "patient needs" in this literature details concerns about an individual's access and ownership to their health information in the context of the healthcare system. Some researchers in the medical informatics community have suggested the term "*patient-controlled* health records" as a way of championing patient rights (Kim et al. 2011, emphasis added), and advocacy for more patient control continues to be heavily reflected in recent definitions of PHRs.

The role of the patient in managing their health information was also being explored through commercial designs as well as policy reports. Gearson (2007) describes the impetus for Internet health start-ups in the late 1990s like Followme.com and WellMed.com as increasing patient safety in the healthcare system by bridging an increasingly fragmented healthcare system. Echoing similar concerns, recent corporate entrants to the web-based PHR market such as Microsoft's Health Vault in 2007 and Google Health in 2008 proposed to entice people to use PHRs by giving users the option of sharing their health information with other health information systems. Despite these efforts, the use of PHRs by the general

public has remained low (Nazi 2013). Citing lack of widespread PHR adoption, Google discontinued Google Health in 2012 and gave users until January 2013 to download their personal health data. Google Health's early demise reflects a general tempering of earlier rhetoric in media and the academy that PHRs would "revolutionize" healthcare.

The conversation, then, has turned to how to unify patient data through the connection of PHRs, EHRs, and other sources of electronic health data (Gearson 2007), instead of discussing PHRs as distinct systems for patient empowerment. Healthcare providers like hospitals, insurers, and employers have offered "tethered" PHRs that are integrated or connected with the organization's information system. One such example of this architecture model is Dossia founded by a consortium of corporations including Wal-Mart and Intel. These integrated health systems often give people access to their medical information through a "patient web portal" that has an array of functions and tools. People can view an abstract of their health record or parts of their clinical record, have their prescriptions filled, and make clinical appointments. In some of these designs, patients also have the ability to add specific types of information about their health status through journals/diary applications or communicate to healthcare providers through secure messaging tools.

In 2003, the highly influential Markle Foundation report (2003), "Connecting for Health," reconceptualized the PHR as a "single, *person-centered* system" (original emphasis). Unlike earlier views, the Markle report highlights the role of the individual. This point is made again through the use of bold underlined text, with the firmly worded statement: "The *individual person* is the primary user of the PHR." Tang et al. (2006) build on the Markle report detailing a spectrum of designs from stand-alone applications to PHRs that are fully integrated with the healthcare provider's EHR system. While the authors note a PHR "includes information managed by the *individual*" (original emphasis), they also acknowledge that PHRs may contain data about other family members and even nonmedical settings such as home and work environments. These nonmedical social contexts, however, are not fully explored.

Defining the personal health record in relation to other electronic patient records like the EMR and EHR has now become a common framing device in much of the medical informatics literature. In 2008, the (US) National Alliance for Health Information Technology published a report called "Defining Key Health Information Technology Terms" that defined EMRs, EHRs, and PHRs (emphasis added):

- An electronic record of health-related information on an individual that can be created, gathered, managed, and consulted *by authorized clinicians and staff within one healthcare organization*
- An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted *by authorized clinicians and staff across more than one healthcare organization*

- An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled *by the individual*

These definitions categorize records as different types of collaborations between people, standards, and data. The EMR is coordinated by clinicians and staff using the standards of a single organization, the EHR is coordinated through national standards by clinicians and staff across multiple healthcare organizations, and the PHR utilizes information based on national standards but is coordinated by the individual. Accordingly, the EMR, EHR, and PHR—if fully integrated in an ideal manner—work together to comprehensively aggregate health information for each individual.

The report notes that given the sharing of data, it is often difficult to distinguish between an EHR and PHR. The authors argue for a PHR that is defined primarily in terms of information access in which the individual has “control” of their health information. How this control actually works in relation to practicalities of system architecture and the power dynamics of the healthcare industry, however, is less clear. The report states, for example, that information found in the “patient portal” interface of a typical PHR are also maintained by the healthcare provider.

Through various technological means, selected content in an EHR can be made available for individuals to view and use in guiding activities of health and wellness through what is called a “patient portal.” The health care provider operating the EHR system typically controls the patient portal. Many of these portals are given the name PHR, but the source of control of the information is important to determining whether this model is a PHR or remains within the scope of an EHR. To be a PHR, access to the record must be managed and controlled by the individual. Information that passes from an EHR to a PHR transfers to the control of the individual. (National Alliance for Health Information Technology (U.S.) 2008)

The report also acknowledges that current PHRs allow individuals to enter only limited forms of information; yet they optimistically maintain that “PHRs have the potential to be a robust, better-assembled and more organized source of both clinical and wellness information.” This robustness would come through the addition of new sources of health information that extend beyond the patient-physician-pharmacy configuration currently available in most PHRs. The report suggests that in the future, PHRs will connect healthcare providers, healthcare clinicians, medical devices, wellness promoters, individuals, health insurers, public health officials, and research institutions promoting medical studies and recent publications.

It is worth pointing out that the report does not provide a discrete category for an individual’s family and friends, at least those who are not formally designated as “proxies” or “agents.” It is puzzling that the people often most intimately involved in a person’s health—a sister, a close friend with a similar health condition—are absent from this lengthy list of health information collaborators that includes everyone from insurance agents to academics running clinical trials.

Finally, a recent article, by Jones et al. (2010), confirms a wider trend toward data integration in the vision of PHRs. After discussing several conceptualizations of PHRs, they offer up a working definition:

Electronic personal health record (PHR): a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or from other sources such as pharmacies, labs, and healthcare providers. (Jones et al. 2010)

To summarize, personal health records are defined as containing a variety of health information, types of users, and technological tools that allow for the collection, sharing, and maintenance of health-related data. In addition, these definitions discuss the aims of PHRs as primarily supporting the communication practices between health professionals and patients and the integration of health information systems. PHR models range from a data set controlled by an individual on a personal computer to information shared between a variety of systems and organizations; however, the definitions found within the medical informatics literature appear to increasingly support a vision of data integration between PHRs and EHRs. The current state of the literature emphasizes a medicalized perspective of health information in which the personal is understood primarily in terms of a patient's role and rights in a wider healthcare context. Hence follows the general preoccupation in these publications with issues of information "access" and "control."

The consequence of the *personal* being increasingly understood in terms of the *patient*, we argue, was the loss of original concern around social context and personal reflection. Interpretations of the personal grounded in family and community life were sidelined; the pressing needs to integrate data across healthcare providers and implement working health and medical systems, especially in the United States, became the focus instead.

Recently, there appears to be a renewed interest in social contexts. Recent position papers outlining future research directions, for example, indicate a need to study PHR use in diverse populations such as "people with chronic conditions, individuals with disabilities, parents with small children, people with a strong interest in maintaining health lifestyles, and the elderly or their caregivers" (Archer et al. 2011) and nonmedical settings like the home (Tang et al. 2006). Furthermore, it is acknowledged that long-term sustainability issues around design and the ways in which people might use PHRs at different periods in their lives are still not well understood (Archer et al. 2011). In the next section, we examine an alternative framing for the PHR that positions *the personal* as inherently *social* and grounded in a diverse range of contextualized practices. This framing both revisits an earlier conceptualization of the personal that guided prior studies on paper-based personal health records and also introduces some new considerations on personhood in an age of digital health technologies.

15.3 Theoretical (Re)framings

We believe a more compelling framing for PchITs can be found in theoretical work that allows for a richer understanding of social complexity. Taken together as a theoretical (re)framing of the personal, it challenges the idea of the per-

sonal represented in PHR definitions as an individual, unified patient and takes instead social arrangements as a starting point for understanding how bodies and selves are situated, enmeshed in local contexts. This alternative understanding of person-centeredness is furthermore explored through attending to *practices*.² These practices might include patient work but also consist of a variety of other non-biomedical activities that are a part of people's everyday life and located within a range of social contexts.

15.3.1 *The Role of the Lifeworld in Healthcare*

Medical sociologists studying doctor-patient communication have long discussed the need to understand how the richness of people's lives might be more meaningfully integrated with professional healthcare work (Rodin et al. 2009; Barry et al. 2001; Mishler 1984). It has often been noted, for instance, that the patient's "voice of the lifeworld" (e.g., contextually grounded experiences) is held in tension with the physician's "voice of medicine" (e.g., technical information) (Scambler and Britten 2001).

The need for health professionals to relate clinical information to the lifeworld is especially important in treating people with chronic illnesses as these health conditions are inextricably woven into the fabric of daily life. For example, Barry et al. (2001) writes:

As the role of the GP [general practitioner] changes with the rise of chronic illness in an aging population GPs may have to change their notions of success from purely technical considerations to include their patients feeling understood, listened to and treated like whole and unique human beings. (Barry et al. 2001)

Studies detailing the patient's lifeworld present a sociological critique of professional medical practice by arguing that institutionalized healthcare too often ignores social context, dehumanizes the patient, and "depersonalizes" health information. Although the literature on medical sociology demonstrates a need to think holistically about health, the ways in which medical information might be integrated with patient lifeworlds are still not well understood (Waizkin 1989, 1991).

It is worth considering then how people's lifeworlds might be better integrated into the design of PchITs. Envisioning users strictly in terms of *individuals*, for instance, might not resonate with people for whom *the family* is the most important social unit. Designs that seek to be "person centered" rather than simply "patient centered" would benefit from future research that investigates the important sets of social relationships found in people's lifeworlds.

²Practices here focus on human action (e.g., *what people do*). Health practices refer to the ways that people manage their health through specific, situated actions. For example, a person organizing their prescriptions on the kitchen counter in order to remember taking their daily medications.

While drawing attention to the social context of health, the medical sociology literature on the lifeworld is limited in its theoretical scope as it does not fully grapple with the complexity of a person being a part of multiple lifeworlds; nor does it offer a nuanced understanding of the role technological artifacts play in shaping the personal. To do this, we turn to social analyses that offer a critique of the self as a unified individual and suggest how PchITs might support socially richer conceptualizations of the personal.

15.3.2 The Personal as Practice: Embodiment, Emerging Selves, and Health Records

Drawing from theoretical traditions across the humanities and social sciences, academic fields like science and technology studies (STS) articulate a conceptualization of personhood that is inextricably entwined with the cultural and material worlds. Posthumanist theorists like Haraway, for instance, attempt to disrupt and subvert an understanding of the body as singularly human: “Why should our bodies end at the skin?” (Haraway 1991). People and technology are in a constant state of flux, shaping and (re)shaping one another through a variety of interactions with different social contexts. This theoretical position implies an inherent multiplicity in a person’s lived experience as different arrangements of technologies, processes, and people perform new self/selves. Furthermore, a growing collection of work has turned to practices as a theoretical lens and design methodology in which to understand and engage with this multiplicity (Orlikowski 2000; Schatzki et al. 2001; Suchman 2007; Danholt 2008).

In *The Body Multiple* (2002), a study of atherosclerosis, Mol conceptualizes the lived experience of a disease as “multiplicities of realities” made visible through the relations between practices of knowledge systems, the human body, and technologies. Information is not neutral but presents a version of reality that is always intertwined with practice (Mol 2002, p. 171). The patient record as an information technology includes an array of discrete logics (and realities) such as images of blood vessels, clinician notes, patient complaints, and numerical lab results that all perform a person’s blood sugar levels. Although this information does not neatly align, Mol maintains that the patient record holds together as a form of coordination across the organizational contexts of healthcare institutions. In *The Logic of Care* (2008), Mol further argues that for healthcare to be person centered, policy-makers and practitioners need to grapple with contextual multiplicity by attending to localized health practices found both within and beyond the world of medicine.

Understanding the ways in which medical and health systems, especially PchITs, are related to embodiment—how the personal is digitally performed—is also a matter of design. Berg and Harterink (2004) trace the history of medical records from the early twentieth century and demonstrate how the medical record has

long conceptualized the patient as a singular, independent, and rational subject. They further argue that emerging technologies have the potential to shift our understanding of personhood to be “decentered, dispersed, and multiplied subjects” (Berg and Harterink 2004). Current PHRs, however, still largely design for a patient in isolation and apart from “the mess³” that is a part of contextual specificity: the localized practices found in particular communities, family situations, and geographies. If one accepts Berg and Harterink’s (2004) postulation that digital patient records can help shape and support new forms of embodiment, then one must also think constructively about how to incorporate the contextual multiplicity of lived experience.

Suchman (2007) presents a practice theory approach that closely examines people’s behavior in a specific context as the starting point for design work. Understanding people’s practices—or in Suchman’s terminology *situated actions*—helps articulate the complicated arrangements of people, social processes, and artifacts. As with Berg’s (1999) “sociotechnical” approach, Suchman holds that good designs should embrace, rather than dismiss, the “mess” found in people’s everyday actions be they in the home, workplace, hospital, or an online forum.

The notion of the postmodern/posthuman self as an assemblage of decentered and dispersed subjects argues for future design directions to help people manage a multiplicity of healthcare practices around different contexts such as family life, religious organizations, illness support groups, and local communities. That different types of personal health information may overlap, conflict, or coexist does not necessarily have to lead to technical chaos or poorer health outcomes. Disparate but meaningfully connected health information might open up new design trajectories that enable a holistic vision of health information technology that is integrated into people’s everyday practices and lifeworlds.

15.4 HCI/CSCW Design Approaches Toward *Personal Health*

As discussed above, the vision of an “ideal” PHR underlying many of definitions in the medical informatics community has come to a view of the “personal” that is based primarily on the idea of a “modern self”: unified, individual, and governed primarily by reason. This view of the personal is translated into the medicalized

³In earlier work (1999), Berg outlined a “sociotechnical” approach to designing health information technology. This framework, he writes, “overtly critical of approaches that denounce the ‘messy’ and ‘ad hoc’ nature of health care work, and that attempt to structure this work through the formal, standardized and ‘rational’ nature of IT systems. [. . .] It engages in constructive critique rather than in delivering yet another set of guidelines for design and implementation.” For Berg, design work should start with a nuanced understanding of health practices, where practices include networks of people, tools, organizational routines, and documents. For another interpretation of “mess” in design, see Dourish and Bell (2011).

PHR as a well-managed data repository and coordination tool between an individual and their healthcare team. On the other hand, the concepts of the lifeworld and posthuman assemblages present a more nuanced understanding of the “personal” that engages with multiplicity, temporality, materiality, and “the messiness” of everyday life. This viewpoint reframes the personal in terms of fully contextualized social arrangements. This would be difficult, at best, to fully incorporate in technical systems.

The HCI/CSCW literature offers a middle ground by considering some, but not all, contexts for situated health practices in technological designs. That is, context is a necessary, albeit imperfect, part of the design process or is to be incorporated partially in the design itself. HCI/CSCW prototypes that have been commonly labeled as personal health applications (PHAs), although differing in key respects from the PHR definitions above (and from one another as well), are aligned in their approach to design. In attending closely to social contexts, they are representative of HCI/CSCW research that has focused on designing health technology in “complex, diverse, and locally situated” settings (Fitzpatrick and Ellingsen 2012).

In the following, we note two studies we believe exemplify the HCI/CSCW approach toward a personal health record. We necessarily privilege some HCI/CSCW studies in the following. There are many more that could have been included (e.g., Bardram et al. 2013; Caine et al. 2010; Kientz et al. 2009; Klasnja et al. 2010; Mynatt et al. 2001; Mamykina et al. 2008) but we did not do so for lack of space.

Enquist and Tollmar’s (2008) *Memory Stone* is a record-keeping system designed to support pregnant women, their families, and health providers in Denmark. Their prototype both explores the personal in the context of family as well as highlights the multiplicity of social roles such patient, parent, and caregiver that are performed at different points in a person’s life. The design specifically engages the issues of temporality and materiality and demonstrates how health technologies might support a range of social “selves.”

In their study, the authors found that during pregnancy women are in contact with multiple healthcare professionals including physicians, nurses, and midwives. Health data is thus distributed between many parties and contexts; furthermore, it is both health related and social (Enquist and Tollmar 2008). One information artifact of particular importance in Denmark is a pregnancy journal kept by women and used as a coordinating device for health information. This journal served as the inspiration for the design of *Memory Stone*, as a communication and coordination artifact that supports the collection, annotation, and sharing of information related to pregnancy and maternity (Figs. 15.1 and 15.2).

Enquist and Tollmar emphasize a lifeworld framing in their design work. “In Denmark,” they write, “pregnancy is not considered a medical condition, but rather a psychological, social and biophysical one. The pregnant woman is not a patient; she is not ill in the medical sense and hence is not treated.” Furthermore, the authors express a clear intention to engage with the theoretical notion of assemblages in their design objective and ask: “How do we design devices/systems that can be

Fig. 15.1 *Memory Stone* prototype



Fig. 15.2 Social context of *Memory Stone* users (Enquist and Tollmar 2008)

manipulated and configured to work as resources in changing settings?" (Enquist and Tollmar 2008).

Memory Stone is designed to support the integration of sentimental/biographical and clinical information. Parents can add personal notations and notes, images, videos, and sound recordings to the medical information that is stored on the device. Different types of health information can include experience-based narratives on what to expect at different stages of pregnancy, media files of the fetus and its mother like ultrasounds and images of a woman's growing stomach, and more clinical information like logs of blood sugar levels for woman with gestational diabetes (Enquist and Tollmar 2008).

Although *Memory Stone* is built as stand-alone device that can currently integrate with only one other healthcare information system (an electronic patient journal used by nurses), the authors imagine a software architecture that makes it possible to run the *Memory Stone* on a variety of technological platforms such as mobile devices or PCs.

The woman should thus be able to construct and deconstruct assemblies, for example, between her *Memory Stone* and other devices with medical record systems at the general practitioner's office, and with different types of displays. Similarly, she should be able to construct connections between her *Memory Stone* and other devices providing services, e.g. biosensors or ultrasound scan machines. (Enquist and Tollmar 2008)

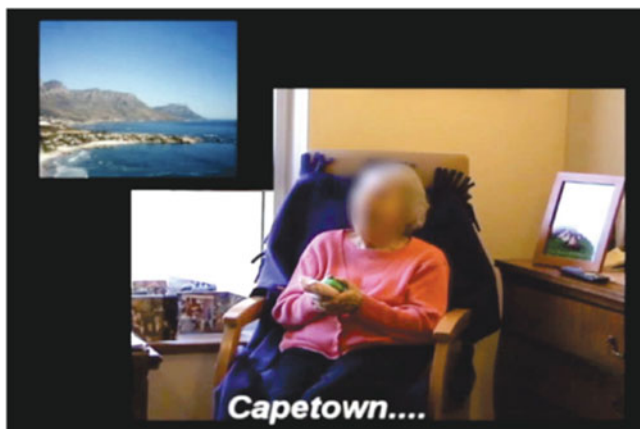


Fig. 15.3 Example of a *Media Biography*

A second study, Crete-Nishihata et al. (2012), describes a series of designs to support older adults with Alzheimer's disease (AD) and mild cognitive impairment (MCI). The intended system users included these adults and their caregivers, such as partners, siblings, and children.

Over the course of three related studies, the authors worked to collaboratively produce *Media Biographies* that "told the life story of patients through various personal media such as photos, home movies, documents, music and audio narration" (Crete-Nishihata et al. 2012). *Media Biographies* were then shown on ambient displays in people's kitchens to provide ongoing memory support of adults with AD and MCI. The authors also designed narrative slideshows comprised of curated selections of SenseCam images for people with AD or MCI and their caregivers (Figs. 15.3 and 15.4).

Crete-Nishihata et al. (2012) reported a positive reception of the designs from both adults with AD and MCI and their caregivers. They note, "family members believed that viewing *Media Biographies* helped third-party caregivers learn about their loved one's history and enabled them to better empathize with them and care for them." On the use of *Media Biographies* with ambient displays in the home and its impact on older adults, the authors found that the use of digital narratives improves positive self-image and a reduction of apathy, even though there was no accompanying improvement in people's memory abilities.

Crete-Nishihata et al. (2012) offer important design implications for PcHITs. The designs in the paper point to a type of personal information management that is narrative based and interwoven with issues of health and emotional well-being in a family setting. These prototypes also provide insight into the management of personal health information as people age. As well, the importance of multiple stakeholders and the psychosocial impacts of health more broadly suggest that all PcHIT designs carefully consider the integration of "nonclinical" framings around memory, identity, and family dynamics. Crete-Nishihata et al.'s (2012) work



Fig. 15.4 Display in kitchen (Crete-Nishihata et al. 2012)

suggests that designing PchIT systems to support storytelling activities might make biomedical data more valuable for many of the people who use them.

The implication of these two systems is that health applications should consider framing the personal in terms of non-patient specific roles, such as that of a parent. Parenthood might involve patient work if a child is sick or if a woman experiences complications with pregnancy such as with gestational diabetes. It also encompasses other types of social relations and activities that are grounded in the lifeworld. A mother, for example, is also a daughter, friend, and partner. As seen in *Memory Stone*, these roles are inextricably tied to parental activities such as sharing a child's photographs with grandparents, discussing concerns about a child with a partner, or debating the benefits of vaccinations with other young parents. Furthermore, these relationships are fluid across a person's lifespan. As seen with *Media Biographies*, a caregiver's role can switch between parent and child later in life. Both of these systems also point to the importance of biographical work that is deeply connected to family life and health.

15.4.1 Community-Based Explorations of "Person-Centered" Health

This chapter so far has been guided by several interconnected inquiries around person-centered health: What sets of social relationships should "person centered" include and exclude? How might family, friends, and caretakers potentially be reflected in PchIT designs? What types of cultural framings might be important to contextualize health data in different communities? Answering these questions has

to be grounded in a thorough examination of people's practices, so as understand what *they* want and need. These concerns have informed our research on designing technology to manage and document chronic illness.

Our field-based research extends current HCI/CSCW arguments that argue for contextually grounded health and medical systems design by focusing on the local needs and values of a *community*. In our research on managing chronic illness in Flint, Michigan, we observed the informational and social complexity of community-based health practices. We present a selection of these practices to help broaden the design space around person-centered health records and suggest socially rich design trajectories around the notion of *lived health*.

15.4.1.1 Living with Chronic Illness in Flint

We have conducted a series of interpretivist-based studies on managing chronic illness in Flint, Michigan (in the American Midwest), a community with significant health disparities. The studies have been interview and focus group based, and our participants have included people living with diabetes, hypertension, and/or kidney disease in Flint. We also spoke with numerous local clinicians, including nurses, physicians, and certified diabetes educators, as well as community health workers active in city churches and “block club” members representing particular neighborhoods.

Flint's history is closely tied to the US automotive industry, and significant layoffs and plant closures over the last 20 years have left the city in deep economic and social turmoil. Flint's neighborhoods vary greatly: There are areas of large houses, well-kept lawns, and an air of prosperity. There are also areas of middle-class and working-class families. The downtown area has been the recipient of recent revitalization efforts, and Flint's Cultural Center boasts museums and a symphony orchestra. Here, we focus on describing the experiences of people living among the “northside” neighborhoods of Flint. A historically African-American community, longtime residents remember it as a swath of once flourishing neighborhoods with many family homes, schools, and parks. The area, however, has changed drastically in the last 10–15 years as a population of less economically stable residents moved in. A rise in violent crime and drug use spurred many remaining families who had the financial means to relocate to safer areas. As the population decreased, abandoned and boarded-up houses began sprouting up and local schools were closed. City services— already limited due to a budget crisis— were further reduced; for instance, our participants mentioned darkened street lights, limited garbage removal, and bus routes that have stopped running. Indeed, there are some sections of the city that participants described as forgotten, a kind of no-man's land where vacated houses are set on fire by bored teenagers.

Healthcare in Flint can be problematic as participants reported a number of challenges when interacting with the local healthcare system. Participants, especially those with marginal health insurance, spoke of difficulties finding doctors who were accepting new patients and often relied upon free healthcare clinics at

different points in their lives. The crowded conditions at these facilities resulted in difficulties getting appointments and long waits to see clinicians. Participants reported extremely rushed consultations, as brief as 5 min in some cases. From the perspective of our participants, this did not leave time for them to find out why medications were being prescribed, let alone have a meaningful dialogue with healthcare providers about treatment plans and healthcare options.

In addition, participants described many interactions with what they called “bad doctors,” doctors who failed to adequately inform them or to inquire about their health and well-being. From our participants’ perspectives, bad doctors spoke too quickly, appeared dismissive or even insulted when a patient asked questions, and didn’t ask questions of the patient. “Good doctors,” on the other hand, were described with deep respect by participants; in fact, some participants worried about losing their physician and expressed concern about disappointing him or her when they did not strictly follow their treatment plans. Sometimes a reluctance to be “fired” by a doctor led to the participants withholding information that would cast them in a negative light during their clinical visits.

At times, participants felt their clinicians gave conflicting advice, which led to feelings of confusion and mistrust. Participants with diabetes recounted that their primary physicians told them to stop eating all “white foods” while diabetes educators taught them it was safe to eat rice and potatoes in moderation. More common during consultations was the experience of receiving generic advice of the “eat better, exercise more” variety that required participants to puzzle out ways to turn clinical information into meaningful practices.

Even when participants were able to discuss their health conditions with medical professionals, they indicated they were often skeptical about the information received. Mistrust stemmed from the lack of time clinicians spent diagnosing patients during clinic visits, personal experiences of medical negligence or malpractice, and a long history of civil rights abuses against the African American community. (Veinot et al. 2013)

Accordingly, community-based health information was especially important in Flint. In past work (Kaziunas et al. 2013), we have detailed the ways in which health information is intertwined with highly situated everyday activities and concerns such as finding affordable, healthy food, exercising in safety, or coping with high levels of stress. We found that people living with chronic illness have numerous strategies for “localizing” health information from clinicians and other sources like the Internet to make it meaningful and actionable in their community context. In the absence of fresh fruits and vegetables at a local grocery store, for example, participants rinsed salt from canned beans and ate frozen fruit. If participants could not afford their prescription medication that month, blood pressure pills were rationed and diabetes test strips could be shared among friends. Many people living with hypertension in Flint turned to alternative, “homemade” remedies passed down in their families such as drinking vinegar to lower blood pressure. Other participants spoke about turning to religious rituals such as prayer to reduce anxiety and stabilize blood sugar levels. While these local health practices can be viewed in part as a pragmatic response to living with chronic illness in a community with

few resources—indeed, many participants in our study are currently or in the recent past without health insurance—our participants also continuously expressed how these practices were personally meaningful, intimately bound up with their family relationships, church life, and even city history.

15.4.1.2 Navigating Multiple Health Viewpoints

Our work in Flint shows that participants drew upon multiple social worlds to fashion their health practices. Two notable social worlds for people managing chronic illness in Flint are local churches and diabetes clinics. Grounded in different perspectives of health (e.g., religious faith and medicine respectably), sometimes faith-based practices clashed with medical treatment plans. Institutional medicine was not necessarily viewed by participants as the most useful or meaningful, an insight recognized by the majority of diabetes educators we interviewed. As people with chronic illness and clinicians navigated these differing viewpoints, the routine overlapping of their social worlds created new sets of health practices that would not have been anticipated—or appreciated—in a medicalized PHR. However, understanding these practices is essential to properly designing a useful and usable PCHIT. We now turn to examining health practices in which people engaged diabetes in the church and faith in the clinic.

15.4.2 “Not Claiming” and Faith Healing Practices in Flint

The vast majority our participants spoke of the important role churches had in their community. Along with religious activities like prayer and worship on Sunday, active members of local churches routinely ate and hung out together during the week, and members and nonmembers alike utilized church services such as food giveaways, van rides, and shelter. It was not uncommon for participants to speak warmly of their “church family.” As explained by one man:

At church it is nothing for them to come over and take you to the doctor or the grocery store, or to take you to pay bills. We had one lady who used to come over and help my wife wash when she was sick, brush the kids’ hair, make sure of this or that. [...] She was like a mother to my kids. Her kids use to spend the weekends with my kids, and my kids would spend the weekends with hers. It was a family-oriented thing.

Health is often discussed at church. People with diabetes might trade tips about what foods to eat, discuss medication side effects, and pray for one another’s health. Additionally, many Flint churches have dedicated health team ministries and offer support groups for people living with chronic illness. Healthcare teams at churches often run health fairs or screenings for the community and organize walking programs to help community members get physical activity safely.

While representing a diversity of Protestant denominations, many African-American churches in Flint practice charismatic forms of faith healing in which the body is healed through spiritual means. In some variations of the faith healing tradition, physical health is an outward manifestation of one's spiritual well-being, and to be ill is to not be well spiritually. Being spiritually strong in one's faith is often seen as the most important part of life (Bowler 2013). We heard reoccurring stories from our participants about people who would "not claim" their diabetes; among certain church congregations in Flint "not claiming" an illness is a respected act of faith. "Claiming" diabetes implies that a person has a distressing lack of faith, and many who would "not claim" their illness believe instead that God can supernaturally heal the sick through devout faith and rituals like prayer or the laying on of hands. A person with this viewpoint may refuse to take medication or go to the doctor to get a medical diagnosis.

While widespread in the community, particularly among the older generation of residents, we found "not claiming" was a contested practice in many churches. Congregations with active healthcare teams, often composed of volunteers from the church who have formal medical training, often seek to help people navigate the biomedical and faith-based worldviews. One man with diabetes shared that people in his church will often go to church leaders such as the pastor or health team for counsel when first confronted with a health concern. They would pray about the health issue together and then the pastor would offer to take them to the doctor. He expressed his view on faith and health:

Faith first, but He [God] wants you to go check out the doctors. That's what He gives us a mind for. I'll never knock faith, but He's showing you that you need to go to the doctor too.

Another man spoke about his wife, a trained nurse, and how she shares nutritional information in a way that helps people at their church connect religious teachings to the traditions of southern soul food cooking.

My wife tried to bring some of these things [health information] to the church to help people understand what is going on with them and connect those to the Bible where God say[s], "Everything is good for you." But we have to do that in moderation, don't be a glutton with it.

For our participants, the boundaries between biomedicine and religion are often fluid in daily life, and participants who practice forms of faith healing draw upon multiple meanings of health. Biomedicine for many people does not hold a place of uncontested authority whether in the church or in the clinic.

This issue was also reflected in the practices of local diabetes educators (both nurses and dieticians) in Flint, since they had also to navigate between these overlapping social worlds. The interviewed diabetes educators we spoke with in Flint were highly aware of the influential role churches had in community life.

While there were diabetes educators who dismissed practices of "not claiming" as a form of denial, many clinicians developed practices around exploring the intersections of faith, diabetes, and medical information so as to move people toward the recommended biomedical treatment plan. One diabetes educator, who described herself as a "faith-based person," often draws upon theological concepts or Biblical

references with patients when talking about diabetes. For example, she explains to her religious patients that “high blood sugar itself begets higher blood sugar” (where “beget” is a term from the Bible creation story). She explains her approach to those who practice faith healing forms of “not claiming”:

I’m not going to argue with them about their claiming, I’m going to try and help them meld both their faith and health. So I do a lot of talking about how the body is created; how it functions. I won’t necessarily use the word “created.” I’ll say “designed” a lot. “The body was designed to function in this way, and so when we honor how the body was designed . . .”

Those diabetes educators who themselves frame issues of religion in strictly medical terms, such as coping with diabetes-related distress, are careful to open up space for alternative meanings. Group classes on diabetes, for example, allow time for people to talk about faith with one another. Diabetes educators less comfortable about drawing on the language of faith themselves facilitate this discussion by asking questions.

We’ll ask, “How does your faith play into your diabetes?” We just ask the question. [. . .] I open it up because I think we often ignore those things and yet you are missing some richness in the conversation. You are missing understanding how people are actually coping with all of this.

In summary, practices around faith healing in Flint demonstrate the necessity for researchers and designers to grapple with the richness of health information in all its varied meanings. In melding blood sugar with scripture, the work of local diabetes educators and community health workers highlights the intersections among social worlds. To be clear, while a lack of resources makes the socially contextualized meaning and significance of health practices stand out more sharply in Flint, the issues and the importance of social context, we believe, are present in all communities. In this regard, our study points to a very different conceptualization of personal health information than what is currently being supported by PHR systems, and we argue that our findings demonstrate how important this difference is in properly constructing useful and meaningful PchITs. In the next section, we articulate a design space that we call *lived health*. It is a conception of the personal that uses practices to critically and generatively engage social complexity in healthcare settings and to imagine technological designs that allow for heterogeneous health information to overlap, collide, and coexist in meaningful ways.

15.4.2.1 Designing PchITs to Support *Lived Health*

We believe our findings fruitfully extend other current work in CSCW and HCI, some of which were highlighted in Sect. 15.3 of this chapter. As with many CSCW studies, we found that it is necessary to contend with social context. Our findings from the Flint studies demonstrate, however, that there is not one predominant social context, but rather an array of social contexts around health. They also show that the boundaries of these social contexts are fluid and shifting. As Mol (2002) points out, chronic conditions are seldom one integrated conceptual entity or activity; instead,

people's perceptions of their chronic conditions change in varying social contexts. Current health systems are brittle and limited, compared to the vast flexibility and nuance that people actually need in their daily lives (Ackerman 2000). Many CSCW systems provide for greater social context but still are largely limited to specific contexts.

Indeed, our findings argue for a different kind of health technologies that extend beyond the PHR. Such a health technology, which we term a PcHIT (a person-centered health technology), would allow a heterogeneity of personal health meanings to exist simultaneously. Furthermore, it would allow interpretations to change over time, as one goes through life, based on the negotiated order and (re)ordering one comes to with medical institutions, other healthcare providers, family, community, and the full range of social contexts. Current HIT is unnecessarily narrow in conceptualizing the social. We recognize that we are limited in our abilities to design systems with this capability; nonetheless, it does not mean that people's practices do not argue for it. A PcHIT is not likely to be unified and completely coherent, but neither are people's practices.

Finally, our findings argue for adopting a stance where people's—not just clinicians'—viewpoints are recognized and respected. This is a strong stance in CSCW, and we reiterate its importance here. A flexible, reinterpretable set of records would appear to better suit people's activities, especially in their social contexts, allowing people to highlight the important characteristics, norms, and values that they carry through their everyday lives. The current health record suggests the rationality of the medicalized viewpoint and the apparent nonrationality of people's everyday health practices. While we recognize the importance of medical knowledge and action based on that knowledge, people's practices still argue for not diminishing their meanings and emotive underpinnings.

Focusing on health as a set of practices interwoven with other aspects of the personal highlights the everyday interplay between institutions and people, memories and things, and inspiration and information. There is a rich and relatively unexplored design space that exists between the rigidity of clinical medicine and individual, idiosyncratic health practices, a design space we think of as *lived health*. We take as inspiration the framing of “lived religion” as described by Robert Orsi whose work details the everyday practices of spiritual life, such as urban shrines and religious street festivals. Orsi (2002) argues that the study of lived religion goes beyond formal theology to understand “how the dead are buried, children disciplined, the past and present imagined, moral boundaries established and challenged, home constructed, maintained and destroyed, the gods and spirits worshiped and importuned” (Orsi 2002, xxxi). Scholars of lived religion are thus critical of hierarchy in terms of understanding beliefs and practices, viewing theological teachings and institutional rituals as intertwined with—rather than in opposition to—people's everyday spiritual activities. Adopting this framework for health contexts calls us to attend to how people use glucometers, pray for healing, cook for their families, and organize prescription medications.

Lived health focuses on how people deal with health as situated in particular social worlds and as negotiated across the boundaries of multiple social worlds.

These practices are often messy and contested. Professional medical recommendations do not always sit easily with everyday constraints, let alone cultural expressions of religious piety. Practices such as enjoying traditional food culture and being a “happy diabetic” or “not claiming” diabetes can be seen to subvert the carefully medicalized boundaries of illness and disease. Lived health encompasses such tensions, bearing what religious historian David Hall refers to as the marks of both regulation and resistance (Hall 1997). In this way, lived health does not displace institutional or normative perspectives on health and medicine but looks to include multiple, overlapping, and even contradictory meanings embodied in health practices.

There are several ways in which a lived health approach can help us aesthetically and technically design a suitable PchIT (or rethink the PHR). First, lived health opens up the design space to consider different configurations of data sharing among family, clinicians, and community members. For instance, how might we visualize relationships between biomedicine and alternative health framings? While boundaries between social worlds were not neatly drawn by the Flint participants, health technologies do not often help people meaningfully engage with heterogeneous, and potentially conflicting, health information. One might imagine a person-centered health record being able to support expertise sharing from a range of divergent perspectives. We are currently exploring how diverse viewpoints, both medical and community based, might be incorporated within a health application. In our FIT (Flint Information Translations) application, users can see a variety of “officially sanctioned” medical views of illnesses and health conditions, as well as the ones offered by community members. In addition, users can see translations of those medical views into practices grounded in their everyday contexts. Figure 15.5 shows the current FIT prototype, although we expect it to change as we codesign it with our participants.

Additionally, lived health expands the design space of “health information” to consider what Orsi (2002) refers to the “the density of practices” that make up social worlds such as objects, gestures, and ideas. Studies of health practices in CSCW have been quick to point to the materiality of health artifacts and the embodied nature of illness, but have less often engaged explicitly with the practices around ideas. What would it look like to engage people’s health imagination through technology? One design trajectory worth exploring, we believe, is the design space around health memory. Viewing health as a form of cultural work means that practices are historically situated and time bound. What health memories are personally and collectively meaningful? How might PchITs help support the long-term sharing of health information across generations? What role does forgetting play in designing for health memories? Furthermore, how do you support people in reflecting on important health information that is often wrapped up in the mundane, everyday elements of life?

In summary, a practice lens has led us to a very different place in considering PHR design and health information in general. Only by examining people’s practices could we understand how people use glucometers, pray for healing, cook for their families, and organize prescription medications. Our work in Flint follows

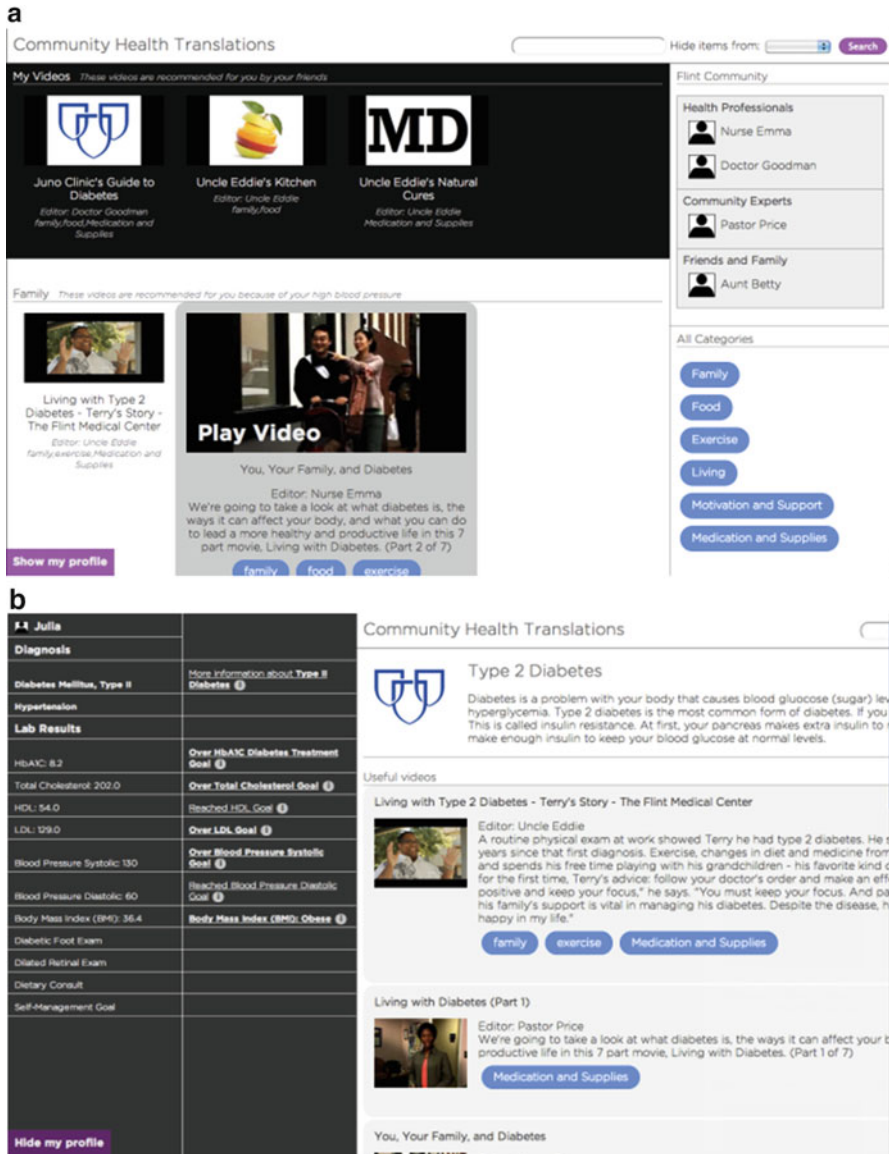


Fig. 15.5 The FIT prototype application to help people understand how others in their community understand and live with a chronic disease condition: (a) A user can see videos describing a condition, showing sample recipes, or strategies for coping. (b) A user can see health information, tailored for him/her by a community member, explaining medical test values and medical instructions as well as videos further explaining what to do

others (e.g., Mol 2002, 2008; Danholt 2008; etc.) who have documented practices around chronic health conditions like diabetes and found that health practices are dynamic, shaping, and shaped by a multitude of social dimensions, including family arrangements, locality, healthcare organizations, and personal beliefs.

In this chapter, we argue for the centrality of a “lived health” viewpoint, which incorporates how health practices must be considered in the full range of people’s lives. People, in the lived health framework, are cast as narrators and (re)interpreters of their own health experiences. We have also argued here that lived health leads to a better design perspective on personal health systems, one that places the design firmly in the social and incorporates how people actually view their health.

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