

Personal Health Information Management

Integrating personal health information helps people manage their lives and actively participate in their own health care.

Personal information management (PIM) pervades every aspect of our lives, including health care. As users of the health care system, we rely on our ability to manage information to combat illness and stay healthy. When seeking help for a health-related problem or question, we navigate a complex system where health services are distributed across multiple clinicians in a variety of specializations and institutions. Within the system, efforts to reduce costs have limited the time clinicians are able to spend with patients. Consequently, patients must prepare themselves in advance of

consultations, communicate effectively with clinicians about unfamiliar health information, and organize and store information gleaned from the consultation for future use. Moreover, many health-care services are now delivered in outpatient settings, where patients receive care, then return home. During such care, patients assume significant responsibility for monitoring their own health status, managing their recovery, and communicating with clinicians from home. This increasingly distributed system of specialized, mainly outpatient, health care places new demands on patients. They are expected to participate proactively, regularly coordinating their care among multiple providers, interacting with health information outside the medical center or clinic, and sharing health information with others in their personal and professional lives (see Figure 1).

This central role means patients must store, maintain, and retrieve many kinds of personal health information, ranging from medication schedules to information researched online about their conditions, to referrals, to contact information for individual clinicians. It also takes a variety of forms, including phone calls, email, paper documents, and Web pages (see Figure 2). Over time, patients accumulate an overwhelming amount of this information, which is inextricably intertwined with their personal and professional lives—and need support to manage it.

Effective management of information is particularly challenging for patients facing conditions (such as cancer) requiring extended outpatient care. For cancer patients, a primary intervention (such as surgery) is generally followed by therapy (such as radiation, chemotherapy, or hormone therapy) that can last additional weeks, months, or years. As a result, they must stay on top of changing treatment regimens while trying to maintain their routine at work and at home. Cancer patients face a variety of decisions concerning their care: How radical must the surgery be? What kind of follow-up treatments should I choose? Will I be able to continue working full time? The

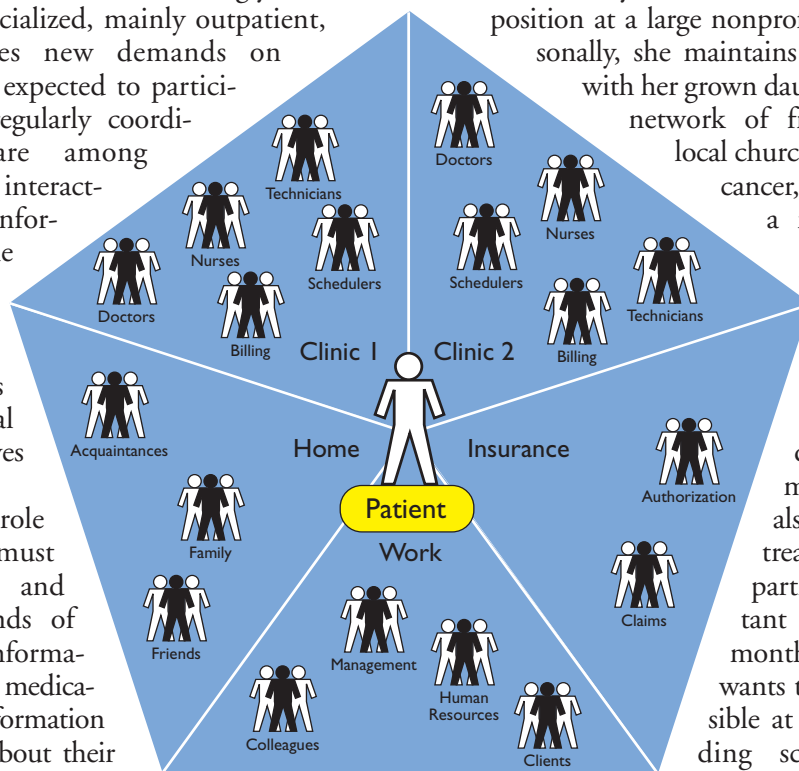
answers often have lifelong impact while influencing the quality of their care.

The scientific complexity of medical treatment and the logistical complexity of insurance procedures, employee benefits, and clinical procedures further challenge patients' ability to manage this information. These demands also impede their ability to participate in their health care. Reflecting the kinds of challenges patients face, consider the following scenario:

Professionally, Irene holds a middle-management position at a large nonprofit organization. Personally, she maintains a close relationship with her grown daughter and has a large network of friends through her local church. She also has breast cancer, recently underwent a mastectomy, and is about to start chemotherapy.

Trying to coordinate her treatment plan with her friend who will drive her to her treatment sessions, she also wants to time the treatments so she can participate in an important work meeting next month. In addition, she wants to feel as well as possible at her daughter's wedding scheduled in three months. These personal and professional constraints indicate Irene must be able to share scheduling information with others and integrate treatment plans into her

Figure 1. Spheres of influence on personal health information management.



personal and professional calendars.

For treatment, she wants the chemotherapy at the regional cancer care center, 50 miles from her home, but plans to have much of her health status monitoring done through her local primary care doctor's office. Thus, she also needs to integrate, track, and share her health information across multiple health-care institutions. Soon she will also need to decide about additional therapies (such as hormone therapy or radiation therapy) when she completes her chemotherapy.

She has been researching her treatment options, trying to understand the implications of her decisions, so she can make the best choice. At the same time, she spends considerable time communicating with her insurance company to determine the extent

of her coverage, ensuring that her treatment choices receive proper authorization, and interpreting the bills as they arrive. All these activities must be accomplished while Irene copes with the fear, fatigue, and nausea associated with her diagnosis and treatment.

This scenario highlights a number of personal health information management (PHIM) challenges, including:

Integrating personal, professional, and health-related information. Such information is often scattered on multiple devices and stored in diverse formats. Patients, like Irene, gather and keep track of it from many sources and in many different forms, including Web pages, appointments, prescriptions, contacts, notes, and email. They need ways to integrate it all; for example, Irene needs to integrate scheduling information about her upcoming chemotherapy treatments with her work calendar and upcoming wedding plans, coordinate her care between regional and local health care centers, as well as reconcile her medical bills and medical insurance information. An integrated view would help her see it all comprehensively.

Using integrated information to make health-related decisions. Patients often face an overwhelming volume of fragmented information, making it difficult for them to gain a proper overview and understand its relevance and implications for their many health-related decisions. Tools that highlight the multiple contexts of personal health information could facilitate different understandings of the same information. These tools might allow patients to group together related information to support specific decisions. Irene needs to pull together the information she has collected about her treatment options to understand the trade-offs of her various choices in terms of treatment success rates, severity of side effects, costs, and insurance coverage. She needs to integrate Web information with information she's received from her oncologist with information she learned from other patients in order to understand

the complexity behind the decisions she must make.

Sharing information with individuals from social, professional, and health-care networks while maintaining personal privacy. Patients must balance their desire to share information with others and the effort required to share it. They also must be able to control how and what information is shared and with whom. For example, one day, while Irene is at work in her cubicle, the clinic calls to report her latest blood test results and reschedule a chemotherapy appointment. Although her colleagues at work do not know about her cancer diagnosis, she decides to have the conversation where her colleagues might overhear her, rather than risk playing phone tag with the nurse. In response to these results, the nurse reschedules Irene's next appointment for an earlier date. Irene adds the new appointment to her personal calendar, then makes a note to tell both her supervisor and the friend who will drive her to the appointment. As she goes to her next work meeting, she remembers that she must also notify her local primary care doctor about the results of the blood test.

Like many patients, Irene needs help to share information selectively with the people in her life. For example, she wants her friend to know what her appointment is for and what to expect during the appointment; meanwhile, she wants to notify her supervisor only that she will be out of the office at a particular time.

Patients need tools that address these challenges and enable them to be involved in their health care, as well as to meet the responsibilities of their daily lives. For cancer patients, studies have shown that patients who effectively manage their personal health information are able to use the information to adjust to the stresses and responsibilities associated with their cancer experience [3]. Participation in one's own health care is also associated with favorable health outcomes and decreased demand for health services [10]. Conversely, patients who cannot access and use personal health information are more likely to experience poor adjustment to their situations [2] and less participation in care [7]. Regardless of whether they are battling cancer or some other condition, patients'

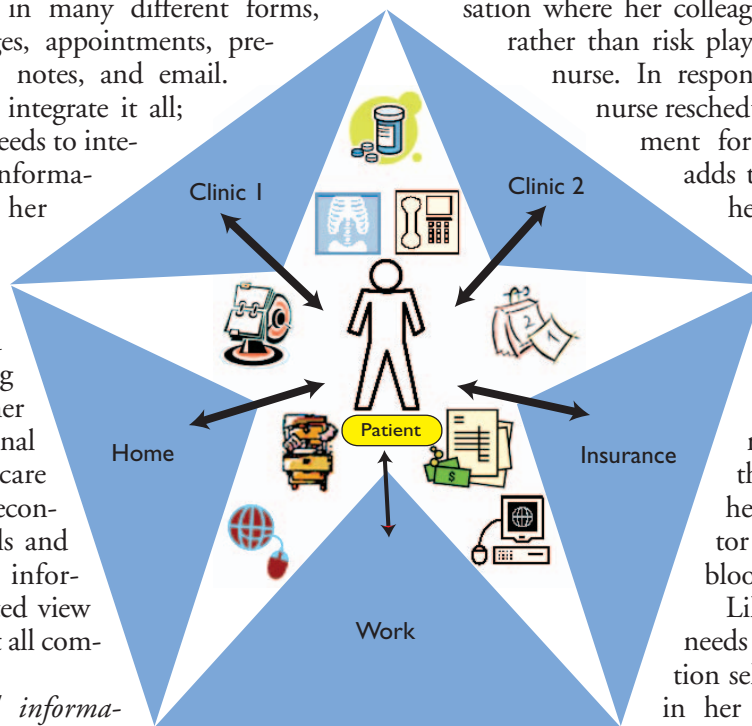


Figure 2. Fragmentation of content and diversity of form complicate patients' information management.

management of their personal health information requires significant time and effort, even as the impact of the condition can reduce the amount of time and energy they contribute toward these activities as they go about their daily lives.

A number of technologies enhance patients' ability to participate. For example, personal health records (PHR) reflect a range of tools that provide patients with a record of their health histories. Such tools include Web-based interfaces that grant them secure Internet access to portions of their electronic medical records maintained and owned by their health-care provider organizations and standalone tools patients use to create and maintain their own medical records. Information in PHRs tends to correspond to health status information in a clinician's patient records (such as health condition, medications, vaccinations, allergies, visit history, and provider communications). For patients with access to a PHR through their health-care organizations, studies have found benefits in both patient satisfaction [11] and patient understanding of their conditions [6].

Irene, for example, has access to her medical records from the regional cancer care center through a PHR that allows her to see notes from its specialists, along with lab reports. In contrast, her local doctor gives her paper copies of lab reports at her request. Irene is responsible for integrating both sets of information to understand the larger picture of her situation and coordinate her care between the two centers. In addition, she must coordinate a comprehensive view of her health information with the personal information she manages among a disparate set of PIM tools (such as calendar systems and email).

Closely related to PHRs are home health management technologies that support patients dealing with diabetes, asthma, post-surgery pain, weight, and other health-related activities, as well as referral management. However, patients often have difficulty using them within the contexts of their daily lives [1]. In particular, the systems focus narrowly on specific aspects of a patient's health without providing the means for smoothly coordinating other related health and personal information. Systems are needed to integrate with other health-specific and PIM tools patients use, though little is known about people's PHIM needs and how using these tools might affect them.

Our research group at the University of Washington is taking the necessary first step of studying the PHIM needs of breast cancer patients. In a recent initial study, we followed seven of them for 12 weeks during their treatment. Following an initial in-depth interview with each of them, we conducted short interviews (two per week per participant) focusing on

their information management activities. We concluded that they needed to integrate personal and health information into a coherent view of their daily lives. They did not, for example, draw distinctions between their personal lives, including at home and at work, and their lives as patients.

Our findings are consistent with the results from general studies of people's personal information management needs:

- Information is fragmented by location, device, form (such as paper, email, e-documents, Web references, and notes), and associated organizations. People complain and experience problems with the many different information organizations they must maintain in parallel [4, 9];
- Encountering useful information, people may not know how and where to keep it or even whether it is necessary to do so [5];
- People often forget to use or cannot find information, even when they have stored it for later use [5];
- People can become overwhelmed by available information, possibly because of its jargon, organization, or overall volume, and experience degradation in the quality of their personal decision making [8]; and
- People's approaches to PIM, which vary greatly across a variety of information forms, need the kind of support that accommodates this variation [4].

Our studies of breast cancer patients also revealed a need for additional information management beyond that found in general PIM studies. In particular, they expressed the desire to share aspects of their personal (as well as health) information with others and frustration at their limited ability to manage the related information exchanges. They routinely made trade-offs between the efficacy of immediate communication about private health information in a public setting and their desire to maintain their personal privacy; for example, they needed to talk to their insurance companies to obtain authorization for special services or with their clinicians to obtain test results or schedule appointments. However, these communications usually could occur only by phone, during working hours while they were in semipublic work settings (such as cubicles). They emphasized the importance of, and frustration with, detailing their interactions with clinicians, tracking unaddressed health issues, and maintaining a running list of questions and concerns.

These patients dedicated valuable time and energy, sometimes to the point of exhaustion, to sharing

information with family, friends, and colleagues. Some employed a broadcast strategy (such as email lists) to minimize the effort of distributing information broadly to their social networks. Unfortunately, those using this strategy could not moderate the information exchange for different relationships within their social networks. Others adopted more personalized communication strategies (such as phone calls and individual email) to customize and filter information exchange with different people.

Those using them enjoyed more privacy by maintaining control over information exchange but confronted two imposing barriers: First, during periods of change in their health situations, most could not meet the demands of their social networks for customized information. Second, the strategies were not scalable to large social networks. The patients struggled with the trade-off between sharing information broadly vs. maintaining privacy by spending more time tailoring information to each person.

In addition, they had to organize and view their information within the context of their health situations in ways that went beyond the support of generic PIM tools. For example, a common method they used to organize their information was by phase of care, grouping their cancer experience around where they were in the treatment process (such as surgery, chemotherapy, radiation, or hormonal therapy). Similarly, they organized information by prominent events that will or that have already occurred during their treatment; the most common were consultations, treatment episodes, and personal events with implications for their cancer care.

They were frustrated by their inability to manage it all, particularly because they received important information in multiple settings (such as at work, at home, and at the treatment center) and through a variety of communication modalities (such as in person, on the phone, via email, and on paper). The difficulty they reported is troubling, given the importance of these activities to their clinical care. In particular, for a few of them who could effectively share information with clinicians, we documented instances where they detected or prevented medical errors from occurring during that care [12]. But without tools to facilitate such information management and sharing, many might miss their own error-prevention opportunities.

CONCLUSION

Our work provides an early glimpse into the PHIM activities of breast cancer patients. Additional studies and more descriptive models could be useful to patient-care coordinators, health care providers, and software developers; the models might also help devel-

opers create tools to support patients' PHIM work. Ultimately, systems that support PHIM will bring us closer to the goal of helping all patients be informed, active participants, increasing the quality of their own care without disregarding important aspects of their personal and professional lives. **C**

REFERENCES

1. Anhoj, J. and Nielsen, L. Quantitative and qualitative usage data of an Internet-based asthma monitoring tool. *Journal of Medical Internet Research* 6, 3 (Sept. 3, 2004); www.jmir.org/2004/3/e23/.
2. Arora, N., Johnson, P., Gustafson, D., McTavish, F., Hawkins, R., and Pingree, S. Barriers to information access, perceived health competence, and psychosocial health outcomes: Test of a mediation model in a breast cancer sample. *Patient Education and Counseling* 47, 1 (May 2002), 37–46.
3. Auerbach, S. Should patients have control over their own health care? Empirical evidence and research issues. *Annals of Behavioral Medicine* 22, 3 (Summer 2000), 246–259.
4. Boardman, R. and Sasse, M. Stuff goes into the computer and doesn't come out: A cross-tool study of personal information management. In *Proceedings of the ACM SIGCHI Conference on Human Factors in Computing Systems* (Vienna, Austria, Apr. 24–29). ACM Press, New York, 2004, 583–590.
5. Bruce, H., Jones, W., and Dumais, S. Information behavior that keeps found things found. *Information Research: An International Electronic Journal* 10, 1 (Oct. 2004); informationr.net/14/10-1/paper207.html.
6. Cimino, J., Patel, V., and Kushniruk, A. The patient clinical information system (PatCIS): Technical solutions for and experience with giving patients access to their electronic medical records. *International Journal of Medical Informatics* 68, 1–3 (Dec. 18, 2002), 113–127.
7. Hack, T., Degner, L., and Dyck, D. Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science & Medicine* 39, 2 (July 1994), 279–289.
8. Hutchins, E. *Cognition in the Wild*. MIT Press, Cambridge, MA, 1994.
9. Jones, W., Dumais, S., and Bruce, H. Once found, what then? A study of 'keeping' behaviors in the personal use of Web information. In the 65th Annual Meeting of the American Society for Information Science and Technology (ASIST 2002) (Philadelphia, PA, Nov.). American Society for Information Science & Technology, 2002, 391–402.
10. Laine, C. and Davidoff, F. Patient-centered medicine: A professional evolution. *Journal of the American Medical Association* 275, 2 (Jan. 10, 1996), 152–156.
11. Tang, P., Black, W., Buchanan, J., Young, C., Hooper, D., Lane, S., Love, B., Mitchell, C., Smith, N., and Turnbull, J. PAMFOnline: Integrating EHealth with an electronic medical record system. In *Proceedings of the American Medical Informatics Association Annual Symposium* (Washington, D.C., Nov. 8–12, 2003), 649–653.
12. Unruh, K. and Pratt, W. Patients as actors: The patient's role in detecting, preventing, and recovering from medical errors. *International Journal of Medical Informatics* (in press).

WANDA PRATT (wpratt@u.washington.edu) is an associate professor in both Biomedical and Health Informatics in the Information School and chairs the Ph.D. Program in Information Science at the University of Washington, Seattle, WA.

KENTON UNRUH (ktunruh@u.washington.edu) is a Ph.D. Candidate in information science and a National Library of Medicine Research Fellow in Biomedical and Health Informatics at the University of Washington, Seattle, WA.

ANDREA CIVAN (andrea@u.washington.edu) is a Ph.D. student in Biomedical and Health Informatics and a National Library of Medicine Research Fellow at the University of Washington, Seattle.

MEREDITH SKEELS (mkskeels@u.washington.edu) is a Ph.D. student in Biomedical and Health Informatics and a National Library of Medicine Research Fellow at the University of Washington, Seattle, WA.