

Insights for Internists: “I Want the Computer to Know Who I Am”

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BACKGROUND: In designing electronic personal health records (PHRs) and related health technologies, lay perspectives are rarely solicited, and we know little about what individuals want and need.

OBJECTIVE: To learn how diverse, primarily lay individuals envision how PHRs and other emerging and future electronic technologies could enhance their care.

DESIGN: Qualitative study of eight focus groups with adult consumers, patients, and health professionals.

PARTICIPANTS: Eighty-two adult frequent Internet users who expressed interest in health-related matters and represented diverse populations and a broad demographic range.

MEASUREMENTS: Focus group transcripts were analyzed qualitatively, using behavioral and grounded theory, employing an immersion/crystallization approach.

MAIN RESULTS: Individuals expect technology to transform their interactions with the health-care system. Participants want computers to bring them customized health information and advice: “*I want the computer to know who I am.*” They desire unfettered access to their health record: “*I don’t know if I want to read [my entire record], but I want to have it.*” They expect home monitors and other technologies will communicate with clinicians, increasing efficiency and quality of life for patients and providers. Finally, especially for the chronically and acutely ill, privacy is of far less concern to patients than to health professionals.

CONCLUSIONS: Focus group participants have dynamic ideas about how information and related technologies could improve personal health management. Their perspectives, largely absent from the medical literature, provide insights that health professionals may lack. Including a diverse array of individuals throughout the process of designing new technologies will strengthen and shape their evolution.

KEY WORDS: health information technology; patient preferences; personal health records.

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New health technologies offer patients online access to parts of electronic medical records (EMRs), options for maintaining their personal histories, and support for day-to-day management of chronic illness.^{1–8} These technologies foster patients’ engagement in their care, and consumers are increasingly expecting to turn to online health tools, just as they use the Internet in other areas of their lives. Patients want to e-mail clinicians and make appointments online, use home monitoring devices to avoid office visits, access their medical records, and maintain personal health records (PHRs). And, as they make decisions about their health, they hope for online information sources they can trust.^{9–14}

When it comes to the future design and utility of these and other elements of care, teams of software engineers, graphic artists and clinicians rarely solicit patient perspectives. The patient’s view is important, both because we want our health-care system to be as patient-centered as possible and because patients have broad and deep experience with technology in other sectors of their lives. Nevertheless, we know little about how they envision the future role of technology in care.

How do patients envision a technology-enabled health-care system? How do they think PHRs and other technologies could change how they interact with clinicians? Hoping to gain new ideas about future practice and to develop hypotheses worthy of further inquiry, we conducted a series of focus groups in widespread areas of the US, seeking insights from diverse patients, and including health professionals in some of the groups.

METHODS

We conducted eight facilitated focus groups (six with consumers and two with professionals, total N=82) from November 2006–January 2007. The overarching purpose was to gain insights from group inquiry into how future technologies might help with information and functionality that diverse consumers and health professionals will need to improve the management of health and illness. In that context, we asked the participants to address issues ranging from health-related decisions made during a normal day to help in interacting with the myriad components of the US health-care system.

A professional facilitator experienced in health care and in working with disadvantaged populations led five of the eight groups, and one of the authors (TD) led three groups. The research team developed a discussion guide with input from the facilitator. We audiotaped and transcribed each group session. The Institutional Review Board (IRB) of Beth Israel Deaconess Medical Center approved a protocol for protection of human subjects, and we presented all participants with the

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approved informed consent document and encouraged them to ask questions about the study prior to signing consent. At the end of each group discussion, we paid participants \$75-\$200, depending on local norms. Some professionals waived the honorarium.

Screening and Recruiting. We chose four cities: Boston, MA; Portland, ME; Tampa, FL; and Denver, CO, selected because they were geographically dispersed, offered the investigators access to individuals from urban and rural locations, had considerable ethnic and cultural diversity, and were accessible to the primary focus group contractor.

Drawing from a diverse population of healthy and chronically ill adults, we established eight focus groups. We sought relative homogeneity within groups (e.g., individuals with chronic illness, healthy individuals, technologically savvy college students, and caregivers), establishing each group essentially as an “n of one,” while seeking heterogeneity across groups. The six consumer focus groups collectively were constituted to include diversity of income, ethnicity, race, age, geography, and urban/rural/suburban settings.

A telephone questionnaire (available from the first author) collected demographic information and assessed consumers’ suitability for a group. We targeted consumers who were concerned about health matters, were less than completely satisfied with services and information currently available to manage their health, and used the Internet at least once a week for at least four different transaction types (e.g., banking, e-mail, and travel reservations). The interview included an open-ended question designed to help identify participants who would engage actively in conversation (“If you could invite anyone to dinner, whether living, dead, or imaginary, who would it be, and what would you talk about?”). To ensure diversity, each group had additional criteria related to age, geography, health status, ethnicity, and/or education (Table 1). In four groups, a criterion was the presence of chronic illness, and participants self-identified one or more conditions on a list of 31 chronic diseases compiled by the investigators.

Consumer candidates were identified through local phone listings, responses to IRB-approved recruitment brochures, and contractors’ databases that contain names of people known to the company from previous recruitment efforts. Our goal was to recruit half men and half women. All consumer groups were held at focus group facilities.

We assembled two groups of health-care professionals from different areas of the country (Boston and Denver) to elicit their perspectives on the role of health information technology (HIT)

and to compare those opinions with the consumers’ perspectives. We believed the views of the professionals could provide a useful reference for unanticipated consumer ideas. These participants were drawn from the investigators’ professional networks; we targeted general internists, nurses, social scientists, and entrepreneurs with strong interest in HIT. These groups were held at a Boston medical center conference room and in a Denver hotel meeting room convenient for the participants.

Discussion Guide. We developed a discussion guide (available from first author) with three parts, addressing: how participants *currently* organize (for clinicians, how they believe their patients organize) the information they need to manage their health and care; how they would *ideally* manage and use such information; how technologies could address gaps. We asked our groups to identify generalizable principles not limited to disease-specific needs and used concept phrases to stimulate discussion, such as “being able to offer corrections to your medical record,” and “being able to chat online with a doctor or nurse whenever you need to.” We used well-tested querying techniques, e.g., “how to...” and “I wish...” to tap into participants’ creativity. We used a modified nominal group technique to encourage all to contribute, but we did not ask group members to vote or reach consensus. We discussed technology in lay functional terms in the consumer groups, rather than using technical names (e.g., “your own electronic medical record with information from your records at doctors’ offices and hospitals, plus information added by you,” rather than “personal health record”). For the professional groups, we did not define the different technology resources. However, we generally adhered to definitions presented in the taxonomy recommended by the National Alliance for Health Information Technology.¹⁵ We performed member checks in the course of discussion, but did not return conclusions to the groups for verification afterwards. At least one of the investigators observed each group.

Qualitative Analysis. We employed an iterative process based on grounded theory to guide the overall evaluation and interpretation of the qualitative data. At the end of each focus group, the facilitator and investigators noted their impressions of significant messages emerging from the group. Next, the audiotapes were transcribed by a well-established transcription company and checked for accuracy by one of the investigators observing the group. We analyzed the ethnographic data with the help of NVivo software, in conjunction with iterative rounds of analysis using immersion-crystallization techniques.^{16,17}

Table 1. Criteria for Recruiting Consumers into Six Focus Groups

Group	City, area	Age	Other
Consumers with chronic illness (n=12)	Boston urban	40–65	African-American or Hispanic. Education high school or less
Healthy consumers (n=11)	Portland, Maine rural	18–40	
Consumers with chronic illness that makes breathing difficult (n=9)	Tampa suburban	50–75	Participants native to Tampa
Caregivers of chronically ill parents, spouse, or children (n=9)	Tampa urban, suburban	25–50	African-American or Caucasian. Participants native to Tampa
Consumers with chronic illness (n=12)	Denver urban	18–65	Hispanic or Caucasian
Young consumers (n=11)	Boston urban	18–25	College students, undergraduate or graduate

Immersion-crystallization is a process requiring “prolonged immersion into and experience of the text and then emerging, after reflection, with an intuitive crystallization of the text.”¹⁸

Next, the four investigators independently printed and reviewed the audio-recorded transcript of each focus group for overall comprehension and to identify coding categories. Each investigator formed categories separately. We then met on several occasions to construct an overall structure of categories to code. In those meetings, we listened to selective portions of audio-taped recordings to clarify questions and/or differences of opinion among authors about key points/themes. To support key themes, as a group we used key word search and text review to identify and document specific quotes and references in the transcripts.

Collectively, the team then developed a codebook to represent significant categories of data (e.g., access vs privacy of personal health records). One of the investigators (LL) then used the codebook to review the transcripts in their entirety. In this study, the coding process was not the end result of analysis. Rather, using an anthropological approach, the codes were categorical place-finders, facilitating the next step in data analysis.

After text review and coding decisions, the team incorporated the coded texts into immersion-crystallization data analysis sessions. Over the course of five group meetings, the team read and discussed the transcripts and coded reports to identify significant categories, themes, and meta-themes arising from the data. We then moved toward developing interpretations of the data, which led to searches through the data set for alternative interpretations before we made final decisions about how to report and discuss the findings.

RESULTS

Participants. Across the six consumer groups, the size of the populations screened ranged from 165 (college student group) to 321 (caregiver group), with an average of 250.2 (SD=56.4). Each group had 9–12 participants; characteristics of the 64 consumers who participated are shown in Table 2.

The professional groups consisted of five general internists, five scientists involved with HIT or home technologies, three nurses, and five participants from public agencies, education, and industry. Nine were men, and nine were women; we did not collect other demographic information.

Participants raised several themes concordant with earlier survey findings: they wanted, for example, to use the Internet to communicate with their providers, to streamline administrative tasks, and to gain information that guides decisions. In addition to such anticipated themes, the participants identified several provocative consumer needs and attitudes toward PHRs and related technologies that are not prominent in the lay and professional literature. We present them in random order:

1. Patients want full access to their provider-based records.

“I don’t know if I want to read [my entire medical record], but I want to have it” (Portland consumer).

In all groups, participants expressed interest in having access to all parts of their provider-based records. They most often specified notes from recent visits. Some wanted copies;

Table 2. Characteristics of 64 Consumers in Six Focus Groups

Gender	
Female	37
Male	27
Average age (SD)	39.9 (4.8) years
Range	18–73 years
Ethnicity	
African American	15
Asian	2
Caucasian	33
Hispanic/Latino	10
Mixed/other	4
Education	
High school or less	17
At least some college	43
Post graduate	4
Internet use	
Daily	46
At least two times per week	16
Few times per month	2

some wanted to write accompanying notes; some wanted to update notes later with the results of treatment; some simply wanted to read what the doctor had written. They also wanted access to test results, medication lists, vaccination records, and billing information accompanied by explanations. Some wanted paper copies of their records, and though a large majority was aware of having legal rights to records, they spoke repeatedly of the “legwork” necessary to get them. A Denver consumer wished for “a standardized computer program where you can check all your records.” While the health professionals agreed generally with the drive toward more transparency, several were hesitant about having patients read the doctor’s visit notes, citing lack of comprehension, possible litigation, and demands on providers’ time.

Except for the college student group, most of these health-conscious consumers indicated they keep records now. Virtually all have some sort of paper system, and some use computers. For the most part, they keep copies of test results and medication information. Many with chronic disease have created their own summaries of their health histories, medications, and physicians’ names; several pulled papers from their pockets and wallets to show one another. Others kept diaries, appointment notes, and lists of questions for the next visit. They considered these documents important, making office visits more productive and, in addition, less prone to error [“doctors and pharmacists make mistakes” (Boston consumer)]. In four of the groups, conversation turned rapidly to various aspects of provider overwork and the need to remind overwhelmed clinicians of pertinent information. As one Tampa consumer put it, “You have to catch the bull by the horns and manage your own care ... doctors simply don’t have time any more ... you have to be proactive.”

2. Patients may value privacy far more when well than when sick.

“If you’re very healthy and you don’t worry about health care very much, you worry about privacy. If you’re pretty sick, you don’t worry about privacy” (Denver professional).

Participants recognized that if they can access their records online, others can too. Every group discussed the privacy and

security of “that information out there in cyberspace” (Tampa caregiver). However, discussion focused far more on the benefits of remotely available records than on concerns over privacy, worries that appeared to fade rapidly in the face of the desire to have records fully available in emergency settings and with multiple and new providers. Given these phenomena, we were not surprised to find that those who were healthy talked about privacy more than did those with chronic illness. Strikingly, the health professionals expressed far more concern about maintaining privacy than did patients.

3. Patients expect computers to foster far more self-care in the future.

“I’d like to be able to treat myself without running to the doctor all the time” (Tampa consumer).

All eight groups entered into animated discussions about self diagnosis and treatment. Some focused on futuristic gadgets, such as in-home scanners, finger sensors, and easy-to-use diagnostic devices that the Boston consumer group felt should be named “iDrug” and “iDiagnose.” The bulk of discussion concerned using the computer to diagnose and manage common recurring conditions. Moving beyond generic disease management algorithms, both consumers and professionals envisioned presenting the computer with a new symptom and then receiving suggestions derived from matching histories, symptoms, and signs both with relevant, unbiased, and scientifically sound online resources, and with the user’s unique medical record.

Participants wanted the computer to provide diagnoses and therapies, including prescriptions for medications. In “unusual” circumstances when the computer suggested referral to a doctor or nurse, many were happy to have an unknown clinician advise them, helped by drawing on the individual’s “personal” computer as a source of data unique to him or her. On the other hand, many participants urged limiting self-care to “small” conditions. One consumer noted, “the machine is essentially just like a filtering machine for the doctors, and so the doctors get less sick patients and more serious cases” (Boston college student). There was widespread sentiment that the power of the individual doctor-patient relationship should center on those with chronic illness.

Participants believed that technologies will enable self-care that will avoid treatment delays, save money, and preserve clinician time for complex care. “The computer should be there to help you and replace part of the doctor” (Boston college student). In the future, some consumers imagined they would no longer need a doctor or nurse when managing much of health and illness. Few voiced downsides, though a Denver professional suggested that society would have to “allow people to make bad decisions.”

4. Patients expect new technologies will watch over them.

“You could have a chip in your arm that was constantly monitoring ... your cholesterol is really high—what the hell is going on?” (Boston college student).

Both professionals and consumers were intrigued by the idea of monitoring via portable devices worn on the person or implanted in the body. Most often, they described scenarios involving chronic illness, where devices collected physiologic measures such as heart rate, oxygen levels, blood pressure,

and blood glucose, and broadcast the information to patients, family, providers, or emergency services. “... (the) glucometer is built into the cell phone. And then the test results are flashed on your cell phone, and then it’s wirelessly sent to the central server and to your doctor so that you can be monitored over the long term with all of this consistent data” (Boston college student).

Participants envisioned a “smart home” that monitors air quality and detects falls and other events. Considerable discussion focused on the use of monitoring devices in healthy people for emergency identification. Others imagined data from biometric sensors that advise their computers to encourage them to exercise for 10 more minutes, to forego dessert, or to take a variety of specific actions. “There’s a device that I can lay my finger on and it will tell me, John, you need to take the medicine that’s in the cabinet” (Boston professional).

Questions were raised about privacy in discussions about monitoring, with most participants stating that it should be “voluntary,” or “a personal choice.” Similarly, they felt privacy should be maintained in controlling access to information generated by such devices. However, others suggested they would be willing to share monitoring data anonymously with researchers.

5. Patients envision a truly personal computer.

“I want the computer to know who I am” (Boston consumer).

Consumers wanted computers to “understand” who they are and to bring them customized health information and advice. This theme surfaced often as participants described their worries about sifting through content from Internet searches. They were frustrated with trying to find information relevant specifically to them and with their efforts to determine which information to trust. “You have to decipher if someone is trying to sell you something” (Tampa consumer). Several imagined their computers “knowing” enough about their medical conditions to act not only as an information filter, but also to notify them of new treatments, important studies, or simply that their medical supplies are on sale at the local pharmacy. Further, they anticipated that future information would be presented in comprehensible ways because the computer would “know” each user’s literacy level and personal preference for receiving information.

Consumers spoke also of knowledgeable computers and devices as personal “coaches.” They described sophisticated advisors that could incorporate the individual’s family history and medical profile into coaching about diet, exercise, and other daily health behaviors, as well as reminders about preventive care. One Boston student wanted the computer to offer weight loss options based on lifestyle and family history. A Portland consumer expected her coach to tell her, “Your mother had breast cancer, and you are over 40 ... you should have a mammogram.”

DISCUSSION

Our findings suggest that consumers and health professionals from widely different walks of life share concrete and congruent ideas about how information technologies will help patients become more proactive in managing health and

illness. Consumers anticipate full access to their medical records, and they expect that information and biomedical technologies will integrate to enable them to monitor and treat themselves. All agree that most clinicians are stretched too thin and expect technologies to substitute for some personal services in the future. Consumers are surprisingly open to implantable devices, and they view computers as becoming personal partners, enabling individuals to take responsibility for health maintenance and minor illness. Finally, privacy takes second place to rapid access and communication, particularly for those acutely or chronically ill.

Consumers were widely aware of stresses affecting today's clinicians. Perhaps because this was not a stated focus of the discussion, they rarely lamented loss of relationships with their clinicians, but they were keenly interested in finding ways to optimize clinicians' services. Many described strategies for improving the efficiency of communications with providers. They would like to prepare for appointments by forwarding their past medical history and current health questions to the clinician before the visit. They expect to research the Internet ahead of time, to batch questions, and to correct misinformation in their records. They see PHRs as the prime mechanism for such communication, viewing them as overlapping with EMRs.

Consumers in our focus groups also want PHRs to integrate their personal health information and preferences with the Internet, enabling them to find information targeted to their unique needs and presented in formats matching each user's literacy level and preference for graphics or text. They spoke time after time of having the computer know enough about them to filter out irrelevant or suspect information from the Internet, suggesting that the inability to sort through infinite information effectively is a major obstacle that prevents patients from becoming more proactive in their care.

We expected to hear a lot about privacy, given ongoing reports in the media about unintended disclosures of health and other information.^{19,20} Consumers do indeed want their information secure, but they also want it readily available for managing chronic illness and in emergencies. Not once did they qualify such discussion with worries about privacy, including the potential release of personal health information. This view may reflect the availability and growing numbers of secure online transactions in all aspects of daily life.

If one assembles and generalizes from all the ideas we heard, consumers in highly industrialized societies will soon have complete and comprehensible electronic records of their care, including test results and physicians' notes. They will seek and receive coaching via the Internet that draws on their own data, will have rapid access to health professionals for advice, and will be connected to communities of individuals with similar health issues. Personalized computers will present information about new drugs, treatments, and clinical trials targeted to each patient's medical conditions and will also identify "opportunities," such as traveling to another state or country for a surgical procedure. Patients may also become comfortable working with doctors who are "virtual physicians," advising patients not known to them via telemedicine, phone, or email. The PHR will be the logical integrator and hub of such a patient-centered universe.

What might all this mean for clinicians, who today often feel harried and undervalued? As e-mail and virtual visits become routine, physicians will spend less time with the well, while monitoring fragile patients in near real time in their homes.

Monitoring devices will produce data streams that clinicians will need to interpret. Physicians will field questions not only about medications bombarding patients on television, but they will also need to address new developments pushed to individuals by their computers. Medical records, including physician notes, will move beyond institutional and physician control to become shared documents, with both patients and clinicians contributing to their final form. Such records, perhaps accompanied by audio or video documentation, may fundamentally reshape patient-clinician relationships. Whether this will improve or further burden the life of the primary care clinician is an open question, one that will need careful, ongoing analysis.

As a vivid reminder of the "flattening" of our world and the steadily narrowing digital divide, we were struck by the similarity of participants' views across race, ethnicity, education, and professional lines.²¹ Since the professionals who joined us expressed similar views, one might argue that professionals now engaged in creating PHRs and other applications can adequately represent consumers' desires for functionality. We are more inclined to conclude that including consumers in their design and development will hasten their realization and utility. Consumers can help us prioritize and fine tune features, reduce the number of dead-end ideas, and serve as engaged pilot testers. We enthusiastically recommend that they join in these processes.

Our study has several limitations. We conducted discussions with a modest number of individuals in only four locations and cannot claim they represent the views of all patients, consumers, or health professionals. In eight groups, we cannot be sure that we reached "saturation" in our search for insights and hypotheses. Indeed, it is likely that additional themes/issues would emerge with further studies. We chose to limit our participants to frequent Internet users who expressed interest in health matters. We did not talk with the sickest homebound patients, with solo practitioners far from the epicenters of health information technologies, or with countless others who doubtless have strong feelings about these topics. Following our focus groups with a large-scale, representative survey would help test and validate our findings, but our scope of work, timeframe, and budget precluded that valuable next step.

Despite these caveats, three hypotheses that evolved from our discussions have enormous implications for the general internist. First, particularly in the world of primary care, patients may be willing to do without a doctor, or to substitute a virtual encounter for a face-to-face visit, even when they could travel to the provider's office. Second, as the population ages and faces more illness, privacy of health information may be far less important than it is today. Finally, patients may demand full access to everything in their records, and many will carefully read and perhaps add to clinicians' notes. As patients and health professionals join in creating the future, both patients and those who care for them should put such hypotheses to the test.

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