

Final Report

Consumer Engagement in Developing Electronic Health Information Systems

Prepared for:

Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
540 Gaither Road
Rockville, MD 20850
www.ahrq.gov

Contract No: 233-02-0087

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HEALTH IT

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Executive Summary

With the passage of the American Recovery and Reinvestment Act of 2009, health care providers are likely to adopt health information technology (health IT) at an accelerating pace in the next several years. This expansion in health IT is widely expected to bring improvements in health care quality and efficiency, and possibly some new concerns, especially about privacy and security. Health care consumers may therefore want to have a role in determining how health IT is designed and used. The purpose of this project was to explore the views of health care consumers toward that role. The principal goals of the project were as follows:

- To gain in-depth understanding of health care consumers' awareness, beliefs, perceptions, and fears concerning health IT.
- To learn how consumers may wish to be engaged in the development of health IT, and at what point they should be engaged.
- To contribute to future AHRQ research initiatives with respect to consumers and health IT.

A total of 20 focus groups were conducted. Because the rate of health IT adoption varies across the country, four groups were conducted in each of five geographic regions of the United States: the Mid-Atlantic, the West, the Midwest, the South, and the Northeast. Most of the groups were homogeneous with regard to HMO membership or non-membership, and frequent or infrequent visits to health care providers. Some participants in several of the groups lacked health insurance. Four of the groups were conducted in Spanish. Two of the groups were held in rural, medically underserved areas. In this way, the groups were designed to study opinions from diverse segments of the U.S. population.

The focus groups were structured in a unique way, to accommodate the many participants who may not arrive with an understanding of the capabilities of health IT and its potential benefits and drawbacks. The first hour was in the form of a focus group, but its primary goal was to educate the participants about the issues surrounding health IT. The moderator presented the capabilities of health IT individually, and led the participants in a discussion of the capabilities and related issues from different perspectives. The participants were then knowledgeable about health IT for the second part of the focus group, in which they discussed the role of health care consumers in influencing the design and use of health IT.

Results of the focus groups suggest that participants were optimistic that health IT would benefit health care quality. They thought that computers may add efficiency to health care and reduce medical errors, such as those associated with illegible handwriting. However, some participants were concerned that health IT might make providers more impersonal, devoting more attention to the computer screen and less to the patient.

A large proportion of the participants initially thought that health care consumers should not help in determining how health IT was designed and used. They stated that health IT was the domain of experts in medicine and computers. They felt that health care consumers like themselves lacked the knowledge needed to have a role in health IT matters. However, upon

further discussion, the participants tended to feel that they needed to have a say about health IT in order to protect the privacy and security of their medical information.

Privacy and security were the main concerns of a large majority of the participants. A substantial proportion felt that health care consumers owned their data and needed a role in ensuring that those data were secure and used only in ways that they authorized. The participants were concerned that hackers or other individuals might gain inappropriate access to patient data. They were also concerned that their data might be shared with persons who want to use the data for their own purposes, rather than to provide care.

Many participants stated that they did not understand the processes by which any decisions were made concerning the design and use of health IT. For that reason, they expressed confusion about how health care consumers might influence those decisions. Some participants guessed that there existed some organization, like the American Medical Association, that made all these decisions.

The participants generally felt that health insurers should not play a dominant role in deciding how health IT will be designed and used. However, there was a great deal of disagreement about the role of government. Some felt that government should not concern itself with health IT at all, saying that market forces should guide those decisions. Others thought that elected officials and government agencies would protect the interests of health care consumers. Some thought that ballot initiatives or elections should be employed to set policies regarding health IT. Some thought that health care consumers could best become involved by writing their elected representatives. However, the participants seemed to be unfamiliar with the current involvement of state and Federal Governments with health IT.

The participants did not spontaneously mention the possibility that health care consumers could serve on advisory bodies for hospitals and providers, helping to set health IT guidelines. However, when the moderator mentioned that idea, many participants voiced their support. There was little agreement, however, about how consumer representatives should be selected.

The participants did not generally support the idea that consumers should work with health IT vendors to help design the technology. They reasoned that the vendors would attend to their customers, not to patients. Also, the participants mostly disagreed with the idea of letting organizations like AARP or the American Heart Association speak for them. The participants felt that these organizations did not necessarily represent their interests.

Some participants expressed the view that the government, health insurers, or others have already found a way to review medical records without patients' knowledge or consent. Some said that insurers have acquired so much political power that they can no longer be restrained from accessing patient data. Some thought that the government has the power to review medical records in the name of national security.

The participants did tend to support the idea that health care consumers should be asked for their consent before their medical data are stored electronically. Many participants felt that consumers should be able to elect to leave their data in paper format. The participants tended to

feel that each individual provider should ask each patient for permission to store the patient's data electronically and to share the data with other providers. Patients should be able grant permission to one provider but deny it to others, in the opinion of many in the focus groups. In this way, the participants felt that health IT restrictions should be set individually for each consumer, rather than by general rules applied to all consumers. The participants were divided on the issue of how electronically stored data could be used for medical research and for market research by pharmaceutical companies.

Results of the focus groups suggest that public education about health IT is needed. The education might address how health IT will affect the experiences of all health care consumers. It might also show the public how patients and consumers can have an influence on how health IT is designed, implemented and/or used.

These focus groups could serve as baseline representations of public opinion regarding health IT. Future focus groups could monitor how these opinions evolve as health IT is more widely adopted and the public gains greater experience with it. Public opinion will provide one important measure of the effects of the expansion of health IT adoption and use.

Introduction

A broad consensus has emerged supporting the universal adoption of health information technology (health IT) throughout the health care system in the United States. Nonetheless, the pace of adoption has been frustratingly slow. The recent passage of the American Recovery and Reinvestment Act of 2009 (P.L.111-5; described at www.recovery.gov), which allocates nearly \$20 billion to spur the adoption health IT,²⁷ is certain to change this situation quickly. New health IT systems are likely to be designed and marketed to meet the demand of growing numbers of providers.

Health IT is widely expected to play a major role in the transformation of the health care system in the United States, by enabling providers to deliver better quality care with greater efficiency. Health IT is also expected to enable patients to participate in their own care in ways that have been impossible with paper-based data management systems. At the same time, health IT may also raise new concerns about data privacy and other important issues.

Because health IT is likely to have such a major impact on their health care, consumers might reasonably insist on having a voice in determining how health IT products will be designed and used. The purpose of this project was to investigate how health care consumers believe that they should be involved in the design and deployment of health IT, to influence the effects of its expanding use.

Past Surveys

Much of the past research on consumers' views on health IT has employed surveys. The results of these surveys point to several general conclusions.

Knowledge About Health IT

Past surveys suggest that the public is not yet well-informed about health IT. In one survey,⁷ 57 percent of respondents thought that their physicians already used an electronic health record (EHR). In reality, less than half of that proportion of physicians actually use EHRs.¹¹ The public apparently overestimates the current prevalence of health IT usage.

The same survey found that only 43 percent of the respondents were aware of the ongoing effort to create a nationwide health information network. The results of several other surveys also suggest that the public has not always paid careful attention to developments in the field of health IT. A survey by Chhanabhai and Holt⁶ found that 63 percent of the respondents had never heard of EHRs. Another survey²⁰ revealed that few Americans knew about, or had any experience with, personal health records (PHRs). Still another survey, by *Medical News Today* in 2006,¹⁵ found that 70 percent of Americans were not aware of the goals of Executive Order 13335 calling for all Americans to have a personal electronic medical record by 2014.¹²

Overall Opinion Toward Health IT

Nonetheless, past surveys suggest that when Americans know about health IT, their opinion toward it is generally positive. For example, a recent survey² sponsored by a consortium headed by National Public Radio (NPR) found that 67 percent of Americans think that EHRs will improve health care quality in the United States. A survey by Accenture¹ found that 66 percent of the American public felt that the use of an EHR was at least a little bit important in their choice of physicians; 24 percent said it was very important. Also, 77 percent thought that they would have greater access and control over their health records when the records are stored electronically rather than on paper. Another survey¹⁹ found that respondents valued the ability of EHRs to provide information at a moment's notice. The respondents believed that in an emergency situation, an EHR could save critical time that would otherwise be wasted retrieving information on paper.

A survey by the Markle Foundation¹⁸ found that 72 percent of the respondents supported the creation of a nationwide health information network. Large majorities thought that the network would enhance the quality and efficiency of health care. Furthermore, a majority of respondents thought that an EHR would give physicians better access to patient data and enable them to find the optimum treatment quickly, improving the quality of health care while reducing costs.

The Markle Foundation survey also revealed strongly positive views toward personal health records (PHRs). Majorities reported that if they had access to a PHR that allowed them to check for errors in their medical records, refill prescriptions, and communicate with their physicians by e-mail, they would use these capabilities. Another survey⁹ found that the most appealing functions of the PHR were, in order of importance: patients' ability to e-mail their physicians, track immunizations, note mistakes in the medical record, and monitor test results. The Accenture survey¹ found that a majority of respondents thought that a PHR would provide them with access to medical information online to confirm diagnoses and to ask physicians better questions.

Privacy Concerns

Past surveys have confirmed that health care consumers' most important concerns about health IT revolve around the issues of privacy and security. In the NPR survey, 76 percent answered "yes" to the question of whether the transition to EHRs will increase the likelihood that unauthorized people will gain access to patients' medical records. A Harris Poll¹³ found that half of the respondents felt that they had lost control of how their medical data are used. This feeling was especially pervasive among people with chronic illnesses. The respondents overall were split roughly evenly about whether the privacy problems about EHRs outweighed the benefits of EHRs. Another survey²⁵ found that many Americans were so concerned about how their medical data would be used that they did not want their data ever to be stored electronically. Some feared that current or prospective employers would get access to their medical data and base unfavorable decisions upon what they found.

Control Issues

Surveys have suggested that health care consumers generally want some say in the way that EHRs are designed and used. A majority of respondents want to “own” their health data, and to decide what goes into and who has access to their medical records. With this kind of involvement, most consumers would be willing to support the transition from a paper-based system to electronic data management in health care.^{6,18}

Rationale for Studying Public Opinion Toward Health IT

If there were widespread and vocal public support for health IT, providers might be more inclined to invest in it. On the other hand, public suspicion about health IT might tend to dissuade providers from making that investment.

Currently, the public has not appeared to be clamoring for greater health IT use in health care. The support for health IT has not generally been “grassroots” support. A survey by the California Healthcare Foundation⁵ found that people would be more accepting of health IT if they understood the safeguards that protect the privacy of the data. The Harris Poll¹³ found that 70 percent of Americans agreed that physicians and hospitals currently do enough to safeguard the privacy of their medical data, and that 63 percent of Americans agreed that EHRs, if correctly designed, could protect the privacy of medical data. Nonetheless, another survey found that a majority of Americans felt that paper records were more secure than electronic records⁷.

With the passage of the American Recovery and Reinvestment Act of 2009,²⁷ policymakers need to understand the public’s current opinions about health IT. Prevailing opinions could help promote or hold back greater adoption of health IT.

Focus Groups as a Research Tool

This project went beyond the many surveys on health IT by employing focus groups, a powerful method for studying opinion. With focus groups, a moderator elicits the participants’ opinions, and encourages the participants to clarify the logic underpinning those opinions¹⁶.

Focus group methods differ from survey methods on a number of dimensions. While surveys usually present a series of questions in a structured way with unvarying wording, focus groups afford the moderator a good deal of leeway to probe and explore the issues that arise. The moderator’s guide provides the questions that the moderator should ask and the probes that the moderator should use to stimulate the discussion. The moderator’s role, however, is not merely to count the answers to the questions, but rather to explore the contrasting opinions that the participants express. The moderator attempts to foster interactions that stimulate the participants to express their memories, ideas, expectations, and opinions. Also, the moderator tries to gain insight into the manner in which the participants frame the issues that are under discussion.

Of course, focus groups do not use the sampling techniques and quantitative statistics that give surveys their scientific rigor. They are a qualitative research method enabling researchers to study opinions in depth.

Purpose of These Focus Groups

This project had the following goals:

- To gain in-depth understanding of health care consumers' awareness, beliefs, perceptions, and fears concerning health IT.
- To learn how consumers may wish to be engaged in the development of health IT, and at what point they should be engaged.
- To contribute to future AHRQ research initiatives with respect to consumers and health IT.

Research Methods

Focus Group Locations

There is some geographical variation with respect to the extent to which physicians have adopted health IT into their medical practices. For example, physicians in the West and Midwest are more likely than those in the South or Northeast to have adopted EHRs.²³ For that reason, focus groups were conducted in each of the five broad geographical regions of the United States defined by the Census Bureau. Four groups were conducted in each region, for a total of 20 groups, as follows:

- **Mid-Atlantic.** Three of these focus groups were conducted at Westat's headquarters in Rockville, Maryland. This area has a diverse range of ethnic and racial backgrounds and a moderate level of health maintenance organization (HMO) penetration. (Approximately 24 percent of Maryland's population is enrolled in an HMO.) One focus group was made up of HMO members, and one group consisted of non-members. The remaining group was mixed with regard to this characteristic. The area has an unusually high concentration of government employees and highly educated people. The number of federal workers and retirees and people with advanced degrees was limited to three participants per group. The fourth focus group for this region was conducted in New York City with Spanish-speaking people, most of whom reported in the screening interview that they were born in Puerto Rico. Both HMO members and non-members were included.
- **West.** These groups were held in Denver, Colorado. The Denver area has a large number of Mexican immigrants, and therefore two Spanish-language groups were conducted here. Colorado has a moderate level of HMO penetration (26 percent), so one of the English-language groups consisted entirely of HMO members.
- **Midwest.** Three groups were conducted in Columbus, Ohio, a medium-sized, racially diverse city. Ohio has a relatively low level of HMO penetration (15 percent), so one group specifically had only participants who were not insured by an HMO. In addition, one-third of the state's population is rural, so the fourth Ohio group was held in rural, medically underserved Vinton County.
- **South.** The Miami, Florida, area was the location for three groups in this region. The Miami area is racially diverse, with many Spanish-speaking Cuban immigrants. Two groups were conducted in English and the third in Spanish. Florida has a moderate level of HMO penetration (24 percent). All three groups included both HMO members and non-members. A fourth group for this region was held in a medically underserved rural location, Bladen County. Five of the participants in this group lacked health insurance coverage of any kind, while most of the rest were covered by government plans (such as Medicaid, Medicare, or the Veteran's Administration).

- **Northeast.** Providence, Rhode Island, another medium-sized city, was chosen because it is racially diverse, and because the State has a fairly high level of HMO penetration (31 percent). One focus group was restricted to HMO members, while another group consisted only of non-members. Two additional groups were mixed with respect to health plan coverage.

Recruiting of Participants

Since the principal objective of this study was to gain a better understanding of health care consumers' perceptions of health IT and of how consumers would like to be engaged in its development and implementation, only people who had visited a health care provider in the recent past were recruited for the focus groups. Specifically, all participants had visited a health care provider at least once in the previous two years, either for their own health care or for that of a close family member. An effort was made to recruit consumers with a wide range of demographic characteristics with respect to age, gender, ethnicity, race, and health insurance status (i.e., people covered by HMOs, fee-for-service plans, Medicare or Medicaid, and people lacking health insurance coverage of any kind).

The reason that some groups contained only HMO members or HMO non-members is that some HMOs, such as Group Health Cooperative (GHC) and Kaiser Permanente, have made extensive investments in health IT. Participants in these HMOs are likely to have noticed their providers using the technology for several years. Also, it is possible that some consumers who avoid HMOs do so at least partly because they want maximum choice and independence with respect to the health care providers they visit. Therefore, the opinions of HMO members toward health IT conceivably may differ from those of non-members.

In addition, most of the groups were homogeneous with respect to the presence or absence of either of the following characteristics: (a) managing a chronic health condition (or the chronic condition of a close family member) or (b) having visited at least three health care providers in the past two years. Consumers with a relatively heavy use of and dependence on health care might be expected to have a very different frame of reference in considering health IT, as compared to people with a lighter use of health care. It was assumed that the potential benefits—as well as the potential risks—of health IT might be more immediately evident to those more dependent on health care.

For three focus groups hosted at Westat's Rockville, Maryland, headquarters, Westat staff directly recruited all participants. They consulted Westat's database of people who have volunteered for research studies, supplementing it with advertising over the Internet (via Craigslist, www.craigslist.com). Westat staff also recruited participants for focus groups in two rural medically underserved locations, generating calls from interested volunteers through newspaper advertising. For focus groups in other cities, Westat staff relied upon established focus group facilities to recruit participants. These firms were given detailed instructions and screening questionnaires designed by Westat for use in recruiting.

An example of a screener used to recruit participants is presented in Appendix A. Tables showing the characteristics of participants for each focus group can be found in Appendix B.

Moderators and Notetakers

A moderator and a notetaker were assigned to each focus group. The notetaker recorded the themes in the discussions, and noted any significant quotations that captured the outlook of any participants. A videotape was made of all the focus groups, except in the two rural settings, where only audiotapes could be made.

The 20 sessions were led by six seasoned focus group moderators. Four moderators were bilingual. All six individuals alternated between the notetaker and moderator roles.

The moderator's guide is attached as Appendix C.

Transcripts and Translations

All of the focus group conversations were transcribed in the original English or Spanish for the purpose of review and analysis. The English transcripts were proofread, and any errors were corrected.

The Spanish transcripts were read by a second person while listening to the sound files, to identify and correct anything the first transcriber might have missed or misheard. Both the Spanish transcriptions and their quality control review were performed by native speakers of Spanish, for whom Spanish was the dominant language. Then each transcript was translated into English by an English-dominant bilingual translator. In each case, the translator first performed a direct translation, rendering the Spanish text into English. Then a second translator read the English translation, proofreading for typographical errors and identifying any statements that seemed unusual, and discussing these cases with the translator to make sure errors had not been made. In cases where a translator had erred, the reviewer made the necessary changes to the translation.

Conducting the Focus Groups

Introduction

In the first section of the focus group, the moderators introduced themselves and explained the roles of Westat and the Agency for Healthcare Research and Quality. They explained their expectations for the participants, and the topics to be covered. They obtained the participants' written consents to take part in the focus groups and to be videotaped.

Awareness

The next section of the focus group covered the participants' awareness of health IT. The topics included the following:

- The participants' awareness of whether their providers used computers.
- The purposes for which they have seen their providers using computers.
- The participants' own use of health IT, such as to communicate with providers or to renew a prescription.

This discussion allowed the moderators to introduce some of the functions of health IT. For example, the moderators asked whether the participants ever saw their providers take notes using a computer, or whether their providers ever received laboratory results via computer, or whether the participants have ever sent e-mail to their providers.

Beliefs and Perceptions

Typically, focus groups participants arrive already familiar with the topics they are about to discuss. In the case of these particular focus groups, however, participants did not necessarily start out knowing the capabilities of health IT or the issues surrounding its use. They may have understood some general concepts, such as that medical information will be managed electronically rather than on paper, but they may not have devoted much thought to the many aspects of health IT.

For this reason, these focus groups took a unique approach. Part of the discussion was in the form of a focus group, but its primary purpose was to educate the participants about health IT, not to elicit the participants' opinions. In the course of this part of the focus group, which lasted approximately an hour, the moderator presented the capabilities of health IT individually, asking the participants for their reactions to each one.

After the participants discussed their opinions about a capability for about 3 to 5 minutes, the moderator offered a potential drawback or contrasting viewpoint on that capability, so that the participants could continue the discussion from a different perspective. The primary goal was to inform the participants about the capabilities of health IT and to encourage them to think about the potential impact of those capabilities on health care. The secondary goal was to gain an understanding of the participants' views. The moderators covered the following health IT topics:

- The use of electronic documentation in place of paper-based data management systems.
- The potential impact of health IT on patient-provider interaction during an office visit.
- The potential for the use of patient data for purposes unrelated to direct patient care, in ways that might not be in patients' interests.
- The security of electronically stored patient data.
- The use of patient data in research.
- The use of technology to manage prescriptions.
- The use of technology to order and receive the results of medical tests.
- Providers' use of clinical decision support applications.
- The role of health IT in managing chronic diseases like diabetes.
- The ability of health IT to spot infectious disease outbreaks.
- Providers' ability to exchange patient data using health IT.
- Monitoring the quality of health care using health IT.
- Patients' use of PHRs.

- The use of telemedicine in rural areas.
- The impact of health IT on health care costs.

The moderator began by asking a general question: “Do you think that your doctor can do a better job by using a computer?” They asked those who answered to explain why they felt as they did.

Then, the moderator presented the various capabilities of health IT. For example, the moderator introduced EHRs by saying:

Let’s start with progress notes—the notes doctors keep in your record about such things as how your treatment is going, how your condition is getting better or worse, and so on. Some people say that it’s good when doctor keeps your progress notes on a computer, instead of on paper. Maybe progress notes are less likely to be lost or misplaced when they are in a computer file than when they are on paper in a folder. What do you think?

After the participants discussed this topic, the moderator said,

But putting something on a computer does not guarantee that there won’t be problems. Those of you who use computers at all, you know that sometimes information on a computer can get lost or misplaced, right? Or sometimes errors are made when entering information into a computer that perhaps would not have been made if the information was being entered into a paper record. What do you think?

This question was intended to encourage the participants to discuss this topic from a different perspective. In this manner, the moderator ensured that the participants became aware of various capabilities, potential benefits, and potential drawbacks of health IT.

If the focus groups had simply begun with the moderator asking “Who should decide how computers are used in medical care?” the conversation very likely would have foundered. Many participants would not have sufficient knowledge about health IT to venture an opinion. By starting the focus groups with an hour-long discussion of the capabilities and potential impacts of health IT, the moderators helped ensure that the participants had health IT issues in mind and were ready for the question on the role of health care consumers.

Consumer Engagement

To start the next part of the focus group, the moderator said,

We’ve discussed a lot of ways that doctors could use computers in health care—to store your medical records; to share your medical records with other doctors; to order prescriptions and medical tests; to get the results of medical tests; to get advice on making a diagnosis or planning a treatment, and so on. Undoubtedly, the use of computers in health care is going to get bigger over time. So who should decide how computers are used in health care, and what limits and rules should be set for using the computers?

The moderator kept the conversation going with a series of questions that explored details about the participant's viewpoints. This second part of the focus group lasted about 45 minutes. Unlike the first part of the focus groups, in this part the moderators consistently tried to explore the participants' opinions in detail. They used probes and followup questions to investigate the participants' statements. They covered the following topics concerning the extent to which health care consumers should be engaged in the design and use of health IT:

- The role of various stakeholders in determining how health IT is designed and used.
- The role of health care consumers in the design and use of health IT.
- The issues that the participants believe health care consumers should help decide.
- The point in the process of developing, marketing, installing, and using health IT where health care consumers should exert their influence.
- The moderators also covered the following topics about *how* consumers should be engaged in decisionmaking about the design and use of health IT.
- The extent to which vendors, physicians, and government agencies should consult health care consumers about health IT.
- Whether focus group results should influence health IT decisions.
- Whether health care consumers should write to their elected representatives about health IT.
- The potential role of patient representatives in health care organizations and hospitals.
- Whether organizations (e.g., AARP, American Cancer Society) can represent patient interests in the health IT field.
- The way in which consumers should communicate their preferences regarding the sharing or use of their medical information, with attention to whether consumers should be asked for consent; and if so, when, for which information, for which uses of that information, and for what period of time.

Wrap-Up

The final section of the focus group was the wrap-up, in which the moderators thanked the participants and asked them if they had anything more to add.

Results

Salience of the Topic to the Participants

Health care was clearly an important topic to the majority of the participants in all the focus groups. Even the participants who seldom used the health care system expressed their opinions in a way that suggested that they had thought about health care in some depth. However, most participants did not seem to have strong opinions specifically about health IT, with the exception of a few particular issues, such as the privacy of electronic data and the manner in which health IT might affect a provider's behavior.

As a result, participants sometimes spoke about aspects of health care that were important to them, but which were tangential to the topic of health IT. For example, they spoke about the quality of health care, the reliability of health-related information on the Internet, or the motives of health insurance companies, even when these topics were not very relevant to the moderator's question. The moderators often had to refocus the discussion onto the topic of health IT.

Awareness

In each focus group, the moderator asked whether the participants had ever seen their providers use computers in the course of providing patient care. Just over half answered that they had. HMO members appeared to be more likely than non-members to report seeing their providers use computers. Participants in the Spanish language groups appeared less likely than those in the English language groups to report that they saw their providers using computers in the course of providing care.

The moderator then asked how the providers were using the computers. The most common response was that the physicians typed into a computer during an office visit. Most participants believed that their physicians were maintaining progress notes electronically.

He keeps his notes. He walks around his computer...and anything I tell him, he types it in.

My doctor, he brings his laptop in and they have hookups in all of the exam rooms. He just connects it. He takes all of his notes in there and reviews my history and stuff all on the laptop right there in the examining room with me.

Several participants also reported instances in which they received an X-ray examination, returned to their physician's office minutes later, and were surprised to see that the physician was already viewing the image on a computer screen. Of course, these participants were being seen at facilities in which the radiology department shared a health IT system with the providers who ordered the X-rays. Some of these participants reported that their physicians pointed to the X-ray image to explain something. This use of health IT was impressive to the participants because it clearly demonstrated how health IT can make health care delivery more speedy and convenient.

I think they can do a better job, because . . . when I broke my ankle last year, you have to go in one department and get X-rayed, and then you have to go see the doctor. And before it was maybe a two or three hour wait. Now you go and get the X-ray, go right upstairs, and he pulls it up on the computer, so it's more convenient for me.

I've had bone density scans and X-rays in the last few years on several occasions. And used to be you had to pick up an X-ray film and then take it to the doctor's office. Now, they've got it right on their computer at the doctor's office. [Moderator: "So, it gets sent by the lab straight to your doctor?"] Right out of the lab, yeah.

Some participants stated that their providers used health IT to print out prescriptions and to check new prescriptions for potential drug interactions. Some stated that they saw their physicians order diagnostic tests using health IT. A few said that their physicians showed them the results of diagnostic tests by pointing to the results on a computer screen.

A small minority of participants stated that they communicated with their providers via e-mail. Most of these participants reported that e-mail was a better tool than telephone for communicating with physicians. They reported that patients rarely could reach physicians by telephone, but that physicians frequently responded to e-mails the same day. HMO members appeared to be more likely than non-members to communicate with their providers electronically.

I've also written to my husband's doctor. His back was hurting, he couldn't go out, he couldn't walk. And it was very hard to track down the doctor on a regular like—you know?—where you leave messages [on voice mail]. So, by e-mail, he answered me in, I don't know, three hours.

A small minority of patients reported that they had refilled a prescription using the Internet, usually through a Website set up by a pharmacy, or that they made appointments with their providers using the Internet.

My doctor just put it up where you could communicate to them via a Website. You log in and you schedule appointments and things like that via a Website.

Beliefs and Perceptions

As mentioned earlier, the primary purpose of the first part of the focus groups was to inform the participants about some of the major issues surrounding health IT. Gaining an understanding of their opinions was only a secondary purpose. Nonetheless, the discussions did provide a few noteworthy insights into the participants' thinking about health IT.

Overall Reaction to Health IT

At the outset of the focus groups, the participants almost universally expressed the opinion that health IT could benefit health care. Most participants in most groups thought that physicians could access patient information more easily when it was stored electronically rather than on paper.

It would be more convenient and more modern.

I just think if [doctors] thought to use computers more often, it would relieve [them of] a lot of the paperwork.

I would think they could provide better analysis of what your problem is.

You get things done faster. Instead of days it's hours, you know, the results of tests.

Many participants also stated that electronic systems would enable providers to exchange patient information among themselves, thereby improving the quality of patient care. A number of participants mentioned that when they went to a clinic or group practice, they could not predict which provider would see them. These participants believed that health IT could allow a provider to learn about any patient quickly from the notes left by other providers.

When my doctor comes in ... she has, like, a big, thick [file] because I've been going to her for years, and ... she'll come and she'll flip the page, flip the page, and flip the page ... But, if she had a laptop or something, she'd be able to go back to that date and time and just pull that up and it would pop right up. It would be easier for her, as far as being organized and being systematic.

I still say the computer is the safest thing, because if you tell them something, he puts it in there, and next month he sees so many people. I go to the ... clinic ... They see so many people in a day that they get confused with people. At least with the computer I can say, "Well, go back and look at it." They can go back and say, "Oh, I did tell you twice a day and not once a day."

A few participants discussed uses of health IT that may be tied to assumptions they have about what health IT can do.

One advantage I see on that, going electronically, would be when they give you a referral to go see a specialist. They could send all your information to the specialist so he'd have more. Because the doctor may not think this one fact is important, but to the specialist it may be important. And ... they would have sent the whole file to him.

Some participants spontaneously mentioned that some physicians had poor handwriting, and therefore electronic management of patient data had the potential to prevent medical errors. In summary, there was general agreement at the start of all the groups that health IT had the

potential to enhance the quality of health care by making the work of providers more efficient and less error-prone.

My son's pediatrician ...called my attention to a lot of graphics, like seeing how his growth was going according to the average. It was very interesting because when you see everything reported, it's kind of boring and hard to understand what he says. But when you see something so graphic, it makes a lot more sense, so I did like that part.

She was prescribing a new drug and I already take herbal supplements and she was looking for interactions.

Effect of Health IT on the Role of Patients

However, almost no participants pointed out that health IT might empower patients to play a larger role in their own care. Even patients who had serious health care needs, or who had relatives with medical problems, did not speak about this possibility. In fact, the concept of patient-provider collaboration was very seldom mentioned in the focus groups, except when the moderators themselves raised the issue. Very few times did the participants spontaneously raise the idea that patients could use health IT as well as providers, or that health IT could enable patients and providers to make decisions together.

In general, the focus group participants tended to view the patient's role as a passive one. Many of the participants' statements implied that the role of the patient was simply to obtain and carry out advice from providers. The participants did not often spontaneously say that patients could use health IT to monitor their own health and to help them adopt more healthful behaviors. Instead, they tended to think of health IT as a tool that providers would use to help them diagnose and treat their patients' medical conditions. They usually thought that the patients' role was to receive these services, not to collaborate with providers or to use health IT tools themselves.

These are medical records for the doctors, not medical records for the patients.

You have to expect that your doctor can be more knowledgeable about that and not be using the same tool that you could be using.

I think it's just like with anything. You rely on the trash man to take your trash to the dumpster. You rely on the postman to put your mail in your mailbox. You can't do every profession yourself. You have to lend yourself to some trust.

In addition, the participants did not tend to recognize the potential value of PHRs until the moderator explained their potential uses. In most focus groups, the participants were unaware that PHRs existed. In several groups, when the participants heard about PHRs, they thought that some patients would use them to bother their physicians with unnecessary reports and complaints.

Eighty-five percent of us in America are hypochondriacs. Everybody's sitting down, trying to put this information that they think is correct into a Website. The doctor's trying to make some kind of evaluation or some sense of it...when most of America will be feeding them misinformation.

Can you see some people on there . . . Some tell their whole life, like doctor today I had for breakfast . . .

I know too many people that would abuse that system. Hypochondriacs. Real, bona fide hypochondriacs. They would drive the doctors nuts.

Privacy and Security

The participants often spontaneously raised concerns about the impact of health IT on the security and privacy of patient data. A few participants raised specific concerns, such as the possibility that an automobile insurance company might use health IT to review applicants' medical histories. However, the issue of data security was important to the majority of participants simply because they believed that their medical data "was no one else's business" and should not be shared without their permission, not because they wanted to prevent some specific use of their data. In other words, they viewed the privacy of their data as a matter of principle.

A small number of participants felt that the privacy and security of patient data was already guaranteed by laws such as the Health Insurance Portability and Accountability Act, so all that was needed was a means to apply these laws to health IT. These participants felt that no further action was needed on the issue of privacy.

Many participants believed that their data could be easily de-identified, in which case they had no objection to sharing the information for purposes of medical research. Only one or two participants recognized that in certain cases de-identified data did not fully guarantee that the identity of patients could not be ascertained. Participants in some groups distinguished between research that led to new medical knowledge and market research by pharmaceutical companies. There was a broad consensus that de-identified data should be freely used for medical research. A majority of the participants who spoke on the topic thought that even de-identified data should not be used for market research whose only goal was to enhance the sales of medicines. However, the participants were not unanimous on that point.

Participants often disagreed as to whether data stored electronically or notes written on paper were more secure. Some participants believed that paper was more secure than electronic storage because breaches of data on paper tended to occur on a small scale, while breaches of electronic data often involved large databases. These participants argued that a breach in the security of large electronic databases could impact a very large number of people. They raised the issue of whether patients should be able to refuse to allow their data to be stored electronically at all.

Many participants noted that electronic systems can be hacked by people who want to pry into other people's records. Fewer participants noted that paper records are not necessarily safe from inappropriate access, either.

I always have that fear of sending information into cyberspace and it getting hacked or getting intercepted in some way. I think it pays to be a little paranoid.

I did two years of computer programming and found that I've got some access to computers that I shouldn't have had access to.

I just think the information is easier to steal on a computer . . . rather than sneaking into the office and stealing a bunch of files. Yeah, I don't think somebody's going to steal a bunch of [paper] files and run down the street.

Everything else has been hacked. Government files have been hacked; banks have been hacked. My credit cards have been stolen. What else is left?

How could you ensure that the people working in the office don't hack into it or take information and sell it someplace?

A few participants believed that electronic health records might be more prone to error than paper charts are. They felt that when an error occurred, paper charts could be corrected more quickly and easily.

Too much personal information. Somebody can always get into the computer somehow. You hit one wrong button on a computer and you can make your whole chart wrong . . . [There is too much] room for mistakes.

A number of participants argued that power outages, natural disasters, and computer malfunctions could make patient data stored in electronic health records inaccessible. They thought that paper records could be more secure in those conditions. Only a few participants expressed the opposite opinion, that paper records are more vulnerable than electronic records in the event of a disaster like Hurricane Katrina. For example, one participant said that he supported the use of electronic health records because he had the experience of his paper health records being destroyed. This person thought that an electronic record would solve this problem.

I am very old fashioned. I prefer that they have my folder with the information, because there is also the issue with computers: one can put in the information, but [what if] the system is down? What happens with that?

My comments . . . on the disadvantage to computers just like when we had the power outage for three or four days. If your information was stored on there, there's nothing that could have been done.

The power can go out, when a hurricane comes, particularly in Florida. [We might have] to go 15 days without computers, unless they have generators at all of the medical offices.

A clear theme in the majority of the focus groups was that health care consumers would be wise to be skeptical of health IT because of the potential breaches of security. Many also expressed their feeling that the diffusion of health IT was inevitable, bringing with it dangers to the security of their medical data.

There's all these strings attached with your information being online . . . There's always going to be some kind of glitch when you're talking about personal information on the computer. There's always going to be . . . some form of, "Am I really secure?" You know, it's always going to be a question mark.

I don't see how there's any way to stop it. Once it's out there, it's out there. There are always people that are willing to sell information and have access to that information, and people willing to buy it. That's just the way it is. I don't think that there's any way you can totally protect . . . privileged information.

Respecting other people's privacy—it doesn't exist anymore when it comes to certain things.

However, there was clearly a sense in many groups that health IT brought both risks and advantages. The participants said that both were important.

It's your information, so sure, why wouldn't you want to have [health IT]? You have your bank information; you have all your other information. Why wouldn't you want to have your health information available on a computer? It just makes sense.

There's always a risk when you have more conveniences, and I guess when you look at it you have to determine whether that would benefit more people than it would hurt.

Computers are just like any other tool. They can be used to enhance efficiency, or they can be used to breach confidentiality. I mean, it depends upon how the tool is used. In terms of storing records, obviously a computer would be more efficient than a paper file six inches thick. But it could work either way.

The Patient-Provider Relationship

The participants in many focus groups expressed some concern that health IT would alter providers' behavior, making health care more impersonal and unpleasant. Participants stated that providers might seem detached when they were entering notes on a keyboard. Some participants thought that when providers used health IT, they might pay too much attention to the technology, and too little attention to the patient. They also felt that when providers used paper and pencil for their notes, this problem did not exist.

As long as they mix in the personal, too, because I think everybody wants a little bit of personal.

I think that in this computerized world, we depend a lot on a computer, you lose that relationship between the doctor and the patient.

I don't mind the computers being there, it's just the paying attention thing.

He types in everything you say, and he repeats it to himself. He doesn't really pay attention to why you're there.

They'll be too busy on the computer instead of looking at me. I want body language, when I say something and I tell you something is bothering me I want to see your reaction.

I think it takes away the human touch. Because it's just like anything else it becomes, especially for HMOs, it becomes a production versus a good visit. It just becomes numbers versus people really getting the treatment they need.

As long as it's a small town like it is here, people have a place with the doctors here, and most doctor-patient relationships have a small degree of a personal relationship here too, because they're so well known. A small town is quiet, and the more you're going to use a computer here, the more the personal relationship is going to go out the window. So, for a small town like this here, it may actually turn around to where the patients aren't trusting the doctors as much.

However, some participants voiced the opposite opinion, that providers who wanted to have a pleasant and an engaging demeanor would not let the computer interfere with the tone of the patient-provider encounter.

I still feel like he's paying enough attention to me even though he's using the computer...He does make eye contact, he stops...when I'm talking...I think he's good at balancing, keeping the human interaction.

I really think it depends upon the doctor. If the doctors have a certain type of bedside manner, regardless if they are doing paper or computer, they multitask and really connect with you. If they don't have a good bedside manner, it doesn't matter what they do.

In summary, the participants were concerned that health IT could alter providers' behavior, but they were not convinced that it would in every case. They did believe that they had little control over this potentially bad effect of health IT.

Telemedicine

In the rural focus groups, the participants routinely drove 30 to 80 miles for visits to health care providers. The moderators brought up the concept of telemedicine, in which the patient and provider interact at a distance using computer technology. The participants perceived the advantages of allowing patients and providers to interact without having to be face to face in the same room. However, many participants thought that face-to-face contact was crucial to quality health care.

I wouldn't go see a doctor if I couldn't look at him face to face.

I want to make sure that doctor's looking at me and understanding what I say and seeing clearly the problems I have. I don't think you can convey everything well enough that way.

In order to trust a doctor you have to try to connect with them and I don't think you can do that over the screen.

In between doctor visits, if we had issues, that might be OK. But as far as examining me, you are not going to do that through a screen. I wouldn't trust it.

Decision Support

The participants tended to agree with the idea that health IT could help physicians make accurate diagnostic and treatment decisions. Many of the participants emphasized that providers should always have the ability to overrule health IT alerts and recommendations. The participants believed that providers should always rely on their own judgment in providing health care. Providers should take advice from health IT into account, but not depend upon it as the sole arbiter.

Health Care Costs

Although many participants argued that health IT could add efficiency to health care, most were skeptical that it could actually reduce their own health care expenses. Many did not believe that any savings would be passed on to them. They wondered whether, to the contrary, they would be asked to share in the costs of health IT.

You're still making the co-pays; you're still buying the prescriptions. You're still having a procedure done. That's where the expense is, it's not in the data.

If they outfit the office with a whole new computer system, they're going to pass that cost on.

Consumer Engagement

Initial Response to the Question “Who Should Decide?”

The moderators introduced the section of the focus groups on consumer involvement by asking the question, “Who should decide how computers are used in medical care?”

In many groups, the participants’ initial reaction was to wonder aloud who was already responsible for decisions related to health IT.

Who are the “they” that are making these decisions? Are they our elected officials who are doing it? Or is it people who are in departments? It seems to me there has to be a little more information for people to understand what’s going to happen. Who is it that’s authorizing it? And who is it that’s going to be reviewing the work?

In many groups, the participants acknowledged that they had little idea about who is supposed to set health IT policy.

Who makes those decisions now?

In no group did any participant mention the Office of the National Coordinator for Health IT, or the Health Information Security and Privacy Collaboration, the Agency for Healthcare Research and Quality, or any similar government office or initiative. No participant in any group appeared to be aware of them. Nor, in the focus groups held after the American Recovery and Reinvestment Act of 2009 was passed, did any participant mention the health IT provisions in that legislation.

In a few groups, the participants sidestepped the question, and spoke about a related matter, such as the inevitability that health IT will be widely adopted, regardless of whether anyone sets policy about it. In one group, the participants avoided the question by discussing whether anyone should have the power to force physicians to adopt health IT. One participant avoided the question by saying that health IT was already in use everywhere, so all decisions about it have already been made.

In several groups, there was a period of silence after the moderator asked who should be involved in deciding how computers should be used in medical care. In one group, after the silence, a participant exclaimed “Good question!” as if to say that somebody should ensure that patients’ rights are guarded, and health IT is implemented in the best possible way. However, at the start of the discussion the participants in those groups had little idea about who would be responsible for setting the direction of policies regarding health IT.

In many groups, participants appeared to be struggling to guess who might be a logical choice for setting health IT policy. They replied by proposing the leaders in the medical field such as the American Medical Association, the Centers for Disease Control, the Surgeon

General, Medicare, the “health department,” the “doctors’ association,” the “Navy medical community,” the Food and Drug Administration, and the Public Health Service. These participants appeared to believe that these agencies are responsible for determining health care policy in general and therefore should be tasked with making decisions about how health IT is designed and used.

A guideline should be set up by the AMA. And as long as the doctors have to follow other guidelines by the AMA, why not include this?

The Role of Medical and Computer Experts

A large proportion of participants expressed the view that health IT should be left to experts. They stated that health care consumers lacked the expertise to make appropriate decisions about health IT. Very often, when the moderators asked who should be responsible for deciding how health IT is used, the reply was “doctors.” Other participants mentioned computer experts should be involved in setting health IT policies. Only later in the discussion, when the moderator introduced the topic of privacy and security, did the participants acknowledge a role for health care consumers.

Some participants revealed their reasons for thinking that decisions about the design and use of health IT should be left primarily to physicians or computer experts. In one group participants said that doctors generally owned their practices, and therefore they should be free to make all business decisions about them, including all decisions related to health IT. In other groups, the prevailing opinion was that physicians should be in charge of all things pertaining to health care.

I've put my health care completely in the hands of my physician. I'm totally prostrate in front of the medical profession to heal me. So yes, they should know everything just because it's only for my own good.

Doctors . . . they have differing opinions about how it will be easiest for them to enter information.

I believe that the proposal has to come from the experts, and the experts are the doctors. From that point, a person as an individual can decide whether or not their information is shared.

I think it is important for the doctors to have a big say on how it is put together because they are the ones that are going to be using it at the end of the day.

The initial reaction in one group was that a “computer security person” had to be involved with setting policy regarding health IT, in order to safeguard patient data. However, others in the group responded that even with such a person making decisions, data security is an unattainable goal.

No one is safe. Everything is computer monitored right now. There is no way to escape. And it's going to get even more than that.

The Role of Health Insurers

No participant thought that insurance companies should have a dominant role in setting health IT policy. However, a number of participants felt that insurance companies will have a strong role because of their financial stake in the health care field. Some of these participants said that they were not pleased with this prospect, but were resigned to it.

In a group held in the Washington, DC, area, the participants discussed how in some countries, like the United Kingdom, the government had a great deal influence in health care, but noted that in the United States, the government's role is smaller, and many insurance companies and other stakeholders influence health care policy. They reasoned that setting health IT policy in the United States will be a more complex process. The interests that win out, in their view, will get to set policy. In the view of some of these participants, insurance companies were powerful enough to win this dominant role for themselves.

The Role of Government

The participants had very divergent views on the role of government in the field of health IT. The manner in which many participants expressed themselves on this matter suggested that they had fairly strong opinions about the role of government in general. Some believed that elected officials could protect the interests of health care consumers.

We're saying that government should be involved and government should help regulate to keep this private, just like how the government keeps your banking private. I think that, yes.

If the government is already involved in [health care], and it is then there's definitely going to have to be some legislation covering all off this. I think it's universal, that everyone is concerned with, how is the information going to be used? What are going to be the pitfalls? Because everything is not going to be absolutely perfect. I know how it's going to benefit me. But is it going to work against me as well?

I like it when the government is involved. I feel more secure, because I think there is oversight. And have there been abuses? Yes, of course. And will there be in the future? Yes. But for the most part, I'm more comfortable with like the CDC. I know they do fabulous stuff. I think they are based out of Atlanta and I heard wonderful things about some of the stuff they are doing. So I have, I like that kind of involvement. It makes me feel more secure.

Others felt that government involvement was undesirable. Many of these participants argued that government becomes intrusive unless its role is contained.

The more the government sticks its hands in, the more it takes out the individual's.

Take the government out of everything. It should [not get] between the health care provider and the patient...I mean when the government gets involved, you don't know what's going to happen. Big Brother has enough to say in our life. That is not the purpose of government, to take care of our health. That's up to us individually.

You can't leave it up to the politicians.

It's a quagmire we're in, because we're so close to socialized medicine . . . and we as individuals don't particularly care for that, but we're forced to. We're slowly being drawn across this abyss into socialized medicine, and we're being forced there by insurance companies, and our social etiquette, our social structure as it stands right now in the United States.

Sometimes the representatives get too involved...more than they are authorized to do. Unfortunately, I think the government is going to end up making the decision. . . As usual... They are going to tell [doctors] what good practice is, what bad practice is, and then come up with some kind of rules. It's probably going to end up being another bureaucracy out there.

They're the government. They know everything about you. More than you know about you.

[Moderator: "Are there any type of organizations that you think would be good at representing you and your concerns?"] Participant: "Well, the government would be at the bottom."

A few participants did not support government involvement, but were resigned to it.

Why not? They [the government] regulate everything anyway.

Some participants were philosophically opposed to a large role for government in health IT because they felt that the best decisions emerged from private enterprise.

I usually leave everything up to a market to decide who's going to be better, or what's going to work and won't work.

The Role of Health Care Consumers

There was a good deal of disagreement about the extent to which health care consumers should be engaged in deciding how health IT should be designed and used. On the one hand, there was general agreement in these focus group sessions that patients' health information

belonged to the patients themselves, not to the providers or anyone else. Most participants thought that patients deserve a right to exert control over how their health data are shared and used.

Because that's your personal information. You should have every right to say how it's used.

Why not? It's our information. We should help be part of it.

I would just make sure that my information's not viewable by anybody else other than people who are supposed to be viewing it, and make sure it's secure.

A few participants mentioned specific examples of how their information might be shared in a way that they did not like. They wished to have some control over those particular circumstances.

I wouldn't like, for example, to have my financial information connected to my health care, because it's based on my finances. Let's say I'm unemployed, then I'm going to be denied health insurance or my payment's going to be higher. I wouldn't like to have those parts connected.

Some participants felt very strongly that health care consumers should have a say in how health IT is designed and used. A number of participants felt that the health care system exists to serve patients, so patients should exert the most control over health IT.

Whatever rules and limits we set.

You should decide, you should decide.

It should be up to the individual, okay, what are the limits and rules that should be set.

Us...Yeah, people... Maybe with weighted input from doctors.

Everything that has to do with my body, I want to make the decision.

Many participants emphasized that health care consumers need a say in how health IT is designed and used so that they can protect their medical data.

We as individuals should have the liberty to decide what will or will not be given [to be entered into an EHR].

This is my personal private data. I'm the one who can tell the doctor what he can do with it. He can determine what he would like to do with it, but I want to be able to say, "You can do this with my data."

However, a sizable number of participants questioned whether consumers should be involved with the design and use of health IT at all. These participants gave three reasons for their stance. First, they believed that they lacked required relevant expertise. Second, they believed that health IT is being developed solely for health care providers, not patients, to use. Third, they thought that health IT already works for the benefit of patients, so patients need not be concerned about it, aside from the data privacy issues.

The participants who believed that health care consumers lack the expertise to participate in decisions about health IT did not perceive that consumers might have valuable opinions about how health IT will affect them, even if they lacked much knowledge about medicine or computers.

No, I don't think we should have a role.

I know how to turn my computer on. That's all. So they are going to ask me for points on how to create systems? No, they're not.

I don't know anything about medicine, so I wouldn't know about the other benefits of having a computer.

A few participants did not go quite as far. They thought that health care consumers should have a role but that the role should be very limited, because of their lack of expertise.

I think that I would love to have a say . . . but . . . there has to be someone or something above us such as a Ministry of Health or a private company that sets guidelines, limits, and controls how medicine goes these days.

Participants who felt that health IT was developed exclusively for providers to use did not perceive any possibility that patients could benefit by using it as well.

I want somebody else to figure out how it's going to work, why it's going to, the best way it's going to work. And I just want it to be there and working when I have to go in there.

Participants who felt that health IT was being developed by others without problems offered words to the effect that health IT had nothing to gain from the involvement of health care consumers. One participant pointed out that her pharmacy had installed a computer system without consulting any customers and that now the system is working well for everyone. Some of the participants, however, recognized that consumers have an interest in safeguarding the privacy of their information on electronic systems.

I think, the role we should have is we should be alerted when somebody accesses our files.

Issues on Which Health Care Consumers Should Have a Voice

The moderators pointed out that the use of health IT will probably expand in the next several years. They asked the participants to identify how health care consumers can help decide how health IT will be designed and used.

Some participants replied by discussing whether consumers should have the right to decide that their medical data will be stored electronically at all. Some participants thought that patients should have the option of keeping their medical data in paper format. In a few groups, there was general agreement that patients should have the choice of refusing to allow their data to be entered into health IT systems. Their point of view seemed to pertain to the earlier discussions on privacy and security.

I think when it comes to them entering your information into it, you should have a say whether it's done or not.

Maybe people could have the option of being part of this database. Like if someone said they didn't want any information on there at all, and they could have the option of not being on it, so when you look them up there is nothing. But it's on you if you decide not to be on it.

You should have a choice. If you want to have your information on there, that's fine. But then you need people to...safeguard and monitor the security...You want to opt in or you want to opt out.

However, in some groups many participants argued that a patient's data would not be available to providers who wished to give them the best possible medical services if that patient elected to forego electronic data storage. These participants' point of view seemed to pertain to the earlier discussions on the advantages of health IT.

There was near universal agreement in all the groups that if medical data are to be stored electronically, health care consumers should have some say in how those data are shared and used.

[Consumers should decide the] rules and regulations as to how to use [health IT], or who's going to use it. ... How is it going to be handled and by whom?

There was no support for the establishment of general rules that apply to all health care consumers. The participants thought that health care consumers should be able to exert some control over their own health information individually, rather than collectively. That is, the participants who spoke on the topic felt that universal rules that applied to everyone regarding the circumstances in which medical information can be shared might not take the individual wishes of health care consumers into account. Most participants believed that health care consumers individually should be able to set limits on the use of their medical information.

It has to be an individual basis. A lot of the other things we've talked about in the last hour or so, most of us seem to feel we have our own individual rights. I don't know how you can get more personal than your medical conditions.

Maybe you don't want the esophagus doctor to know that you had the abortions, or something else. . . On the other hand, there's some information you wouldn't mind sharing with people, because you want them to know. And then there's some information you feel like, "This is private; it's none of your business."

Why are we making it so complicated? I mean, why can't the doctor say: "I want to put your medical records on a file. You'll be able to access them and I'll be able to access them. Only us, and anybody else that you want."...It's a simple thing. It's between me and whoever I want to have access to it, nobody else should be involved.

Participants generally agreed that if they were in need of emergency care and unable to speak due to illness or injury, their treatment outcomes likely would be better if emergency physicians had ready access to their medical histories. Still, many participants wanted to give advance consent for their medical records to be released, even under emergency conditions.

I've been to the emergency room with someone who's been undergoing care for something . . . and then we have to start all over from scratch to give all this background. I would really like it, if I told my doctor, if I go to Riverside [Hospital], if I go to Mt. Carmel [Hospital], and they want to access my records, I want them to be able to do that. I would be fine with that. If I have given them permission to do it and I know what it's going to be used for.

The focus group participants did not agree, however, on whether consumers should be able to edit the content of their electronic health records. In particular, they disagreed about whether patients should be allowed to withhold some potentially sensitive medical information from those records, such as a sexually transmitted disease, psychiatric disorder, or vasectomy. Some participants felt that such a policy would give patients too much power. They thought that some patients might try to falsify their records, in order to reduce their insurance premiums.

I guess I was still thinking if there was something, just because I've heard different cases that it is possible that they could discriminate against you if you do have [certain conditions]. Unfortunately, that happens to people all the time. So I think that's something to take into consideration.

Some individuals felt that, even when the information is sensitive, patients would only benefit from their physicians' having a comprehensive understanding of their medical history. For these individuals, the potential benefits outweighed the risks.

What if you broke your arm, and what if they see that you have MS and alcoholism? I think that is pertinent to your prescriptions. Number one, if someone is a recovering alcoholic you don't want certain prescriptions going into that person's system. And if someone needs to be contained or quarantined somehow for whatever kind of disease, that may be something you need to know. And maybe if someone is unconscious, he or she wouldn't be able to say, 'Hey, time out. Don't give me that.' I think that's definitely helpful.

If I'm unconscious or something, I gave them permission for my medical [records] to be there. So I have to take some of those consequences. . . .I think that if you're in that position, you really don't care what the doctor knows. . . .You're not [going to] die, but you might be a little embarrassed.

You go out of town, out of state somewhere. And you've got this splitting headache, this migraine headache and they're going to rush you to the emergency room in Japan somewhere... And then they're going to take your name and everything and put it in the computer for you, "Oh, OK. How did your urinary tract infection affect you last week?

Did you get that taken care of?"...Then you go, "Wait a minute, wait a minute, I'm here about my headache."

I don't want to have to give my information all over again. If somebody in Japan can see my medical records and say, "Well, you have high blood pressure. Is your blood pressure up? Maybe that's why you have a headache."

When you're in the hospital and you think you're dying, who cares who knows what? Help me and get me alive and if they have your information, I'd be thrilled to death. I don't care. I could be a drug addict, I could have HIV, STDs...I don't care. If they have my information, I'm happy.

Also, the individual knows that in case of emergency any information that you leave out from the file, it can hurt you in your treatment. And they have an understanding that there are also disclaimers, that any information that is not provided could cause a misdiagnosis.

Participants in two of the focus groups said that they wanted to have a say in ensuring that the electronic health information system has accountability structures built into it. They reasoned that the use of health IT is expanding but that patients have become distrustful that their information will truly be held in confidence.

I mean, if you learn that some information is released to someone who shouldn't have had it, your recourse is the Department of Computer Ethics. If I feel like my documentation on the computer has been violated, I need to know who I can go to—a 1-800 number or whatever, that I can call to get it looked into.

[We need] accountability, audit trails; for example, we have these electronic voting machines which they tried to ram down other states' throats, and those things didn't have paper trails. There have to be paper trails.

Feelings of Disempowerment

In three groups, many participants predicted that health care consumers would never have a meaningful influence on how health IT is rolled out. Some expressed skepticism that medical or other personal information would be kept private in the aftermath of the events of September 11, 2001. Participants in other groups suspected that the government was already accessing personal information about them without their knowledge or consent.

Other participants felt that health IT decisions were going to be made by physicians and others, without any input from health care consumers.

There is really not a whole lot that anybody can do about it. It all ends up with the doctors' offices and departments. If you want to see a doctor, well this is what his preference is. I guess that is what you are going to go along with.

Some participants expressed a resignation to their own disempowerment.

I don't know if that stems back to distrust somewhere? A lie, like you said, and I think it's a big thing. A lot of people are pretty certain that their voice does not matter.

I feel a safety in numbers only because I really feel like why would they care about me specifically.

How Consumers Could Be Engaged in Health IT Decisionmaking

The moderators asked the participants how health care consumers should be engaged—that is, through what avenues and procedures consumers might prefer to influence the design and use of health IT. A number of possibilities were discussed to varying degrees across groups, including the following:

- Companies that design and sell health IT applications asking consumers for their views.
- Providers asking patients for their views.
- The federal government conducting surveys or more focus groups.
- Elections or referenda.
- Patients writing their congressmen and senators.
- Organizations speaking out on behalf of health care consumers (e.g., AARP, the American Heart Association).
- Patient representatives serving on the advisory committees of hospitals or health care networks.

The participants overwhelmingly expressed a desire to be able to communicate directly with their health care providers with respect to how their personal health information is handled, including with whom it may be shared and for what purposes. In a few of the groups, the participants agreed that physicians should have the job of obtaining patients' consent on the use of their data. In one group, most participants felt that patients needed to be automatically granted the right to correct misinformation in their records.

Of course! We're the ones they're going to put in the system, so it's us [that providers] need to ask.

The participants seemed to have relatively little interest in communicating their desires regarding their health care information to other parties, because they felt that other methods would be ineffective in addressing the confidentiality issues they cared most about. For example, only a handful of participants expressed a clear interest in communicating with companies that designed health IT. Many others felt they either lacked the expertise necessary to give meaningful input or saw no reason why their input should matter.

I don't know what I would tell them other than say, "Don't give my information to people that shouldn't have this."...What goes into it and what doesn't go into it... I am not the expert on that. There are doctors and nurse and people that work with it.

That's their business. Let them design it.

They are the ones that design the technology. They should be going to the decision makers, such as the FDA, the government.

There was little consensus with regard to using focus groups to elicit opinions from health care consumers. Some participants viewed surveys and focus groups as potentially valuable tools for gathering consumer input, while others did not.

Only a few participants stated that organizations such as AARP and others should have input in health IT decisions. These participants felt that these bodies speak on behalf of large portions of the public.

AARP speaks loudly and plainly on the views of folks my age.

However, most did not think that organizations such as the Red Cross, AARP, or disease-oriented groups like the American Heart Association should be assumed to represent their views. Some participants had specific criticisms of some of these groups. For example, one participant disapproved of some past actions of the Red Cross, and another thought that AARP was too involved with the insurance industry.

That's where you get into the whole lobbyist effect. And that's what I worry about with all those records, all those organizations lobbying for these things, is our voices won't be heard."

I don't know. I'm just racking my brain trying to think of an organization that I would say, “. . . they should represent us.” I think we have a good representation right here and I think we are all showing that people do care about how their records are used. And perhaps input from this type of panel discussion should be used rather than another organization to represent the public.

One participant suggested that organizations representing people with AIDS should have a voice, since these patients have much to lose should their personal health data not be adequately protected. But others did not trust the motives of such organizations, or just did not agree that any organization could truly represent their individual points of view.

One participant suggested there be an organization that advocates on behalf of patients.

I just realized, what I'm looking for is more of a patients' advocate organization. Where...they can set up that whole thing but we would...have an organization that simply looks at things strictly from our side, as opposed to the other side. Just from our side. Not to be against [doctors], basically, but to convey our feelings, or from a patient's standpoint.

Numerous participants seemed initially intrigued by the notion of patient representatives serving on advisory groups for hospitals and health care networks. However, there was no consensus. Participants expressed concerns about how representatives would be selected so as to be truly unbiased, and how knowledgeable these people would be. Some felt that the representatives should be people with chronic health conditions because they would be likely to be affected by policy decisions regarding health IT; others felt that the representatives should be people with some degree of expertise in health IT. Still others felt that the person should be chosen “at random,” to ensure that the representative's motives were only to help patients, not to represent a special interest.

A few participants thought of holding a special election or proposition initiative to set health IT policies.

The easiest way probably would be to put it on a ballot for an election.

However, others thought that an election would be inappropriate because health IT policy needed to be set individually for each health care consumer.

Many participants mentioned the possibility that health care consumers could express their opinions concerning health IT most effectively by writing to their elected representatives, who would then pass appropriate legislation.

Legislatures I suppose would probably have to set up some kind of subcommittees or people we could talk to.

I think there is going to have to be legislation. Because if you leave it to special interest groups, such as the American Medical Association, or the insurance companies, or even individuals, everybody is going to have their own opinion. There is going to have to be legislation.

You could write your congressperson and give your opinion.

Yeah, you want to have a voice on it. The only way to give it any teeth though is to have it through legislation...Our only alternative is to contact our congressmen.

It seems to me elected officials should have to provide that opportunity to their constituents. I think that there needs to be some published information.

Legislation—I mean we could vote on what ways we want them to use it.

A few participants expressed some skepticism, however. They thought that their opinions might be ignored.

I send a letter to my congressman and . . . he gets deluged with letters, and where do they go? What happens to them? What results did we point out?

When Consumers Should Become Engaged

The moderators asked the participants about the appropriate times for health care consumers to become involved in the design of electronic health records and other health IT. Both heavy and light users of health care preferred to have an early voice in the design of health IT systems. But they were more interested in influencing how the system was *used* than in how the system was *designed* – which was seen as a more technical issue.

It should be done in the beginning. We should be in the design. I want to know from the get-go.

Some participants were concerned that if health care consumers were involved too late in the process, they could not have input into something that's already moving along. Others thought that technology was progressing so quickly that it might be difficult for them to have an impact on it.

I think by the time you're getting involved in the process, it's already leaped over you and gone down the highway, and you're behind.

We all know that it is going to steamroll over all of us.

The Need for Consent

A very large proportion of participants felt that they should be asked for their consent before their information was stored in an electronic system. The consent would specify what information could be shared with whom, and under what circumstances.

On the consent forms you could have lines and then check boxes.

I authorize this, this, and this, maybe not this.

Yeah, something like that, where you've got check boxes that you could check what you would allow to be shared. You could have a consent form, but certain conditions could change, and stuff like that...They would come to you and say, "Beyond this, if this situation occurs while I am with you...?" Then you could opt to expand the information to other people.

I think that there should be a list of every single entity that could possibly access your medical records. And then you would check off the ones you would allow.

Researchers should not have access to your medical files unless you give consent to something like that...Even if somebody is tapping into my record just for training or something like that, I'd still have a problem. Unless they asked you "if you agree or not agree" to have that done. And if I say "yeah, go ahead and do it."

However, some participants argued for a simple consent form, in which the consumer either gives or withholds consent to allow the provider to use the consumer's medical data however the provider wishes. One participant thought that a new bureaucracy would be needed if there were too many health IT consent forms, or if the consents were too complicated.

I think there's only one situation and it's either yes or no. You either give it out, you assume responsibility, or the doctor assumes responsibility for your information. He'll give it out or no, he can't touch it. No if's, and's, or but's. Because you can't determine by giving him a list. "Oh, I didn't want this to go to cancer research. I wanted this only for lymphoma." He checked the wrong box or you checked the wrong box. You made a mistake. Boom. So it's either yes or no situation as far I'm concerned on that. It's either the information goes out for whoever wants or it stays right there.

I'm big on consent. I think you should have consent. One of the ways you can probably do that is have some kind of code on your [driver's] license. On the identification, then if you put this code in the computer they know all the information will pop up. But, just having access to it, I have a problem with that.

Separate Consent for Mental Health Information

When asked specifically about having a separate consent for mental health, some consumers immediately endorsed the idea. They gave two reasons for this position: first, mental health

issues may have limited impact on physical diseases or injuries; second, release of mental health information might impact a patient's employment opportunities. Some participants pointed out that psychotropic medication can influence treatment choices for physical disease. One participant expressed a concern about the safety of health care workers who might not realize they were dealing with a psychologically impaired individual. The discussions never reached a consensus on whether a separate consent was needed for mental health information.

Time Limits on Consent

Most of the focus groups were receptive to time limits on consent. The participants' conceptions of time limits generally took one of two forms: either the consent should be reviewed or renewed after a definite duration, or the consent would be revised when the consumer wanted to make changes. Most commonly, the participants suggested that consents be renewed annually. Some participants suggested every two years, or every three years. Other consumers suggested that the consent form be available for the patient to revise at will, or that the consent should remain in force until changed by the consumer. Focus group participants noted that the patients' concerns might change as they age or suffer from different ailments, and that their consent might need to change to reflect their new circumstances.

[The checklist should be] subject to review after two years, three years. I think that's a good idea, because how I felt in '75 was a whole lot different than how I felt in '08.

As you get older, too, things become more important in some areas than they were when you're younger. Things that were important to you when you were younger are like, "Hey, that's old! This is more important to me today."

Who Should Ask for Consent?

The participants in most groups thought that consumers should be asked for consent at their doctor's office, either directly by the doctor or by office staff before or during the initial visit. Participants in several groups thought that if a patient did not consent to electronic storage of their information, then the records should be kept as paper copies.

The participants in most groups thought that each provider should ask for consent separately. That way, patients would have the power to provide different instructions for each individual provider. Patients could then decide which providers had sensitive information about them and tailor their consent accordingly.

At the doctor's office, everybody who comes in that doctor's office has to sign a form either consenting to or against your information being shared. One or the other . . . it's bottom line, end of story.

Conclusions

The focus group results point to a number of conclusions.

Salience of the Topic

The focus group discussions suggest that health care is a very important issue to most people, but that the specific issue of health IT is not, because they do not perceive a strong connection between health IT and health care quality. The participants tended to perceive that health IT could affect health care quality only in limited ways, such as by making health care more convenient, adding speed and efficiency, and avoiding errors such as those caused by poor handwriting. There was little sense in any of the focus groups that the participants believed that health IT would have an important impact on health care consumers' experiences obtaining care or that consumers needed to be empowered to control that impact.

However, the participants consistently had strong feelings about the effect of computers upon the privacy of personal information. Their concern extended to all forms of information, both sensitive and non-sensitive. The participants wanted some assurance that their medical data would be secure and used only in ways that they authorized. They generally believed that health care consumers needed to be involved in deciding how health IT was used, in order to protect their own medical information.

These results suggest that many people may not understand the emphasis on health IT in the current debate on health care reform, and the funds allocated in the American Recovery and Reinvestment Act of 2009 to foster the adoption of health IT. They may not perceive health IT as a central issue in the ongoing health care debate, outside of the narrow area of data security and privacy.

Awareness

A majority of the participants believed that their providers were already using health IT to manage their patients' medical data and for other purposes. Recent provider surveys, however, suggest that only a relatively small proportion of providers use health IT.¹¹ The reason for this discrepancy may pertain to the participants' expectations. Perhaps many participants reasoned that computer usage has become nearly ubiquitous, so they strongly expected their physicians to be using computers. They therefore erroneously reported that their providers were using health IT.

Across all the focus groups, HMO members appeared to be most likely to report that they used computers themselves to interact with their physicians and that their physicians used computers in the course of providing health care. This result is not surprising, since many HMOs have already adopted health IT.

Participants in the Spanish language groups appeared less likely than those in the English language groups to report that they saw their physicians using computers in the course of providing care. The reasons for this finding are not clear from the conversations in the groups. Perhaps physicians serving Spanish-speaking patients are less likely than other physicians to use health IT. Some of the participants in the Spanish focus groups were uninsured, who received their health care in safety net clinics. While some of these clinics are adopting health IT, many still use paper-based records. Also, the Spanish-speaking participants may not have had the expectation that their providers would be using health IT.

In all, the results from the focus groups point to a need for public education. Many people apparently incorrectly assume that health IT is very widely adopted throughout the health care system. That, coupled with an incomplete understanding of how health IT might affect health care quality, could hinder health care consumers from perceiving the full breadth of reasons why they might want to be involved in determining how health IT is designed and used.

Beliefs and Perceptions

Overall Reaction to Health IT

The results suggest that most people generally have positive opinions about how health IT could affect health care. Those opinions could generally be summarized as: health IT can make providers more efficient, allow them to offer speedier and more diverse services, and eliminate some medical errors. That is, they view health IT as helpful, but not as a source of fundamental change in health care.

Effect of Health IT on the Role of Patients

The results also suggest that people view their role in health care as a passive one. They do not perceive a role for themselves in actively collaborating with their providers in their care. They may not support the idea that health care consumers could help design health IT to enable patients to play a greater role in their own care.

The results also suggest that people are generally unsupportive of PHRs. This result seems to conflict with the experience of many providers who are offering PHRs. People may not perceive a strong advantage to being able to view their own health records electronically using a PHR system, or using a PHR system to change their health behaviors, or using a PHR to share decisionmaking with their providers. They tend to view health IT as being solely the domain of providers.

If the participants in these focus groups are similar to health care consumers generally, then this passive attitude may slow PHR adoption across the country. Providers may have little motivation to adopt a technology for patients to use when the patients do not perceive a reason for using it. Until the use of PHR expands over time, and health care consumers gain experience with it, there may not be strong public support for a role for consumers in the design of PHRs.

Privacy and Security

The results strongly suggest that the public is very concerned about the privacy and security of their medical data. With only a few exceptions, this concern is a matter of principle—a feeling that one’s medical data is “no one else’s business.” Participants appeared not to fear specific problems that might arise from breaches of privacy and security.

The threats to privacy and security that may be a source of concern are that hackers or other people would gain inappropriate access to other people’s data, that power outages and system failures might cause problems for health IT systems, and that even small errors in a patient’s medical data might cause large problems in an electronic system. Some of the focus groups were held in a city where there had been much publicity over the loss of a CD containing medical data about a large number of people. Also, some of the focus groups were held where there had recently been a power outage lasting several days. In those groups, many participants pointed to these events as evidence that health IT was vulnerable to problems. Only a few participants expressed the opposite view: that in the event of a natural disaster like Hurricane Katrina, electronic records are more likely to persist than paper records, or that paper records are more likely than electronic records to be misplaced.

Members of the public may feel that health care consumers should have a role in making important decisions about health IT in order to safeguard the privacy and security of their medical data. They believe that if health care consumers did not participate in making these decisions, then parties who did not have the best interests of patients in mind might make these decisions. In the focus groups, some participants were concerned that health insurers might make the decisions, and some were concerned about government agencies.

These results suggest that public attitudes toward health IT will evolve as more people get experience with the technology.

The Patient-Provider Relationship

The results of the focus groups suggest that as consumers gain greater experience with health IT, they will observe how it affects the behavior of providers. If people perceive that health care becomes more impersonal and that providers seem more detached, they may become less supportive of health IT.

Telemedicine, Decision Support, Health Care Costs

In the immediate future, health IT may prove its worth to health care consumers by enhancing their experience of health care. Consumers may perceive that health care becomes more accessible via telemedicine, that outcomes improve because of decision support systems, and that health care costs moderate. If so, they will support greater adoption of health IT.

Public support for health IT may be important in the immediate future, when physicians and hospitals are considering sizable investments in the technology. The extent of public support may influence the rate of adoption of health IT.

Consumer Engagement

Initial Response to the Question “Who Should Decide?”

The results suggest that people do not know how health care policy is debated and adopted. Many mistaken beliefs surfaced during the focus groups. For example, it was widely held that some organization like the American Medical Association was totally in charge of determining how health IT was to be designed and used.

The results also suggest that people are largely uninformed about health IT. No focus group participants appeared to be aware of the Office of the National Coordinator for Health IT, the Health Information Security and Privacy Collaboration, or any other existing Agency or Federal initiative created to support the adoption and use of health IT. No participants in the focus groups that occurred after passage of ARRA mentioned reading about how that act helped to set policy about health IT. However, in the particular case of health IT, the lack of knowledge pertains to an issue that will be the subject of great governmental effort and spending in the immediate future. Conceivably, the lack of knowledge could pose a challenge the success of ongoing health IT efforts.

The Role of Medical and Computer Experts

The results suggest that many participants believe that that only those with expertise in medicine or computers should participate in decisions regarding health IT. Participants stated that they themselves lacked sufficient knowledge about medicine or computers to dare to venture an opinion on these subjects. The moderators usually attempted to persuade these participants that they could have an opinion about how health IT will affect them, even when they had little expertise in medicine or computers. The moderators usually had only limited success in persuading the participants that this was the case.

The Role of Health Insurers

The results suggest that some focus group participants believe that insurance companies have too much influence in the health care field. Many think that the companies try to maximize their profits without serving the public interest. Many are concerned that insurers would try to obtain private medical data in order to serve their own purposes. Some wonder whether insurers could already access and use medical data in ways that patients might not like, such as for market research.

The Role of Government

In the focus groups, some participants felt that government was in the best position to serve the public interest. They favored legislation or referenda on health IT. Some believed that health care consumers could best influence the adoption and use of health IT by writing to their elected representatives. Some called for an election—meaning a ballot initiative or proposition

on health IT. Other participants took the opposite view. They did not like the idea of a government role in health care. Many of these participants appeared to be philosophically committed to a limited government role in general.

A number of participants were concerned that government might seek to view people's health records for its own purposes. These participants did not present any evidence or details. They mistrusted the government, and in some cases mentioned the possibility that government workers already had found a way to obtain private medical data of patients. Some mentioned that in order to combat potential terrorism, the government will seek to access all manner of private records.

In actuality, Federal and State governments are playing very prominent roles with regard to health IT. The American Recovery and Reinvestment Act of 2009 contains many pages devoted to health IT policy and particularly the security of patient data. The act sets up advisory committees to help guide health IT policy. The Office of the National Coordinator for Health IT, which is a part of the Department of Health and Human Services, the National eHealth Collaborative, which is a public-private collaboration, and many other committees are also helping to steer health IT policy. State governments are helping to design and build health information exchange organizations. The participants in the focus groups, however, did not spontaneously mention the possibility of consumer involvement in these efforts. They did not by themselves bring up the possibility that health care consumers should be members of health IT advisory groups, or should act as consultants for them. When the moderator brought up this possibility, however, some participants seemed interested, while others remained skeptical of the role of government. Over all, these focus groups suggest that only some members of the public will support a role for health care consumers in working closely with government health IT efforts.

The Role of Health Care Consumers

The focus group results suggest that participants believe that health care consumers need to have a role in setting policies concerning health IT in order to safeguard their own private medical data. They feel that if health care consumers do not exert an influence in this regard, then other parties such as the government and health insurers would exert their influence, and gain access to patients' medical records. That is, participants feel that if health care consumers do not act to protect their own interests, those interests might not be protected at all. At the same time, they are not certain how health care consumers might best exert their influence. Many focus group participants expressed a lack of understanding about how health IT decisions were made in general; as a result, they also could not understand how consumers could influence those decisions.

Issues on Which Health Care Consumers Should Have a Voice

The results suggest that many participants do not see a role for health care consumers in influencing the adoption and use of health IT outside of the areas of privacy and security. At the present time, the issues of privacy and security are the most important ones to large portions of

the public on the topic of health IT. Other topics, such as how health IT can affect the quality of health care and the experience of patients, may be important to much smaller numbers of people.

Feelings of Disempowerment

The results suggest that many focus group participants feel that the needs of health care consumers often are different from those of the government and health insurers. Some participants expressed a despairing feeling, that there was no way to protect the privacy and security of medical data because government and health insurers had too much power and health care consumers had too little. Some also said that hackers and criminals would always find a way to circumvent any efforts to safeguard data. Many members of the public may feel similarly.

How Consumers Could Be Engaged in Health IT Decisionmaking

The results suggest that the participants feel confusion over how health care consumers could best be engaged in influencing the adoption and use of health IT. They nonetheless see the need for consumers' involvement, primarily to protect the privacy of patients' data.

The results suggest that participants believe that organizations such as AARP and the Red Cross were not positioned to represent their interests in health IT. Almost no participants thought that health IT vendors would be interested in hearing input from the public. Some participants felt that patients could exert their influence simply by communicating with their elected representatives, who would pass appropriate regulations. Other participants felt that this was a futile approach.

No participant spontaneously mentioned the idea of putting patient representatives on the committees that set policy at health care organizations. The participants seemed unfamiliar with this approach and did not have well formed opinions about how it could be implemented. However, when the moderator mentioned the idea, some participants appeared to be interested in it. Its appeal centered on how it involved patients directly in the process, while still leaving the decision making with medical and computer experts. Clearly, this is an idea that could appeal to many people.

A few participants favored surveys and focus groups as a way for health care consumers to express their views. Many participants remained uncertain about whom the surveys and focus groups would influence.

When Consumers Should Become Engaged

The many participants who expressed concern with the privacy and security of their medical data tended to feel strongly. They wanted health care consumers to have a role quickly in protecting the data. Many members of the public may feel similarly.

The Need for Consent

Some participants thought that consent forms would be the best way to allow individual patients elect to grant or deny their permission for their data to be stored and shared. Most participants agreed that these consent forms should not provide blanket consent, but should allow patients to set rules separately for especially sensitive information such as HIV status, mental health, and reproductive health. The participants felt that the consent forms should also have time limits and should be administered by individual providers. For example, each individual practice would ask each patient to sign. The participants in these focus groups did not have strong opinions about the wording for these consents.

The idea that seemed to garner the most support was that each individual provider should ask each patient for consent to keep that patient's data in electronic format, and to share those data with others. The participants seemed to feel that if the patient withheld consent, then that patient's data should remain in paper format. Or, the data might be stored electronically, but never shared. In this way, a patient who was seeing one physician for a sensitive condition like HIV infection might not sign that physician's consent, even though that patient signed the consent for other physicians.

If this consent arrangement were implemented, it would present numerous challenges. First, it is not clear how applications would be designed to do so. Perhaps, data for one physician would be tagged as "never share." It is unclear, then, what might happen if sensitive data got into a health IT system anyway, in the notes of another physician. Is it the nature of the information, or is it the physician who entered it, that triggers the "do not share" tag? Also, what would happen in an emergency situation? Would the patient be granted the opportunity to remove the "do not share" restriction?

Most importantly, the results suggest that the participants do not have a clear idea about how these policies on getting consent could be set in place, or on how health care consumers could influence these policies. Although many focus group participants feel the need to exert an influence to protect their data, they do not understand how or with whom they could exert that influence.

Next Steps

Public Education

The results of the focus groups suggest that public education about health IT is needed. The education might address how health IT will affect the experiences of all health care consumers. It might also address how and why public opinion about health IT will influence the ways that health IT is designed and used. It might also show the public how patients can influence how health IT is designed and used.

Patient education about the privacy of medical data also seems to be needed. The potential impact of technology on privacy is very much on the minds of patients. To many patients, the

issue of privacy overrides all other issues. These focus groups suggest that the public tends to perceive that electronic data storage poses threats to privacy that are qualitatively different from those posed by paper-based systems. Some believe that the government or health insurers are already accessing patient data for their own goals, unrelated to patient care. Clearly, an open public discussion on these matters is appropriate.

For example, the participants in the focus groups said that patients should have a say in privacy and security issues right away. The participants were unsure of how health care consumers could exert their influence, however. The means for them to have a say should be established and publicized. For example, opportunities for patient representation on governmental and provider advisory committees might be publicized. Without such publicity, some health care consumers may become cynical, thinking that all decisions are made by insurance companies, government, or special interests.

Future Focus Groups

These focus groups could serve as baseline representations of public opinion, as health IT expands throughout the health care system and patients have more experience with it. Future focus groups can demonstrate whether the public has gained a greater understanding about the potential impact of health IT on the quality of care and the experience of patients. In particular, the focus groups could explore whether the public's major concerns about health IT have extended beyond the issues of privacy and security.

The two-part method used in the present focus groups could be used in future focus groups. In the first part, the participants discuss the capabilities of health IT. They are then familiar with the issues surrounding health IT for the second part of the focus group, when they discuss the specific issue of consumer empowerment.

Future focus groups could also demonstrate whether public fears about the security and misuse of their medical data have grown or diminished. The focus groups could also suggest whether health care consumers believe that they are having an adequate say in the design and use of health IT. In sum, focus groups may be an effective way to gauge whether health care consumers feel empowered in influencing the expansion of health IT in the health care system.

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Appendix A: Sample Participant Recruiting Screener

We are looking for people willing to come to Westat for a focus group discussion being conducted for a government health agency (Agency for Healthcare Research and Quality). It will take up to 2 hours (topic is related to health care), and we're paying people \$75 for participating. The focus groups are being held Thursday and Friday, January 29th and 30th.

In order to find out if you are eligible to participate in this study, I need to ask you a few questions.

Q1a. What is your age? _____

Q1b. Have you participated in any type of focus group study, either for us or another firm, within the past 6 months?

1. YES (NOT ELIGIBLE)
2. NO

Q1c. Have you worked in a health care setting at all since 1998? (e.g., Doctor's office, hospital, medical clinic, nursing home)

1. YES (NOT ELIGIBLE)
2. NO

Q1d. Have you worked in information technology at all since 1998? (e.g., network administrator, systems analyst, computer programmer)

1. YES (NOT ELIGIBLE)
2. NO

Q2. When was the last time you visited any type of health care provider for your own care? (By health care providers, we mean medical doctors, nurses, or hospitals, but not dentists)

1. MORE THAN TWO YEARS AGO/BEFORE DECEMBER 2006] (SKIP TO Q4)
2. WITHIN THE PAST TWO YEARS / SINCE DECEMBER 2006]

Q3. How many different health care providers have you visited for your own health since December, 2006? (this includes medical doctors, nurses, or hospitals, but not dentists)

NOTE: Seeing different doctors in the same clinic/hospital counts as multiple providers

1. ONE
2. TWO
3. THREE OR MORE

Q4. Have you visited any type of health care provider for the care for a close family member since December, 2006? (By health care providers, we mean medical doctors, nurses, or hospitals, but not dentists)

1. YES
2. NO (SKIP TO BOX 1)

Q5. How many different health care providers have you visited for the care of a close family member since December, 2006? (this includes medical doctors, nurses, or hospitals, but not dentists)

NOTE: Seeing multiple doctors in the same clinic/hospital counts as multiple providers

1. ONE
2. TWO
3. THREE OR MORE

BOX 1

IF NO VISITS AT ALL TO A HEALTHCARE PROVIDER SINCE DECEMBER 2006
THEN NOT ELIGIBLE

OTHERWISE, CONTINUE

Q6. Are you managing any chronic health conditions, or assisting a close family member in the management of their chronic health condition? (By “managing” we mean something has to be done with respect to the health condition, such as taking medication, making regular doctor visits, or following a strict diet)

1. YES – MY OWN CONDITION
2. YES – ASSISTING CLOSE FAMILY MEMBER
3. NO

Q7. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare or Medicaid? (This is about you, yourself. I will ask about your family member in a moment)

1. YES
2. NO (SKIP TO BOX 2)

Q8. What kind of health care coverage do you have? (NOTE: Persons on Medicare/Medicaid or VA/Military care can also be HMO, PPO, etc.)

SELECT ALL THAT APPLY

1. HMO
2. PPO
3. MEDICARE
4. MEDICAID
5. VA/MILITARY
6. OTHER (SPECIFY): _____
7. DON'T KNOW

BOX 2

IF MADE HEALTHCARE VISITS FOR A CLOSE FAMILY MEMBER, ASK Q9

OTHERWISE SKIP TO Q11

Q9. Does the family member for whom you have visited a health care provider have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare or Medicaid?

1. YES
2. NO (SKIP TO Q11)

Q10. What kind of health care coverage does this family member have? (NOTE: Persons on Medicare/Medicaid or VA/Military care can also be HMO, PPO, etc.)

SELECT ALL THAT APPLY

1. HMO
2. PPO
3. MEDICARE
4. MEDICAID
5. VA/MILITARY
6. OTHER (SPECIFY): _____
7. DON'T KNOW

Q11. I have just a few more questions. What is your race or ethnic background? [CAN SELECT MORE THAN ONE]

1. WHITE
2. BLACK OR AFRICAN-AMERICAN
3. HISPANIC OR LATINO
4. ASIAN
5. AMERICAN INDIAN OR ALASKA NATIVE, OR
6. NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER
7. OTHER: _____

Q12. [IF NOT OBVIOUS, ASK] Are you male or female?

1. MALE
2. FEMALE

Q13. How often would you say that you use a computer for any purpose? Would this be....

1. Often
2. Now and then
3. Only rarely, or
4. Never?

Q14. What is the highest level of education you completed?

1. LESS THAN HIGH SCHOOL
2. HIGH SCHOOL GRADUATE
3. SOME COLLEGE/VOC. ED
4. COLLEGE GRADUATE
5. ADVANCED DEGREE

BOX 3

CHECK RECRUITING TARGETS TO DETERMINE WHETHER THIS PERSON IS
NEEDED AND FOR WHICH GROUP

IF NOT, THANK AND TERMINATE

IF SO, CONTINUE

We would like to invite you to attend a focus group discussion with about 10 other people. Can you attend on....

- Thursday, January 29th from 3pm to 5pm
- Thursday, January 29th from 6pm to 8pm
- Friday, January 30th from 12 noon to 2pm

Thank you for agreeing to participate. We will be mailing you a letter and calling you the day before the discussion to confirm the time and location. Could I (get/confirm) your name and mailing address?

NAME: _____

ADDRESS: _____

_____ ZIP: _____

PHONE: (home)_____ (work)_____

Thank you for your time, and we look forward to seeing you on [DATE].

Appendix B: Tables of Focus Group Participant Characteristics

Midwest: Group 1
 Location: Columbus, OH
 Number of Participants: 10

Number of health care providers visited in last two years
 One: 0
 Two: 2
 Three or more: 8

Presence of chronic illness (self or family member)
 Yes: 5
 No: 5

Health insurance coverage (self and family member; some participants may have more than one)
 None: 3
 HMO: 1
 PPO: 5
 EPO: 1
 SSI: 0
 Medicare: 5
 Medicaid: 2
 VA: 1
 Don't know: 0

Age range: 22-54

Sex
 Male: 5
 Female: 5

Race
 White: 8
 African American: 2

Education
 <HS grad: 0
 HS grad: 3
 Some college: 3

College grad:2

Post grad education:2

Use of computer
 Never:0
 Rarely:2
 Now and then:1
 Often:7

Midwest: Group 2
 Location: Columbus, OH
 Number of Participants: 8

Number of health care providers visited in last two years
 One:4
 Two:4
 Three or more:0

Presence of chronic illness (self or family member)
 Yes:0
 No:8

Health insurance coverage (self and family member; some participants may have more than one)
 None:2
 HMO:4
 PPO:1
 EPO:0
 SSI:0
 Medicare:0
 Medicaid:0
 VA:0
 Don't know:1

Age range: 22-61

Sex
 Male:5
 Female:3

Race
White: 6
African American: 2

Education
<HS grad: 0
HS grad: 2
Some college: 3
College grad: 3
Post grad education:

Use of computer
Never: 0
Rarely: 0
Now and then: 2
Often: 6

Midwest: Group 3
Location: Columbus, OH
Number of Participants: 10

Number of health care providers visited in
last two years
One: 7
Two: 3
Three or more: 0

Presence of chronic illness (self or family
member)
Yes: 1
No: 9

Health insurance coverage (self and family
member; some participants may have more
than one)
None: 1
HMO: 0
PPO: 7
EPO: 0
SSI: 0
Medicare: 1
Medicaid: 2
VA: 0
Don't know: 0

Age range: 25-70

Sex
Male: 5
Female: 5

Race
White:7
African American:3

Education
<HS grad:0
HS grad:3
Some college:1
College grad:4
Post grad education:2

Use of computer
Never:0
Rarely:0
Now and then:2
Often:8

Midwest: Group 4
Location: Rural Ohio
Number of Participants: 9

Number of health care providers visited in
last two years
One: 0
Two: 1
Three or more: 8

Presence of chronic illness (self or family
member)
Yes: 8
No: 1

Health insurance coverage (self and family
member; some participants may have more
than one)
None: 2
HMO: 1
PPO: 2
EPO:..... 0
SSI: 1
Medicare: 2
Medicaid: 5
VA: 2
Don't know: 0

Age range: 20-76

Sex
Male: 3
Female: 6

Race
 White:9
 African American:0

Ethnicity
 Hispanic: 10

Education
 <HS grad:0
 HS grad:5
 Some college:3
 College grad:0
 Post grad education:1

Education
 <HS grad: 2
 HS grad: 2
 Some college: 2
 College grad: 3
 Post grad education: 1

Use of computer
 Never:0
 Rarely:4
 Now and then:0
 Often:5

Use of computer
 Never: 2
 Rarely: 0
 Now and then: 2
 Often: 6

West: Group 1
 Location: Denver, CO - Spanish
 Number of Participants: 10

West: Group 2
 Location: Denver, CO - Spanish
 Number of Participants: 10

Number of health care providers visited in last two years
 One:7
 Two:3
 Three or more:0

Number of health care providers visited in last two years
 One: 0
 Two: 3
 Three or more: 7

Presence of chronic illness (self or family member)
 Yes:0
 No:10

Presence of chronic illness (self or family member)
 Yes: 7
 No: 3

Health insurance coverage (self and family member; some participants may have more than one)
 None:2
 HMO:5
 PPO:2
 EPO:0
 SSI:0
 Medicare:1
 Medicaid:0
 VA:0
 Don't know:0

Health insurance coverage (self and family member; some participants may have more than one)
 None: 3
 HMO: 3
 PPO: 4
 EPO: 0
 SSI: 0
 Medicare: 0
 Medicaid: 0
 VA: 0
 Don't know: 0

Age range: 27-57

Age range: 25-48

Sex
 Male:5
 Female:5

Sex
 Male: 4
 Female: 6

Ethnicity
Hispanic:10

Education
<HS grad:2
HS grad:3
Some college:3
College grad:2
Post grad education:0

Use of computer
Never:0
Rarely:0
Now and then:1
Often:9

West: Group 3
Location: Denver, CO
Number of Participants: 10

Number of health care providers visited in last two years
One:7
Two:3
Three or more:0

Presence of chronic illness (self or family member)
Yes:0
No:10

Health insurance coverage (self and family member; some participants may have more than one)
None:10
HMO:0
PPO:0
EPO:0
SSI:0
Medicare:0
Medicaid:0
VA:0
Don't know:0

Age range: 40-59

Sex
Male:5
Female:5

Race/Ethnicity
White:8
African American:0
Hispanic:2

Education
<HS grad:0
HS grad:2
Some college:3
College grad:3
Post grad education:2

Use of computer
Never:0
Rarely:0
Now and then:2
Often:8

West: Group 4
Location: Denver, CO
Number of Participants: 10

Number of health care providers visited in last two years
One:2
Two:0
Three or more:8

Presence of chronic illness (self or family member)
Yes:6
No:4

Health insurance coverage (self and family member; some participants may have more than one)
None:1
HMO:6
PPO:0
EPO:0
SSI:0
Medicare:2
Medicaid:0
VA:1
Don't know:0

Age range: 28-70

Sex
Male:4
Female:6

Race/Ethnicity
 White:6
 African American:1
 Hispanic:3

Education
 <HS grad:0
 HS grad:2
 Some college:5
 College grad:3
 Post grad education:0

Use of computer
 Never:0
 Rarely:1
 Now and then:0
 Often:9

Northeast: Group 1
 Location: Providence, RI
 Number of Participants: 10

Number of health care providers visited in last two years
 One:0
 Two:3
 Three or more:7

Presence of chronic illness (self or family member)
 Yes:6
 No:4

Health insurance coverage (self and family member; some participants may have more than one)
 None:3
 HMO:0
 PPO:4
 EPO:0
 SSI:0
 Medicare:3
 Medicaid:1
 VA:0
 Don't know:0

Age range: 22-58

Sex
 Male:3
 Female:7

Race
 White:9
 African American:1

Education
 <HS grad:0
 HS grad:3
 Some college:3
 College grad:3
 Post grad education:1

Use of computer
 Never:0
 Rarely:0
 Now and then:2
 Often:8

Northeast: Group 2
 Location: Providence, RI
 Number of Participants: 10

Number of health care providers visited in last two years
 One:1
 Two:2
 Three or more:7

Presence of chronic illness (self or family member)
 Yes:6
 No:4

Health insurance coverage (self and family member; some participants may have more than one)
 None:1
 HMO:1
 PPO:6
 EPO:0
 SSI:0
 Medicare:0
 Medicaid:1
 VA:1
 Don't know:0

Age range: 35-65

Sex
 Male:4
 Female:6

Race/Ethnicity	
White:	4
African American:	4
Hispanic:	1
Asian:	1

Education	
<HS grad:	0
HS grad:	2
Some college:	4
College grad:	2
Post grad education:	2

Use of computer	
Never:	0
Rarely:	0
Now and then:	0
Often:	10

Mid-Atlantic: Group 3
 Location: Rockville, MD
 Number of Participants: 8

Number of health care providers visited in last two years	
One:	4
Two:	4
Three or more:	0

Presence of chronic illness (self or family member)	
Yes:	1
No:	7

Health insurance coverage (self and family member; some participants may have more than one)	
None:	0
HMO:	0
PPO:	6
EPO:	0
SSI:	0
Medicare:	1
Medicaid:	1
VA:	1
Don't know:	0

Age range: 20-55

Sex	
Male:	3
Female:	5

Race	
White:	3
African American:	5

Education	
<HS grad:	0
HS grad:	0
Some college:	3
College grad:	4
Post grad education:	1

Use of computer	
Never:	0
Rarely:	0
Now and then:	0
Often:	8

Mid-Atlantic: Group 4
 Location: Rockville, MD
 Number of Participants: 10

Number of health care providers visited in last two years	
One:	10
Two:	0
Three or more:	0

Presence of chronic illness (self or family member)	
Yes:	1
No:	9

Health insurance coverage (self and family member; some participants may have more than one)	
None:	3
HMO:	4
PPO:	2
EPO:	0
SSI:	0
Medicare:	2
Medicaid:	0
VA:	0
Don't know:	0

Age range: 24-68

Sex	
Male:	6
Female:	4

Race/Ethnicity	
White:	4
African American:	1
Hispanic:	2
African American/Asian:.....	2

Education	
<HS grad:	1
HS grad:	1
Some college:	3
College grad:	3
Post grad education:	2

Use of computer	
Never:	0
Rarely:	1
Now and then:	1
Often:	8

South: Group 1
 Location: Miami, FL - Spanish
 Number of Participants: 9

Number of health care providers visited in last two years	
One:	9
Two:	0
Three or more:	0

Presence of chronic illness (self or family member)	
Yes:	0
No:	9

Health insurance coverage (self and family member; some participants may have more than one)	
None:	1
HMO:	6
PPO:	0
EPO:	0
SSI:	0
Medicare:	2
Medicaid:	2
VA:	0
Don't know:	0

Age range: 32-57

Sex	
Male:	4
Female:	5

Ethnicity	
Hispanic:	9

Education	
<HS grad:	1
HS grad:	3
Some college:	0
College grad:	2
Post grad education:	3

Use of computer	
Never:	1
Rarely:	0
Now and then:	1
Often:	7

South: Group 2
 Location: Miami, FL
 Number of Participants: 9

Number of health care providers visited in last two years	
One:	0
Two:	3
Three or more:	6

Presence of chronic illness (self or family member)	
Yes:	7
No:	2

Health insurance coverage (self and family member; some participants may have more than one)	
None:	1
HMO:	7
PPO:	0
EPO:	0
SSI:	0
Medicare:	1
Medicaid:	3
VA:	0
Don't know:	0

Age range: 23-72

Sex	
Male:	4
Female:	5

Race/Ethnicity
 White:6
 African American:0
 Hispanic:3

Education
 <HS grad:0
 HS grad:2
 Some college:1
 College grad:4
 Post grad education:2

Use of computer
 Never:0
 Rarely:0
 Now and then:1
 Often:8

South: Group 3
 Location: Miami, FL
 Number of Participants: 10

Number of health care providers visited in last two years
 One:0
 Two:5
 Three or more:5

Presence of chronic illness (self or family member)
 Yes:7
 No:3

Health insurance coverage (self and family member; some participants may have more than one)
 None:2
 HMO:7
 PPO:0
 EPO:0
 SSI:0
 Medicare:3
 Medicaid:2
 VA:0
 Don't know:0

Age range: 37-72

Sex
 Male:5
 Female:5

Race/Ethnicity
 White:6
 African American:1
 Hispanic:3

Education
 <HS grad:0
 HS grad:3
 Some college:2
 College grad:3
 Post grad education:2

Use of computer
 Never:0
 Rarely:0
 Now and then:1
 Often:9

South: Group 4
 Location: Rural NC
 Number of Participants: 10

Number of health care providers visited in last two years
 One:9
 Two:1
 Three or more:0

Presence of chronic illness (self or family member)
 Yes:3
 No:7

Health insurance coverage (self and family member; some participants may have more than one)
 None:5
 HMO:0
 PPO:1
 EPO:0
 SSI:0
 Medicare:1
 Medicaid:3
 VA:1
 Don't know:0

Age range: 24-65

Sex
 Male:5
 Female:5

Race/Ethnicity	
White:	7
African American:	1
Native American:	1
White/Native American:	1

Education	
<HS grad:	1
HS grad:	3
Some college:	4
College grad:	2
Post grad education:	0

Use of computer	
Never:	2
Rarely:	1
Now and then:	2
Often:	5

Appendix C: Focus Group Moderator's Guide

[Health IT Focus Group Discussion Guide, January 19, 2009]

Thank you for joining us. Let me tell you what this discussion is about.

I work for Westat, a research company based in Rockville, Maryland that conducts studies on many different topics, for many different clients. This particular project is for the Agency for Healthcare Research and Quality, a Federal Government Agency with a leading role in research on the quality and effectiveness of health care. Today we're getting your thoughts and ideas on a specific issue within the health care system that has come about in the last several years, and will likely continue to be an important issue in the future – the issue is the increasing use of and reliance on computers in providing health care. I'll be asking about your opinions and beliefs on certain things related to this.

Before we go on, I need to make a few things clear.

- First of all, unless it's critically important for you to leave your cell phones and pagers on, I'd appreciate it if you could turn them off, so that they won't interrupt our discussion.
- I have to emphasize that there are no right or wrong answers to the questions I'll be asking of you. The whole point of this discussion is to obtain your thoughts, experiences, and ideas on some topics I'll be giving you. It doesn't matter whether you have a positive or a negative opinion about something, as long as it is your honest opinion. And with some of the questions I ask, I understand that you may not really have an opinion – that's okay too.
- Next, I want to assure you that everything we discuss today will remain absolutely confidential: whatever information we obtain from you will not be shared with anyone in a way that identifies who you are.
- Behind me is a one way mirror. But no one is observing us, in case you were wondering.
- Also, this discussion is being videotaped and audio-taped – this is so that we have something to review later on for writing my report. But I assure you that no one who is not directly involved in this research will see the video.
- We have quite a bit of material to cover in about two hours, and I want everyone to get a chance to speak when they have something to say. So I ask that you try to keep your comments brief and related to the issue at hand. If I interrupt you at some point, please don't take it personally – it's just that I have to keep us focused and moving along. Please speak up so everyone can hear you. And I'd appreciate it if you wait until another person is finished speaking before speaking yourself.

Before we start the discussion, why don't we briefly introduce ourselves. Let's go around the room and have everyone state their first name, and tell us what kind of work you do, or what you like to do in your free time, or something else about yourself.

A. Awareness of Health IT (20 mins)

Note to the moderator: Ensure that the group keeps discussing the advantages and drawbacks of physicians' use of computers. Refocus the group if it begins to discuss tangential topics such as patients' use of the Internet to learn about diseases, or the merits of certain diagnostic tests, or lists of good doctors, and so on. The discussion should always be about the impact, good or bad, of physicians' use or lack of use of computers. The goal is to force the participants to think about the potentially good and bad effects of health information technology for them. Later on, when you ask the participants about their role in the design and use of health information technology (section C), they should have gained an understanding of why this question is important. Watch the time; you do NOT need to cover every item in sections A and B.

Health Care Providers' Use of Health IT

First, I'm going to ask you to think about the doctor visits you've had over the last year or two, including visits to a doctor for your own health reasons, and also visits where you may have met with a doctor for your child, or for another family member.

During your visit with the doctor – did the doctor use a computer at all (**GET COUNT**)?

- a) Did the doctor enter notes into a computer during the appointment?
- b) Did the doctor use a computer in some way to give you a prescription? For example, did the doctor use a computer to print out a prescription, or did the doctor use a computer to send the prescription to a pharmacy? Or did the doctor just give you a hand-written prescription?
- c) Did the doctor use a computer to order any blood tests or to order anything else for you?
- d) Did the doctor use a computer screen to look at an x-ray?
- e) Did you see the doctor do anything else using a computer? (What was it?)

Participants' Use of Health IT

Have you ever communicated with your doctor by e-mail? (For what sort of purpose?)

Have you ever requested or ordered a refill for a prescription over the Internet? (**if needed:** such as through a website that connects to your doctor's office or a medical clinic)

Have you ever used the Internet to learn the results of a medical test, like the results of a blood test, a urinalysis, a pap smear, and so on? (**if needed:** such as through a website that connects to your doctor's office or a medical clinic)

B. Beliefs and Perceptions of Health IT (50 mins)

Let's go back to thinking about your doctors...

Do think that your doctor can do a better job by using a computer, or no?

- a) Those of you who say "yes," tell me more about that? In what ways can a computer help your doctor do a better job?
- b) Those of you who would say "no," let's hear from you.
- c) Some of you may have a "mixed opinion" about this – can we hear from you as well?

Let me ask you about some specific things that a doctor might do for you – for each, let's talk about how using a computer for it might be helpful or not.

Let's start with progress notes – the notes doctors keep in your record about such things as how your treatment is going, how your condition is getting better or worse, and so on. Some people say that it's good when doctor keeps your progress notes on a computer, instead of on paper. Maybe progress notes are less likely to be lost or misplaced when they are in a computer file than when they are on paper in a folder. What do you think?

But putting something on a computer does not guarantee that there won't be problems. Those of you who use computers at all, you know that sometimes information on a computer can get lost or misplaced, right? Or sometimes errors are made when entering information on a computer that perhaps would not have been made if the information was being entered into a paper record. What do you think?

Do you think the doctor is more likely to have good eye contact with you when talking to you if he or she is keeping notes on a piece of paper or typing into a computer keyboard?

Is it all right for a doctor to be looking at a computer keyboard and computer screen instead of looking at you when the doctor is talking to you?

If your health information were stored on a computer, do you feel confident that the information would be used only to help with your health?

If your health information were stored on a computer, might the information be sent to employers to decide whether to hire you or to fire you? Might your information be sent to an insurance company to decide whether to give you health insurance?

Some people think that your medical information is less likely to fall into the wrong hands if it is stored on a computer. For example, someone could try to steal another person's identity, and claim to be that person, just to use that person's health insurance. Do you think that your medical information is more secure when it is on paper or when it is stored on a computer?

You've probably heard about hackers breaking into computer systems. If your information is stored on a computer, how much would you worry about hackers breaking in and stealing information?

Some say that keeping people's medical information on computers can help with medical research. The researchers will have the information that they need for their studies conveniently on the computer. For example, they could easily look at blood test results for patients who are taking a certain medication. What do you think?

What if a big drug company wanted to get all your doctor's medical records so that they could do research that would help them sell their medicines? Do you think that your doctor should be permitted to give the drug companies your medical record without telling you?

What about prescriptions...Some people say that doctors should always use a computer to print out prescriptions. That way, the pharmacist won't make a mistake because of the doctor's sloppy handwriting. Also, computerized prescriptions can be sent electronically to pharmacies, so that patients don't have to hand-carry the prescription themselves. What do you think?

But can't a doctor enter the wrong prescription using a computer? If the doctor is rushed and doesn't pay careful attention, can the doctor click the wrong medicine, or click the wrong dosage, and not even notice?

Computers can be programmed to give the doctor advice. For example, the computer could point out to the doctor when one medicine might interact with another medicine, or that the

dosage level the doctor is considering is too high given the patient's characteristics. Is this a good thing? [IF PARTICIPANTS RESPOND BY TALKING ABOUT DOCTORS' EXPERTISE: Even though the doctor has years of medical training, new knowledge in the field of medicine becomes available all the time, and it's impossible to anyone to keep up with it]

What if the computer tells the doctor not to prescribe a medicine even though the doctor believes it's the most appropriate medicine? Should the computer's advice override the doctor's judgment?

Now let's cover the possibility that computers might help doctors treat patients with chronic diseases like diabetes. Some say that computers are a good thing for this because they be programmed to search a patient's record and remind doctors when patients are due for prescription refills, followup appointments, medical tests, and so on. Or the doctor's computer system could be programmed to send e-mail reminders directly to patients, thus helping you to remember such things. What do you think?

But people who use computers never use all the features on their computers. If you use a computer yourself, you probably get "pop-up" reminders about things, many of which you ignore. Do you think that doctors will really pay attention to the reminders that computers give them?

Here is another example of how computerized medical records could be used. The Centers for Disease Control, which is a federal government agency, currently monitors some electronic reports from medical laboratories looking for signs of disease outbreaks. They also monitor electronic data looking for signs of terrorism in the form of deadly biological agents. Some people say that as more patient medical information becomes computerized, and the computers are linked together in a network, these monitoring activities can help keep us safe from disease outbreaks and terrorism. How do you react to that?

[IF PARTICIPANTS SAY THAT DOCTORS TALK TO EACH OTHER SO COMPUTER MONITORING IS UNNECESSARY: Will computers do a better job of monitoring for outbreaks than simply relying on doctors to notice outbreaks themselves?]

But do you want your medical information being shared this way? How much access should the government have to your health information?

Computers could make your health information available anywhere it is needed (through the Internet). For example, if you have to see several different doctors for a variety of health conditions, they could easily get access to your medical information. This could be very convenient for patients, as they would not to keep repeatedly giving the same information to doctor after doctor. As another example, imagine you are on vacation somewhere far away, and had to go to an emergency room. The doctors there could potentially get important medical information about you very quickly over a computer, directly from your own doctor's records back home. What are your thoughts about this?

Suppose a patient went to the emergency room with a broken arm, and in that patient's medical records on the computer there were information that the patient considered embarrassing and private, such as such as a history of mental illness, sexually transmitted diseases, or alcoholism. What do you think about that?

Some people say electronic health records can make it easier to monitor the quality of health care that doctors are providing. For example, the agency that reimburses doctors for treating patients on Medicare is currently testing out a system where they can see whether doctors are following guidelines that have been set down for care of specific medical conditions. It's much easier to monitor such things over a computer than it is to examine paper records. What do you think about this?

But sometimes doctors need to think creatively and try something innovative based on their own judgment. If we monitor doctors this way, do you think they may be less likely to do this?

Some doctors and health plans are offering patients "personal health records." Patients can use their computer at home to access their personal health records and read their medical data -- like the results of recent examinations, blood tests, x-rays, and see the medications they are taking, and read about health conditions. Also, the patients can enter information about themselves for their doctors to see, like blood pressure readings the patients took themselves, or blood glucose measurements that they took themselves, or even the times that they got exercise. They are also designed to help people keep track of such things as their children's immunizations and monitor chronic conditions they may have. Can you see any benefits for this? Can you see yourself using this kind of technology?

Sometimes people get overwhelmed with information, especially when the information is made available on a computer. Do you think these personal health records might swamp patients and doctors with so much information that they won't be able to tell what information is important? Could they make it harder to see the truly critical details about one's health, for example?

Some people have said that computers could help make health care less expensive, perhaps by allowing many things to get done more easily and more quickly. Do you agree?

Will health care actually become *more* expensive when doctors buy computers for their offices, and have to upgrade them every so often?

D. Consumer Engagement (30 mins)

Note to the moderator: This section is the most important part of the focus group. Up to now, you have made the participants think about the advantages and drawbacks of health information technology. Now elicit from them their views on their own role. Learn how, when, and why they want to have an impact on these issues.

We've discussed a lot of ways that doctors could use computers in health care—to store your medical records; to share your medical records with other doctors; to order prescriptions and medical tests; to get the results of medical tests; to get advice on making a diagnosis or planning a treatment, and so on. Undoubtedly, the use of computers in health care is going to grow over time.

- a) So who should decide how computers are used in medical care, and what limits and rules should be set for using the computers?
- b) Should people like you have any say in that, or should this be left up to others?
- c) When it comes to the use of computers in health care, what kinds of things or issues would you want to have a voice in?

So to the extent that people like you are to be given a say in the how these computer systems are used ...

- a) How do you think that process should work, exactly? (Probe: How could your ideas and concerns be communicated? And who would you want to communicate with?)
- b) Should the companies (like Microsoft, Google, and Cerner) that make the computer systems and software for electronic health records ask you for your input? (Remember, some of these systems are being designed for health care consumers to use, not just doctors)
- c) Should your doctor (or someone at the doctor's office) ask you for your input? (What should the doctor ask you about, specifically?)
- d) Should a federal government agency conduct a nationwide survey, where the federal government sends you a questionnaire in the mail or call you on the phone to ask you?
- e) What about through focus groups like this? (Probe: Who should run the focus groups and interpret the results?)
- f) What about writing your representatives or Senators in Congress? Attending a government sponsored town-hall meeting?

- g) At what point in the process should you be asked? (Probe: While the computer systems are just being planned? Or during their development? When your doctor is thinking about buying the computer system? Or perhaps later, when the doctor begins to use them?)

Some hospitals and health care networks have “patient representatives” – these are patient volunteers encouraged to participate on decision-making committees with doctors, nurses and administrators. This role is designed to provide the patient's perspective on important decisions that face the hospital or health care network. How do you feel about individuals, who are not medical professionals, serving on committees with doctors, administrators and other experts and making decisions about the use of electronic health records?

- a) Do you believe these patient representatives could represent your views?
- b) How should these patient representatives be selected?
- c) If patient representatives serve on such committees, what specific issues regarding the use of computers do you think patient representatives should have a say in?

There are organizations that represent (or claim to represent) various groups of people, who might speak on your behalf when it comes to how these computer systems are ultimately used.

- a) Are there any organizations you would trust to speak out for you on these matters? (**Probe:** Some groups that might speak out include the AARP, the American Cancer Society, and the Heart Foundation. What about groups such as these?)

Completing Consent Forms at the Doctor's Office

(Some people say / Some of you have said) that patients should be able to fill out a simple form at the doctor's office, which would indicate the patients' allowing or not allowing various things regarding their computerized health records. It might be a series of questions, where you check a “yes” or “no” box for each question.

- a) As specifically as you can, tell me what should be on that form? (What should the questions be?)
- b) When it comes to the sharing of your medical information, would you want give a separate consent for different uses of the information? (That is, sharing information for research purposes versus another doctor needing it to treat you in an emergency, for example). Or would giving a single blanket consent for sharing information be enough?
- c) What about psychiatric information versus information regarding physical health? (Separate consent or a single consent that covers both?)
- d) Should there be a time limit on granting your consent? That is, should expire after a certain amount of time unless you have renewed it?

E. Wrap-up (5 mins)

I want to thank you for a useful discussion.