Consumer and Patient Health Information Needs: Defining “Access” to Information

The American Recovery and Reinvestment Act of 2009 (ARRA) contained significant public funding for health information technology (HIT) adoption. This expenditure of taxpayer money will be judged by the public based on whether their experience with the health care system is improved and whether it meets their needs more effectively as a result of this spending. One of the most immediate needs patients and their caregivers have is direct access to health information that supports them in managing their care and making health care decisions. The HIT Policy Committee recognized this need, and included in its proposed definition for “meaningful use” of HIT, which is linked to provider incentives for HIT adoption, a requirement that patients be provided access to their personal health information in an electronic format, beginning in 2011. The recommendation advances this concept by including real-time access for patients to their information as part of the definition of “Meaningful use” beginning in 2013.

Consumer and patient input is critical for shaping this requirement in ways that ensure meaningful and useful access to information. Key research findings provide an initial picture of how, and for what purposes, consumers would like to access their health information. In the studies, consumers indicated one or more of the following:¹

1. The **types** of health information to which they would like to have access;
2. The **immediacy** with which they would like to have access to their health information;
3. The **medium** they would like to use to access their information; and
4. Their **expectations of and experiences** with how electronic health information would help them.

Additional resources contribute ideas about the anticipated impact of empowering individuals with much broader access to health information. While “meaningful use” is tied specifically to provider incentives, ultimately, providing patients access to information that is housed and controlled by others is just the first step toward empowering consumers and patients through access to information. Subsequent steps will engage patients by creating an ecosystem of tools that help them understand and interpret information they generate and use on their own and in partnership with their providers.

1. **Consumers would like to have access to:**

   • All health information in their electronic medical record (all parts of their provider-based records) even though they may not choose to read/use it all. Specifically, they would like to be able to:
     - Read their doctor’s notes.²
     - Add their own notes to their doctor’s notes.²
     - Update notes with relevant treatment results at a later time.²
   
   • Test/lab results accompanied by explanations.² ³
   • Medication lists accompanied by explanations.²
   • Vaccination records accompanied by explanations.²
   • Billing information accompanied by explanations.²

2. **Timeliness of information:**

   • Patients would like to have immediate access (within hours) to some test results, such as radiological tests, and defined an undesirable “delay” as taking anywhere from days to weeks.³
3. Patient preferences for how information is presented and received include:

- Patients want easy access to their health information in a way that does not require so much “legwork.”  
- Focus group participants felt it would be important to have an option to obtain a paper copy of medical records.
- Focus group participants felt it would be important to be able to access test results online.
- One individual expressed a desire to have a “standardized computer program where you can check all your records.”
- Remote and full access to information in emergency settings and with multiple and new providers was important to most focus group participants.
- Many saw value in receiving information tailored to their preferences for literacy level and graphics/text format.
- Patients expect computers in the future to filter through spam and present to them customized information (e.g., new treatments and drugs, opportunities for treatment in a different location based on their needs).

4. Consumers’ expectations of and experiences with how electronic health information would help them:

- They want to use the internet or a personal health record to communicate with their providers.
- They want to use the internet to streamline administrative tasks (not specified).
- They want to obtain the information necessary to help guide health care decisions.
- Patients indicated that timely access would allow them to:
  - Better prepare for and make the most of their next physician visit,
  - Facilitate their ability to learn more about their conditions,
  - Empower them to work in partnership with their providers for decision making,
  - Facilitate their success in seeking social support, and
  - Likely decrease the delay in care.
- Patients expect computers in the future to support self-care for common and recurring conditions based on their individual symptoms and drawing from medical record information. This includes providing possible diagnoses, treatment options, including electronic medication prescription services, and referrals as appropriate.
- Patients expect technologies to keep vigil over their health via monitoring devices, implanted or worn, that collect individual information, e.g., blood pressure, heart rate, blood glucose, etc., and broadcast information to them and to their caregivers and providers as needed.
- California consumers used health information they accessed online to:
  - Seek social support and help with decision making (71%)
  - Seek more information and medical attention from their provider (48%)
  - Help a friend or family member seek medical attention (45%)
  - Begin self-management activities related to their health situation (39%)

5. Anticipated impact of patient access to health information:

- There is evidence that a significant number of abnormal lab and imaging results – even in integrated electronic medical record systems – go unacknowledged by clinicians, leading to lack of follow-up that has measurable clinical impact for patients.
- While clinicians should not be absolved of accountability for tracking and follow-up, patients play a vital role in care coordination. Online access to abnormal imaging studies empowers them to seek additional information and the next steps in their care process. Those who do not have such access lack the information necessary to take action if test results are not acknowledged or acted upon by
their clinician in a timely manner. This is one example of how HIT can be used as a tool for achieving better coordinated care and improving both the quality and safety of care.7

- For most individuals in study focus groups, the benefits of technology outweighed the privacy risks. Many patients seemed much less concerned about privacy than health professionals were. Patients who had recently interacted with the health care system, especially those with a chronic illness, were less worried about privacy than individuals who had not had recent interaction with the health care system.2

AHRQ found variable results when evaluating the impact of consumer health informatics applications across different health conditions. However, in several instances study results suggested a positive effect on monitoring and therapeutic adherence, as well as on health care utilization. Better social support and information competence was associated with use of a consumer health informatics intervention used with cancer patients. In addition, patients who had access to personalized information on the computer had higher levels of satisfaction with their care than those who were just given general information, either on the computer or in booklet format.8

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1 In the first study, 64 consumers who were internet users and indicated an interest in health-related matters were divided into 6 focus groups and asked about their needs and preferences for access to their health information, PHRs, and related health technologies. The participant group represented diverse populations and a broad demographic range. In the second study, 11 outpatients who recently had MRIs were divided into two focus groups and were asked about their views and preferences on access to their health information, specifically their MRI results.


