*Final Report*

# Evaluation of Health IT Tools and Resources Available at the AHRQ NRC for Health IT Web Site

## Deliverable 8.6

**Prepared by:**
Jonathan S. Wald, M.D., M.P.H.
Jennifer Alexander, M.S.W., M.P.H.
Jennifer Webb, M.A.
RTI International
3040 Cornwallis Road
Research Triangle Park, NC 27709

**July 2013**

# Contents

# Figures

# Tables

# Appendixes

# Executive Summary

The Agency for Healthcare Research and Quality (AHRQ) Health IT Portfolio has a public Web site (http://healthit.ahrq.gov) that offers more than 10,000 documents, presentations, articles, and tools to health information technology (IT) researchers, implementers, and policymakers. The National Resource Center of Health IT (NRC) Web site offers over 20 tools and resources to support health IT research and evaluation. AHRQ periodically reviews these tools and resources to ensure they are useful and easy to use, and that accurate and up-to-date information is offered to stakeholders.

AHRQ tasked RTI with evaluating the Health IT Literacy Guide (the Guide), which has been maintained on the NRC Web site since 2007. The Guide was intended to help ensure that consumer health IT applications are accessible for individuals with low literacy, which in the health context, reduces the capacity of an individual to obtain, communicate, process, and understand basic health information and services (Koh et al., 2012). Literacy has been conceptually broadened from the ability to read, write, and understand language, to the ability to "identify, understand, interpret, create, communicate, and compute, using printed and written materials associated with varying contexts" (UNESCO, 2003). It is this broadened concept of literacy that is most relevant in the health context. In the 2004 IOM Report, *Health Literacy, a Prescription to End Confusion*, health literacy is defined as having the capacity to "obtain, process, and understand basic health information and services needed to make appropriate health decisions." Health literacy is the term favored in this report, being similar in meaning to literacy, in a health context.

Limited health literacy remains a significant challenge for most of the U.S. population, making it difficult for most patients to understand and apply health information for a variety of life events. Since a growing amount of health information is accessed through health IT, usable health IT for individuals with limited literacy is an important aim (AHRQ, 2010; DeWalt et al., 2011; IOM, 2004; Koh et al., 2012). This report summarizes findings and develops recommendations based on an environmental scan, expert interviews, and focus groups conducted with the intended audience of the Health IT Literacy Guide: developers and purchasers of health IT.

The 26-page Health IT Literacy Guide introduces literacy challenges and states the importance of ensuring that health IT addresses the needs of as many users as possible, including those with limited access to technology or limited literacy. It provides some examples of health IT specifically geared toward individuals with limited literacy, identifies principles of accessible and usable health IT, provides a list of additional resources, and includes a checklist intended to help purchasers and developers identify best practices when purchasing or designing systems that support patients, especially those who might have limited literacy or limited access to health IT.

This report is organized into four chapters. Chapter 1 provides project background and context and then identifies the research questions that guided the evaluation of the Health IT Literacy Guide and served as the focus of this report. Chapter 2 summarizes the approach used to evaluate the Health IT Literacy Guide, which included (1) a focused environmental scan to identify a number of resources relevant to health IT design, usability, literacy, and health literacy (i.e., literacy in the health context); (2) individual interviews with nine experts in the areas of health literacy, usability, consumer health IT, and human-computer interaction (HCI); and (3) 10

focus groups—six with developers of health IT and four with purchasers of health IT—to explore their use of and views about the Guide. Chapter 3 summarizes the findings from the environmental scan, expert interviews, and focus groups by research question. Chapter 4 presents recommendations based on the research findings.

Evaluation results show that (1) developers and purchasers were largely unaware of the Guide; (2) developers and purchasers had limited agreement on definitions of health literacy or the role of health IT in supporting individuals with low literacy; (3) information in the Guide appeared to be outdated; (4) experts and focus group participants were highly interested in the checklist; and (5) the Guide could be useful during system development or product evaluation if it was used at appropriate points during product testing or system selection.

Chapter 4 contains several recommendations regarding the Health IT Literacy Guide. The first recommendation is that the Guide should be retained. There appears to be a gap in knowledge and use of available resources to improve health IT design for limited literacy users. Findings from the environmental scan, expert interviews, and focus groups confirm that limited health literacy remains an important barrier to health knowledge, decisionmaking, and engagement among patients, despite the increasing availability of mobile and Internet technologies to connect with health resources and increased consumer use of them.

The second recommendation is to take steps to disseminate the Guide much more broadly. Experts and focus group participants were largely unaware of the Guide, and Web statistics tracking page views show limited use. However, evaluation participants were enthusiastic about gaining access to the information in the Guide, especially the checklist, once they became familiar with the Guide.

The third recommendation is to enhance the checklist found at the end of the Guide to assist users in designing and selecting health IT, and to tailor the checklist for users who are in the process of making design or purchase decisions. In addition to redesigning and testing the checklist with actual users, the intended audience of the Guide should be expanded to include business decisionmakers in management or executive roles, since individuals with the authority to purchase health IT, and those responsible for the development of IT at a senior level, may not focus on its suitability for low-literacy users.

The fourth recommendation is to update the content of the Guide to address current technologies, advances in the use of the Internet and mobile devices, and new findings concerning the prevalence of limited health literacy. Although the content areas of the original Guide are an important starting place when planning updates to the Guide, they should not impose unnecessary constraints. For example, new methods such as computer-based assessment and tailoring content based on user needs may need additional attention in an updated Guide.

# Chapter 1.  Introduction

## 1.1   Report Overview

Chapter 1 of this report provides an introduction to the overall project, research questions, introductory information about the National Resource Center for Health IT (NRC), and the Health IT Literacy Guide. Then the current state of health literacy and health IT literacy is presented, including definitions and theoretical constructs. In Chapter 2, methods are described for each of the three phases of research. In Chapter 3, research findings are presented to address the research questions 1, 2, 3, and 4 as stated in Section 1.3. In Chapter 4, recommendations for changes to the Guide are presented based on the research findings. *Table 1* outlines the report structure.

Table 1. Report overview

| Chapter | Content |
|---|---|
| 1. Introduction | Summary information about this project, the topic of health literacy, the research questions, the NRC Web site, and the Guide |
| 2. Methods | Methodology for each of the three phases of research |
| 3. Findings and Evaluation Results | Research findings to address research questions 1, 2, 3, and 4 |
| 4. Recommendations | Recommendations for changes to the Guide based on findings |

## 1.2   Background

The NRC was initially launched in 2004 to deliver technical assistance to AHRQ Health IT Portfolio grantees. Since then, it has become a public resource for sharing research findings, best practices, lessons learned, and funding opportunities with health IT researchers, implementers, and decisionmakers. The NRC Web site contains over 10,000 freely available documents, presentations, articles, and tools. As one of the largest repositories of information related to health IT, it has become a primary "go-to" resource for AHRQ's health IT stakeholders.

### 1.2.1   Project Background

Literacy, especially in the health context, is an important and evolving area of research (Berkman et al., 2011; U.S. Department of Health and Human Services, 2010) (McCormack et al., 2010). Low literacy can reduce the capacity of an individual to obtain, communicate, process, and understand basic health information and services (Koh et al., 2012). Literacy, defined narrowly, is the ability to read, write, and understand language. The term is also understood more broadly to mean the ability to "identify, understand, interpret, create, communicate, and compute, using printed and written materials associated with varying contexts" (UNESCO, 2003). A related term, health literacy, is the focus of the 2004 IOM Report, *Health Literacy, a Prescription to End Confusion*, which defines health literacy as having the capacity to "obtain, process, and understand basic health information and services needed to make appropriate health decisions". Health literacy is the term used more commonly in this report.

Engaging patients and their family members in care activities using health IT requires reliable methods to ensure technology accessibility (Koh et al., 2013) and health IT resources that serve individuals regardless of their level of health literacy. Health IT is viewed as an

essential component for addressing health literacy (U.S. Department of Health and Human Services, 2010). System designers and Web content suppliers can develop IT resources that address health literacy and accessibility gaps if they apply relevant training and resources when health IT is designed and implemented, such as the Health IT Literacy Guide. However, the NRC Web site activity for the Health IT Literacy Guide was minimal (34 hits during March 2011, as compared with 1,486 view of the Health IT Tools and Resources home page). This raises questions about how these important resources are sought out and accessed by developers and purchasers of health IT and how to increase the Guide's impact.

The purpose of this evaluation was threefold: (1) to evaluate the Health IT Literacy Guide and determine how useful and easy it is to use for its intended audiences; (2) to provide specific recommendations for revising the Health IT Literacy Guide, including how the changes should be implemented and maintained; and (3) to offer general guidance on how to develop similar tools or resources for use in future AHRQ projects.

This evaluation will provide a better understanding of the strengths and weaknesses of the Health IT Literacy Guide and how to improve the Guide based on an environmental scan of relevant literature and Web sites, expert interviews, and focus groups with developers and purchasers of health IT. By implementing evaluation results, the health IT community will be better informed about effective ways to address health literacy, and AHRQ will have recommendations and guidance for offering more current and effective tools and resources to support health literacy through health IT.

## 1.3   Research Questions

To determine whether the Heath IT Literacy Guide is effective both in terms of the quality of its content and its accessibility by its intended audience—Web and software developers and purchasers of health IT products—in providing effective health IT interventions that are accessible to patients with limited health literacy, the following research questions were used in evaluating the Guide:

1   To what extent does the Health IT Literacy Guide aid developers in designing health IT applications that are accessible to adults with different levels of health literacy?

2   To what extent does the Health IT Literacy Guide aid purchasers in selecting health IT applications that are accessible to adults with different levels of health literacy?

3   In what ways can the Health IT Literacy Guide be improved or updated to be more timely, relevant, and useful to developers in designing health IT applications that are accessible to adults with different levels of health literacy?

4   In what ways can the Health IT Literacy Guide be improved or updated to be more timely, relevant, and useful to purchasers in selecting health IT applications that are accessible to adults with different levels of health literacy?

## 1.4   Terms Used in this Report

Common terms and concepts used in this report are provided in *Table 2*.

**Table 2. Common terms used in this report**

| Term | Definition | Source |
|---|---|---|
| General literacy | The ability to utilize reading, writing, and computational skills to function in society. | AHRQ Health IT Literacy Guide (Eichner and Dullabh, 2007) |
| Health literacy | The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. [A variant of this definition is used in the 2007 Health IT Literacy Guide] | HealthyPeople.gov (2012) |
| eHealth literacy | The ability to seek, find, understand, and appraise health information from electronic sources and apply this knowledge to addressing or solving a health problem. | AHRQ Health IT Literacy Guide (Eichner and Dullabh, 2007) |
| Accessibility | Having equal access to Web-based information and services regardless of physical or developmental abilities or impairments. | (John Hopkins University, 2013) |
| Usability | How well users can use a product to achieve their goals and how satisfied they are with that process. | Usability.gov (U.S. Department of Health and Human Services, 2013) |
| Health IT | The use of information and communication technology in health care to support the delivery of patient or population care or to support patient self-management. | AHRQ (Agency for Healthcare Research and Quality, 2008) |
| Examples of health IT applications | Electronic health record (EHR), electronic medical record (EMR), personal health record (PHR), telemedicine, clinical alerts and reminders, computerized provider order entry, computerized clinical decision support systems, consumer health informatics applications, and electronic exchange of health information. | AHRQ (2008) |
| Consumer health IT application | Refers to a wide range of hardware, software, and Web-based applications that allows patients to participate in their own health care via electronic means. | AHRQ (2013) |
| Developers | Those working for health IT vendors or organizations that create health IT tools providers use to convey information to patients. They may also include researchers, many of whom are also developing or evaluating tools aimed at health care consumers, defined for this project. | RTI (for this project) |
| Purchasers | Those working in organizations involved in the selection of health IT tools or products for use by consumers, often in coordination with health care providers (e.g., hospitals, physician practices, and community health centers). They also include health plans, pharmaceutical companies, foundations, other nonprofit organizations, and government purchasers at the Federal, State, and local levels, defined for this project. | RTI (for this project) |
| User-centered design | An approach to design that grounds the process in information about the people who will use the product. Its processes focus on users through the planning, design, and development of a product. | Usability Professionals' Association (2013) |
| Universal design | The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. | Center for Universal Design (NC State University) (2011) |
| Usability testing | A technique used to evaluate a product by testing it with representative users. | Usability.gov (U.S. Department of Health and Human Services, 2013) |

## 1.5 Background on the Guide

The Health IT Literacy Guide was one of several tools developed for the AHRQ Health IT Portfolio by the National Opinion Research Center (NORC) under an AHRQ contract. Its purpose was to provide developers and purchasers of health IT with information about limited literacy populations and the principles of accessible health IT design (see *Appendix A*). The preface of the Guide states that health IT developers are the intended audience because they often have little knowledge of populations with limited health literacy, or technical standards and aspects of accessible health IT design. The Guide is also intended to be used by purchasers of health IT for evaluating health IT products and for directing and evaluating contracted development work. *Table 3* lists the sections of the Guide along with each section's objective.

**Table 3. Sections of the Health IT Literacy Guide**

| Guide Section | Section Objective |
|---|---|
| Section I. Introduction | To provide definitions of "literacy," examples of health IT applications used by populations with limited literacy, and benefits of limited literacy accessible health IT design (See also *Table 4* below, with definitions) |
| Section II. Overview of Health IT for Limited Literacy Populations | To provide advantages offered by health IT for limited literacy users and examples of predominant health IT used by consumers |
| Section III. Principles of Accessible and Usable Health IT | To provide the importance of universal design and a description of universal design principles and to provide accessibility guidelines for general health IT and recommendations for specific health IT |
| Section IV. Additional Resources | To provide articles, Web sites, and other resources on the topics covered in the Guide |
| Appendix. Checklist | To provide accessibility guidelines for general health IT and specific health IT in the form of a checklist |

Section I of the Guide includes (1) definitions of literacy terms, such as general literacy, health literacy, and eHealth literacy as shown in more detail in Table 4; (2) examples of a few health IT applications successfully used by populations with limited literacy; and (3) discussion of the importance to developers and purchasers of addressing the needs of limited literacy users. The introduction identifies limited health literacy and limited accessibility as important barriers faced by consumers seeking to use health IT as an aid in understanding health information, performing self-care, decision making, connecting with providers, communicating with others (such as patients), and storing and accessing personal health records.

**Table 4. Definitions from the Health IT Literacy Guide**

| Term | Definition |
| --- | --- |
| General literacy | The ability to utilize reading, writing, and computational skills to function in society |
| Health literacy | The ability to obtain, process, understand, and act on health information |
| eHealth literacy | The ability to seek, find, understand, and appraise health information from electronic sources and apply this knowledge to addressing or solving a health problem |
| Accessibility | How well users can use a product to achieve their goals and how satisfied they are with that process |

Section II of the Guide provides a brief description of some of the advantages offered by health IT for limited literacy users, including four types of health IT used by consumers (i.e., Internet Web sites, touchscreen kiosks, personal wireless devices, and home monitoring devices). The table included on page 3 of the Guide describes the four types of health IT, and is reproduced in *Table 5*, below.

**Table 5. Types of health IT used by consumers (from the Health IT Literacy Guide, page 3).**

| Predominant Health IT for Use by Consumers | |
| --- | --- |
| Internet Web sites | Along with making health information available on almost any subject, Web sites offer interactive health tracking tools, message boards and chat rooms, and host interfaces such as Web portals, personal health records, and secure patient–provider messaging. |
| Touchscreen kiosks | Commonplace in shopping malls, grocery stores, and banks, kiosks provide educational sessions aimed at improving self-care for a specific health condition. |
| Personal wireless devices (cellphone, BlackBerry, and PDA) | Small, portable, and private, these devices have the ability to send and receive text messages and e-mail, host games, and interface with the Internet. |
| Home monitoring devices | For use by patients and/or home care providers, these devices are tied to an information system and give actionable information to patients and/or providers. |

Section III of the Guide describes the importance of universal design, accessibility guidelines for all health IT, and guidelines for specific types of health IT. The definition for "accessibility" as defined in the Guide is included in Table 4. The authors of the Guide note that "some call this usability." Section III of the Guide describes basic universal design principles, plain and clear language, content relevance and format, and content iterative testing and revision. It also makes specific recommendations for the four types of health IT identified in Section II.

Section IV of the Guide provides two pages of resources: articles and Web sites that elaborate on the topics covered in the Guide.

The appendix for the Guide presents the principles from Section III in the form of a checklist with yes/no checkboxes next to the text descriptions drawn from the principles for general health IT and for specific health IT. *Figure 1* presents a screenshot of a portion of this checklist.

**Figure 1. A portion of the checklist found in the Health IT Literacy Guide**

## Accessible Health Information Technology (IT) for Limited-Literacy Populations Checklist

*Checklist for Developers and Purchasers of Health IT*

| For All Health Information Technologies and Applications | Yes or No | |
|---|---|---|
| **Plain and Clear Language Is Used** | | |
| Words are short, simple, and familiar (1-2 syllables, no jargon, acronyms, abbreviations) | ☐ Yes | ☐ No |
| Unavoidable technical terms are explained | ☐ Yes | ☐ No |
| Sentences are short | ☐ Yes | ☐ No |
| Written in "active" voice, rather than "passive" voice (Use "Mary visited the clinic," rather than "The clinic was visited by Mary.") | ☐ Yes | ☐ No |
| Consistent use of words throughout | ☐ Yes | ☐ No |
| Reading level is not above 6th grade | ☐ Yes | ☐ No |
| **Content Is Relevant to Audience** | | |
| Assumes little or no background knowledge (including understanding of the body and health care system) | ☐ Yes | ☐ No |
| Information is relevant to users | ☐ Yes | ☐ No |
| Limited number of messages are delivered | ☐ Yes | ☐ No |
| Numbers and percentages are appropriate | ☐ Yes | ☐ No |

According to the preface of the Guide, the process used to develop the Guide included "a review of the IT and health IT literature; examination of products' and organizations' Web sites; and discussions with developers and purchasers of health IT as well as researchers involved in the evaluation of health IT for limited-literacy populations." In the preface, the authors also noted that more research was needed to address accessibility standards for emerging technologies, and that the initial checklist they compiled would need updates over time.

## 1.6    State of Health Literacy and Health IT Literacy

The concept that health consumers need to be health literate—defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions—has been evolving since its introduction in the 1970s (Sørensen et al., 2012). It is now widely accepted that low health literacy is associated with many negative health outcomes, including low levels of health knowledge, increased incidence of chronic illness, and less use of preventive services (Berkman et al., 2011).

Addressing health literacy is a crucial part of any attempt to provide guidance to developers and purchasers of consumer health IT products and applications. However, this is a challenge because health literacy is a concept that is in a state of constant flux. For example, there is no

single accepted definition of health literacy and even less consensus on the conceptual models underpinning it.

## 1.6.1   Definitions

There are at least 25 different definitions of health literacy in the scientific literature; three of the most widely used are presented in *Table 6*.

**Table 6. Varied definitions of health literacy**

| Source | Definition |
|---|---|
| Ratzan and Parker (2000), IOM (2004), and HealthyPeople.gov (2012) | The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions |
| Nutbeam (1998) | The cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health |
| American Medical Association (AMA) Ad Hoc Committee on Health Literacy (1999) | The constellation of skills, including the ability to perform basic reading and numerical tasks, required to function in the health care environment, such as the ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials |

## 1.6.2   Theoretical Constructs

As with definitions, there are many different constructs that underpin health literacy. *Table 7* describes several of the conceptual frameworks.

**Table 7. Health literacy conceptual frameworks**

| Source | Focus of Framework |
|---|---|
| Baker (2006) | Identifies moderators and mediators; emphasizes role of prior knowledge |
| Lee et al. (2004) | Focuses on intermediate factors through which health literacy affects outcomes |
| Mancuso (2008) | Focuses on interaction between six competencies and three attributes of health literacy |
| Manganello (2008) | Focuses on adolescents; adds media literacy to skills related to health literacy |
| Nutbeam (2000) | Identifies three progressive levels of health literacy: basic/functional, communicative/ interactive, and critical literacy |
| Paasche-Orlow (2007) | Focuses on pathways between health literacy and outcomes |
| Rootman et al. (2002) | Focuses on the broader concept of literacy: general, health, and other |
| Schillinger (2001) | Focuses on the association between functional health literacy and chronic disease |
| Sørensen et al. (2012) | Provides broad perspective of health literacy based on review of existing models |
| Speros (2005) | Uses concept analysis to clarify attributes, antecedents, and consequences of health literacy |
| von Wagner et al. (2009) | Uses constructs from social cognition models to integrate health literacy into a wider framework of health actions |

# Chapter 2.  Methods

The evaluation of the Health IT Literacy Guide was composed of an environmental scan, expert interviews, and focus groups with developers and purchasers of health IT. Office of Management and Budget (OMB) clearance was secured for the focus group research by AHRQ. RTI Institutional Review Board (IRB) clearance was secured for the focus groups and interviews. *Table 8* provides a summary of the methods, and the following sections describe each method in greater detail.

**Table 8. Methods summary**

| Method | Strengths | Why Chosen? | Limitations |
|---|---|---|---|
| Environmental scan | Summarize and categorize available resources | Efficient and effective method to identify relevant guides, best practices, and "model" health IT products released since 2007 | It is difficult to capture all resources. This scan was not intended to be an exhaustive literature review. |
| Expert interviews | Hear directly from experts about resources, best practices, and their impressions of trends in health IT literacy | Excellent way to gather rich data that go beyond what can be listed in a survey and to collect information to inform the focus groups | Small number of interviews (n = 9) means that not all resources and best practices were discussed. Qualitative research findings may not be generalizable; these were the experiences of 9 experts only. |
| Focus groups with developers and purchasers | Hear directly from intended audiences regarding whether the Guide is reaching them and meeting their needs | Ability to gather rich data from a large number of intended audience members | Intended users may not have experience using the Guide. |

## 2.1    Environmental Scan

### 2.1.1   Introduction and Purpose

From August to November 2011, the RTI project team conducted an environmental scan to identify examples of tools, resources, products, and best practices published since the release of AHRQ's Health IT Literacy Guide.

The purpose of the scan was twofold: (1) to help answer research questions 1 and 2 (To what extent does the Health IT Literacy Guide aid developers in designing and purchasers in selecting health IT applications that are accessible to adults with different levels of health literacy?) by determining if the information provided in the Health IT Literacy Guide was up to date, and (2) to help answer research questions 3 and 4 (In what ways can the Health IT Literacy Guide be improved or updated to be more timely, relevant, and useful?) by determining what, if any,

guidance documents and best practices have emerged since 2007 and might be suitable for a future version of the Guide. The environmental scan built on the recently released AHRQ report, *Improving Consumer Health IT Application Development: Lessons Learned from Other Industries.*

The environmental scan included three parts:

1. Identify tools and resources released since 2007 that can aid purchasers and developers of health IT, including guidance documents, how-to's, and checklists.

2. Identify examples of recent best practices from the literature (published since 2007) pertaining to developing accessible health IT products (including universal design principles).

3. Identify examples of recent (since 2007) health IT products that have been found to be effective with populations with limited literacy skills.

The following sections describe the environmental scan methods used to accomplish each part of the scan, including:

- search criteria,

- parameters for sources reviewed,

- databases and other sources searched, and

- data collection and analysis.

## 2.1.2   Part 1: Identify Tools and Resources that Can Aid Purchasers and Developers of Health IT

**Environmental Scan Part 1 Activities**

1. Review of relevant materials from AHRQ's Health IT Bibliography.
2. Review of resources provided by and linked to on health IT–related organization Web sites.
3. Web search using approved search terms.
4. Review of IT forums and discussion groups for suggested tools and resources.

**Inclusion Criteria for Environmental Scan Resources Retained**

1. Published later than 2007.
2. Provides specific guidance, recommendations, how-to's, and/or checklists.
3. Addresses literacy and/or health literacy accessibility issues such as physical, cognitive, and technology challenges, or guidance for consumers in making health IT product choices.

The following is a detailed description of each scan activity for Part 1.

**AHRQ Health IT Bibliography Review.** The AHRQ Health IT Bibliography (AHRQ, 2011) consists of approximately 140 resources, including both peer-reviewed articles from professional journals and Web-based resources from highly respected health care and IT

organizations. The AHRQ Health IT Bibliography is organized under the following five umbrella categories:

- Organizational Strategy,
- Technology,
- Evaluation,
- Operations, and
- Populations and Perspectives.

To identify relevant resources from the AHRQ Health IT Bibliography, the RTI project team reviewed abstracts and summaries of all articles and resources in the bibliography based on the inclusion criteria. Based on this review, **0 resources** were retained.

**Health IT Organizations and Web site Resources Review.** The RTI project team conducted a Web search using the approved search terms listed in *Appendix B* to identify organizations that provide health IT–related information and tools. Resources were reviewed that were provided by and linked to on the following organizations' Web sites:

- Agency for Healthcare Research and Quality (AHRQ) (http://www.ahrq.gov/),
- American National Standards Institute (ANSI) (http://www.ansi.org/),
- American Medical Informatics Association (AMIA) (http://www.amia.org/),
- American Society of Health Informatics Managers (http://www.ashim.org/),
- Center for Strategic and International Studies (http://csis.org/),
- Certification Commission for Healthcare Information Technology (CCHIT) (http://csis.org/),
- European Institute for Health Records (http://www.eurorec.org/),
- Health Information Technology Standards Panel (http://www.hitsp.org/),
- National Association of Station Chief Information Officers (NASCIO) (http://www.nascio.org/),
- National Institute of Standards and Technology (NIST) (http://www.nist.gov/index.html),
- Office of the National Coordinator for Health Information Technology at the U.S. Department of Health and Human Services (ONC) (http://www.healthit.gov/), and
- Partners in Information Access for the Public Health Workforce (http://phpartners.org/).

The RTI project team reviewed the summaries and introductions of the eligible resources using the inclusion criteria to determine which resources would be retained.

**Web Search.** The RTI project team conducted a Web search using the set of approved search terms listed in *Appendix B*. The project team used a Boolean search combining general search terms and Part 1–specific search terms. For example, the following search was performed:

- (health IT OR electronic medical record OR health Web site) AND (accessibility OR literacy) AND (checklist OR guidelines OR design principles).

The RTI project team reviewed the summaries and introductions of each of the eligible resources using the inclusion criteria to determine which resources would be retained.

**IT Forums and Discussion Groups Review.** To identify IT forums and discussion groups, the RTI project team conducted a Web search of the most active IT developer discussion groups. Based on that search, the team examined the following forums for suggested tools and resources:

- Android (http://developer.android.com/support.html),

- Apple (https://developer.apple.com/devforums/),

- Chrome/Google (https://groups.google.com/forum/?fromgroups#!forum/google-chrome-developer-tools),

- CodeGuru (http://forums.codeguru.com/),

- Dev Shed (http://forums.devshed.com/),

- Facebook (https://developers.facebook.com/docs/reference/fbml/board/),

- Google (https://developers.google.com/speed/public-dns/groups),

- Mozilla (https://developer.mozilla.org/en-US/docs/Developer_Guide), and

- XDA (http://forum.xda-developers.com/).

The RTI project team scanned each forum for relevant discussion threads based on the approved search terms in *Appendix B*. The RTI project team then reviewed resources and tools suggested in relevant discussions using the inclusion criteria.

## 2.1.3   Part 2: Identify Examples of Best Practices from the Literature Pertaining to Developing Accessible Health IT Products (Including Universal Design Principles)

<div style="border:1px solid black; padding:10px;">

**Environmental Scan Part 2 Activities**

1. Review of relevant materials from AHRQ's Health IT Bibliography.
2. Literature scan using approved search terms and parameters.

**Inclusion Criteria for Environmental Scan Resources Retained**

1. Published later than 2007.
2. Addresses value of clear communication principles in consumer health informatics products to improve user experience; needs of populations with limited health literacy or accessibility issues such as older adults, minorities, and individuals with disabilities; patient-centered or consumer-focused design and development process; or implementation and evaluation of consumer health informatics products.

</div>

The following is a detailed description of each scan activity for Part 2.

**AHRQ Health IT Bibliography Review.** To identify relevant resources from the Health IT Bibliography, the RTI project team reviewed abstracts and summaries all articles and resources in the bibliography using the inclusion criteria for Part 2.

**Literature Scan.** The RTI project team conducted a literature scan using a set of approved search terms and parameters. The search included research in peer-reviewed academic journals, research reports, dissertations, and symposia. The RTI project team used a Boolean search combining general search terms and Part 2–specific search terms. For example, the following searched was performed:

- (health IT OR electronic medical record OR health website) AND (accessibility OR literacy OR universal design OR patient-centered) AND (best practices OR design considerations OR evaluation OR implementation).

See *Appendix B* for a full list of search terms.

The project team scanned articles from the following databases:

- Academic Search Premier,
- PubMed,
- Association for Computing Machinery (ACM) Digital Library,
- Computer Database,
- ArticleFirst, and
- PsycINFO.

The project team reviewed each of the article abstracts using the inclusion criteria for Part 2.

## 2.1.4  Part 3: Identify Examples of Recent Health IT Products that Have Been Found to be Effective with Populations with Limited Literacy Skills

---

**Environmental Scan Part 3 Activities**

1. Web search using approved search terms.
2. Reviewed resources provided by and linked to from health IT–related organizations and Web sites.
3. Literature scan using approved search terms and parameters.

**Inclusion Criteria for Environmental Scan Resources Retained**

1. Released later than 2007.
2. Product with a specific name or brand (excluded references to general products such as EHRs or personal health records [PHRs]).
3. Developed specifically to meet the needs of individuals with accessibility challenges such as limited literacy, cognitive delays, hearing impairment, visual impairment, dexterity issues, etc.; tested with individuals with accessibility challenges; or exemplified best practices identified in Part 2.

---

The following is a detailed description of each scan activity for Part 3.

**Web Search.** The RTI project team conducted a Web search using a set of approved search terms listed in *Appendix B*. The RTI project team used a Boolean search combining general

search terms (e.g., health literacy, usability, accessibility, health) and Part 3–specific search terms (e.g., application, decision-aid, personal health record). For example, the following search was performed:

- (health IT OR personal health record OR health application OR personal health tool) AND (accessibility OR literacy OR patient-centered OR easy to use).

See *Appendix B* for a full list of search terms.

The RTI project team reviewed descriptions of each of the products using the inclusion criteria.

**Health IT Organizations and Web Sites Resource Review.** The project team reviewed the organizations' Web sites listed in Part 1 for examples of products that met the inclusion criteria for Part 3.

**Literature Scan.** The RTI project team reviewed the 36 articles yielded in the Part 2 literature scan for product examples. Each article was reviewed for products that met the inclusion criteria for Part 3.

## 2.1.5   Analysis

The results from the environmental scan were analyzed and synthesized to focus on identifying patterns and common themes both within and across resources. Analysis of the environmental scan results involved the organization of findings into an Excel spreadsheet, with the results of each part included on a separate tab. A systematic review of all items that met the inclusion criteria was conducted independently by two team members, with an eye toward identifying themes and trends across resources. The results of the environmental scan were compared to the Guide recommendations to assess areas of ongoing consistency as well as technology-related updates to the recommendations (e.g., exponential increase in mobile device usage). Finally, conclusions and recommendations were developed that flowed logically from the findings.

## 2.2   Expert Interviews

## 2.2.1   Introduction and Purpose

This section summarizes the methods from nine telephone interviews with experts in the areas of health literacy, consumer health IT, usability, and HCI. The purpose of the interviews was to

1. Ensure that all of the best tools and resources published after January 1, 2007 related to developing and purchasing health IT tools and applications accessible to individuals with low health literacy have been captured.

2. Ensure appropriate examples of emerging best practices in developing health IT tools and applications accessible to individuals with low health literacy and relevant gaps in the Health IT Literacy Guide have been identified.

3. Understand participants' perceptions of the types of tools and key issues in health literacy that need to be considered if developers and purchasers of health IT are to improve how they address health literacy and, in turn, ensure that consumer health IT is accessible and understandable regardless of literacy level.

## 2.2.2   Recruitment

Participants were recruited from a master list compiled by AHRQ and the RTI project team. This compilation drew on existing relationships with groups such as the Health and Human Services Health Literacy Working Group, the Literacy Information and Communication System Health Literacy Discussion List (http://lincs.ed.gov/lincs/discussions/healthliteracy/about_health.html), and patient advocacy groups.

Twenty-one prospective participants were contacted by e-mail. Two attempts were made to contact participants by e-mail, followed by one telephone call from a project staff member. Ten participants agreed to participate. One of these participants was unable to schedule an interview time.

## 2.2.3   Segmentation Strategy and Affiliations of Participants

Four areas of participant expertise were identified (health literacy, usability, consumer health IT, and HCI), with two or three individuals representing each area for a total of nine interviews. The segmentation strategy for the nine interviews is shown in *Table 9*.

**Table 9. Segmentation and description of participants for expert interviews (n = 9)**

| Area of Expertise | Description | Number of Interviews |
|---|---|---|
| Health literacy | Professionals with expertise in the development of messages, materials, and IT applications for individuals with limited health literacy skills | 3 |
| Usability | Professionals with expertise in the evaluation and study of user interfaces, especially those specific to health | 2 |
| Consumer health IT | Professionals with expertise in the development and design of consumer health IT tools and applications, such as electronic personal health records and health Web sites | 2 |
| Human-computer interaction (HCI) | Professionals with expertise in the design, evaluation, and implementation of interactive computing systems for human use, especially those specific to health | 2 |

## 2.2.4   Data Collection

After recruitment and scheduling, each participant was sent an e-mail invitation, which included a toll-free number to call at the scheduled time, a consent form (*Appendix C*), and a list of the questions that would be asked during the hour-long interview. Participants were instructed to read the consent prior to the time of the interview. The interviewer began by confirming that participants had read the consent form and answering any questions they had.

The interviewer used a semistructured interview guide (*Appendix D*) that was developed by the RTI project team and AHRQ. Each interview lasted approximately 60 minutes, and each participant was offered an honorarium to thank them for participation. Two participants, including one who was a Federal government employee, declined the honorarium.

## 2.2.5   Analysis

Analysis of the expert interview data was used to identify key areas of strengths, weaknesses, and opportunities for improving the Health IT Literacy Guide, including content, usability, and dissemination. The analysis involved (1) a systematic review of all recordings and observer notes to identify, where possible, trends across segments; (2) an examination of findings to detect differences among segments; (3) an examination of findings, topic by topic; and (4) development of conclusions and recommendations that flowed logically from the findings.

A qualitative thematic and grounded theory analysis was used to identify thematic consistencies across participants and groups (Miles and Huberman, 1994). Using this approach, a matrix was created with each interview question in one row and the responses from each participant in subsequent columns to make comparisons across the groups and look for themes and patterns in the findings.

## 2.3   Focus Groups

After recruitment and scheduling, each participant was sent an invitation via e-mail, which included a toll-free number to call at the scheduled time, a consent form (*Appendix E*), and an electronic copy of the Health IT Literacy Guide. Participants were instructed to read the consent form and Guide prior to the time of the focus group. The moderator began by confirming that each participant had read the consent form and answering any questions from the participants.

The moderator used a semistructured interview guide (*Appendix F*) that was developed by the RTI project team and AHRQ. Each focus group lasted approximately 90 minutes, and each participant was mailed an honorarium afterwards to thank them for their participation. Two participants, including one Federal government employee, declined the honorarium.

## 2.3.1   Introduction and Purpose

The focus groups were the third step in the overall evaluation and were completed in June 2012. This series of focus groups with developers and purchasers of consumer health IT was intended to determine the following:

1.   how developers and purchasers consider/define health literacy in health IT tools;

2.   what sources of information they may use to assess health literacy in products or to have conversations about health literacy with vendors/developers they may be working with;

3.   what they believe are the key issues or have experienced as issues regarding health literacy when developing or implementing health IT tools for consumers; and

4.   at what point in the process of developing or purchasing health IT they consider issues such as patient accessibility and health literacy.

## 2.3.2   Recruitment

Recruitment involved working in collaboration with individuals, Federal purchasers, and professional organizations and societies representing the target audiences (e.g., Association of Medical Directors of Information Systems; Healthcare Information and Management Systems Society [HIMSS], AMIA) to electronically distribute information about the focus group opportunities through their listservs or membership lists.

## 2.3.3  Segmentation Strategy and Affiliations of Participants

Eligibility criteria for focus group participation included the following:

• involved in development or selection of consumer health IT tools at their organization;

• able to participate in a 60- to 90-minute discussion; and

• English-speaking.

Because the intended audience for the Health IT Literacy Guide included both developers and purchasers of health IT, RTI created a segmentation strategy for the focus groups, including audience descriptions and participant targets, as shown in *Table 10*. Within the main segments of developers and purchasers, participants came from many types of companies and organizations, including hospitals, health care facilities, universities, insurers, and health industry associations. More information on the affiliations of the focus group participants is presented in *Table 11*.

Up to three attempts were made to contact each participant. The first two attempts were made by e-mail, followed by one telephone call from a project staff member. The focus groups were announced on several e-mail lists, which generated hundreds of inquiries from prospective participants. A staff member corresponded with prospective participants and screened them for suitability based on the criteria above.

**Table 10. Segmentation strategy for 10 focus groups**

| Target Audience | Description | Number of Focus Groups | Number of Participants |
|---|---|---|---|
| Developers | Those working for health IT vendors or organizations that create health IT tools providers use to convey information to patients; this may also include researchers, many of whom are also developing or evaluating tools aimed at health care consumers. | 1 (in person) 5 (telephone) | 30 |
| Purchasers | Those working in organizations involved in the selection of health IT tools or products for use by consumers, often in coordination with health care providers (e.g., hospitals, physician practices, and community health centers); this may also include health plans, pharmaceutical companies, foundations, other nonprofit organizations, and government purchasers at the Federal, State, and local levels. | 4 (telephone) | 26 |

**Table 11. Affiliations of focus group participants**

| Organization Type | Purchaser Affiliations (n = 26)* | Developer Affiliations (n=30) |
|---|---|---|
| Research/academic | 8% (n = 2) | 27% (n = 8) |
| Health care provider | 58% (n = 15) | 13% (n = 4) |
| Local/State/Federal government | 19% (n = 5) | 3% (n = 1) |
| Vendor | 12% (n = 3) | 57% (n = 17) |
| Insurer/health plan | 12% (n = 3) | — |
| Association/nonprofit | 8% (n = 2) | — |

*Note: Some participants matched more than one organization type.

### 2.3.4  Data Collection

The majority of focus groups took place by telephone. One focus group was held in person at the HIMSS Annual Conference in February 2012 (Las Vegas, Nevada).

For the telephone focus groups, after recruitment and scheduling, each participant was e-mailed a toll-free number to call at the scheduled time, a consent form (*Appendix E*), and an electronic copy of the Health IT Literacy Guide. Participants were instructed to read the consent and review the Guide prior to the time of the focus group. The moderator began by asking participants if they had read the consent form and answering any questions from the participants.

The moderator used a semistructured interview guide (*Appendix F*) that was developed by the RTI project team and AHRQ. Each focus group lasted approximately 90 minutes, and each participant who accepted an honorarium was mailed one afterwards to thank them for their participation.

### 2.3.5  Analysis

Similar to the analysis for the expert interviews, the focus group analysis involved (1) a systematic review of all recordings and observer notes to identify, where possible, trends across segments; (2) an examination of findings to detect differences among segments; (3) an examination of findings, topic by topic; and (4) development of conclusions and recommendations that flowed logically from the findings.

To analyze the focus groups, a data matrix was created with each focus group question in one row and the responses from each focus group in subsequent columns to make comparisons across the groups and look for themes and patterns in the findings.

# Chapter 3.  Findings

## 3.1  Findings that Address Research Question 1: To what extent does the Health IT Literacy Guide aid developers in designing health IT applications that are accessible to adults with different levels of health literacy?

**Familiarity with Limited Health Literacy.** Information gathered from the focus groups highlighted a lack of emphasis on the concept of health literacy among developers, or with the concept that limited health literacy users needed support from health IT. Through interview probes, developers reported inconsistent sources of information about health literacy; inconsistent ideas about who was ultimately responsible for ensuring that a product supported limited health literacy users; little knowledge of tools for measuring product performance for limited health literacy users; and that designing a product that supported limited health literacy users was a low priority given the weak market demand for this.

Focus group participants were asked to define health literacy as it applies to their work as developers. Overall, participants had many descriptions and definitions of health literacy and pointed out that there is no universally accepted definition of health literacy. Developers were somewhat familiar with the concept of health literacy. The following are some examples of developers' descriptions of health literacy:

- "the ability to say 'I can have education materials that are understandable from someone that has little education'; It has to be about the language you use, concept, and different languages and culture";

- "presenting information in a way that the education level, culture, and experience in health care settings of the audience do not need to be considered";

- "the ability for bidirectional communication with comprehension of all aspects related to health";

- "being able to understand medication labels, physician's advice, and health care issues"; and

- "the motivation to access and to take responsibility of one's own health and family health with health promotion and safety and community health; the ability to interact with health care providers."

**Awareness of the Health IT Literacy Guide.** A majority of developer focus group participants stated that they were not aware of the Health IT Literacy Guide nor did they believe their peers were familiar with it. Of the 30 developer focus group participants, only 1 developer said they were already aware that the Guide existed.

**Main Focus of the Health IT Literacy Guide.** Focus group participants were first asked their thoughts on the main point of the Guide. Developers responded that the Guide provided guidelines and principles to apply when designing health IT products and contained information that was designed to aid developers in making better design decisions. They also felt the Guide provided a centralized source of resources on health literacy and health IT design that may be beneficial to developers. A number of developers described the Guide as serving more as an

introduction to health IT design by covering only the basics; they suggested that perhaps it would be more useful for developers who are just starting out and are not already familiar with health literacy concepts.

**Usefulness of the Health IT Literacy Guide.** Focus group participants were next asked how useful they thought the Guide was for helping developers and purchasers to evaluate health IT products.

Developers thought the Guide was a good starting point for beginner developers and contained some good, simple design points and helpful additional health literacy resources. However, developers also felt the Guide's design points were vague and needed more detail. One developer commented that the Guide was too basic and contained information they already knew. Another developer noted that if developers did not already know the information included in this Guide, they probably would not be successful in developing health IT products. Another common theme from developers was that the Guide, which was published in 2007, was already outdated. Developers felt there had been a lot of changes in health IT since 2007, although they did acknowledge the difficulty in producing resources that stay current over time despite rapid changes in technology and continual upgrading of health IT products.

The findings from the focus groups echoed those from the environmental scan. The scan identified 9 tools and resources, 22 best practices manuscripts, and 30 examples of health IT products (see *Appendix G*) that support the notion that the Guide is out of date.

**Accessible Health IT for Limited-Literacy Populations Checklist.** When focus group participants were asked specifically about the checklist located in the appendix of the Health IT Literacy Guide, a majority felt it was the most useful part of the Guide. Many developers stated that, realistically, they would most likely use only the checklist and would *not* take the time to read the information in the body of the Guide. Developers thought the checklist provided a quick executive summary and was a great resource to have as an evaluation tool for health IT products. Some developers stated that if they were given this Guide, they would be interested only in the checklist and thought most developers would not be concerned with the background information on health literacy in the body of the Guide. A few developers commented on the checkboxes included in the checklist, observing that not all items can be answered with a simple "yes" or "no" and that there was no opportunity for a respondent to provide an explanation for the answer they choose. These developers felt the checklist was not useful without some explanation of the reasons for marking "yes" or "no" for each item on the checklist.

**AHRQ as the Source of the Health IT Literacy Guide and Literacy Information.** Some focus group participants, developers in particular, stated that although giving guidelines for developing health IT products and receiving literacy information could be useful, AHRQ (or other governmental entities) should not force developers down a path that might stifle innovation and quell creativity when developing innovative products. Developers did not want guidelines to be seen as requirements but more as recommendations for designing health IT products. These comments were similar to developers' statements when they were asked about responsibility for ensuring that products considered health literacy.

**Use of the Health IT Literacy Guide.** Focus group participants were asked if other developers would use the Guide for its intended purpose. Most developers agreed that they would use the checklist located in the appendix of the Guide most frequently. When asked *when* in the software design process they might anticipate using this Guide, most developers said they

would anticipate using it during beta-testing or when checking if the content met the guidelines set forth in the Guide for the populations served by their products. One developer commented that he would share the Guide with community health centers and work with their staff to make sure they were following the recommendations laid out in the Guide related to computer kiosks, which are often used in their waiting rooms. One developer mentioned that he anticipated using the Guide at the beginning of the software design process by reviewing the information in the Guide with project members as a way to start thinking about product direction and how to expand on what has already been developed in similar health IT products.

**Audiences.** Focus group participants were asked for whom they thought the Guide was written, and responses from developers varied to some degree. Some participants thought the Guide was written to provide guidance for purchasers such as health providers and practices when evaluating health IT products for purchase. They felt it gave purchasers information on what they should be looking for when buying health IT products. Participants also felt that the Guide was written for health providers and practices including community health clinics that may be developing their own materials and Web sites in-house to provide to patients. They thought the Guide was intended for practices to use to ensure they were providing materials that followed the recommended guidelines

Developers thought some additional audiences might benefit from using the Guide, such as insurance companies that tailor e-mails and other information to send to consumers.

**Sources of Information on Health Literacy**. When asked where they learned about health literacy, focus group participants mentioned various sources. A few said that they had taken part in trainings; plain language trainings were mentioned the most frequently mentioned. Others said that they learned about health literacy from experts, studies, journal articles, professional colleagues (including physicians and social workers), through work on grant applications, and from the Institute of Medicine's report, *Health Literacy: A Prescription to End Confusion*.

Developers were asked about resources they have used and found to be helpful that address health literacy specifically. Overall, very few used resources specifically dealing with health literacy in their development. One developer mentioned Plainlanguage.gov, stating "The principles carry over…clean design, simple interface, and finite info" (plainlanguage.gov, 2011). Another mentioned http://www.readabilityformulas.com, which he uses for testing (ReadabilityFormulas.com, 2013). One developer recommended the Microsoft Office Readability Toolkit, a built-in part of Microsoft Word that displays a readability score of text. The majority of developers did not name any specific resources they had used.

**Developers and Health Literacy.** Almost one-third of developers (9 of 30) said that they conduct some sort of testing of their products for health literacy. Testing included using a Web site like http://www.readabilityformulas.com, using a company identified as "literacy experts," and conducting usability testing with the intended audience. However, the majority of developers said that they do not conduct any health literacy testing of their tools and resources. Nonetheless, many developers stated that health literacy should be addressed throughout the design process. One developer stated that health literacy should be considered "from the very beginning of design. [From the] start of design, from design review and then circle back to testing and user testing. Every step along the way." The concept of considering health literacy at the beginning of the design process was echoed by several developers. For some, this consideration went beyond product development: "it's a cultural element in the organization." Despite this belief that health

literacy must be addressed early and often, one developer stated, "The customer is the physician who writes the check…. not the patient (right now). When the patient is spending money, the incentives will change; if we had evidence that we could sell more systems with more literacy-conscious buyers, we'd adjust."

Developers as a group felt that it was important to take responsibility for health literacy during the design process, although many were unsure who currently was responsible in their organizations. Participants were split on who specifically should be responsible for health literacy. Although many felt that they were responsible, some participants who work in the for-profit industry said that the market should drive consideration of health literacy. Comments from participants on the responsibility of health literacy and the necessity of compliance standards, regulations, or certifications concerning health literacy included:

- "That is a huge gray area. I don't think anyone is [responsible]."

- "I have no idea [who is responsible]; in the for-profit world, this is hard to implement."

- "We need national standards that abide by national regulations. Before products come on the market, they should meet standards. The best way is to have these standards in place."

- "With having a requirement of the vendor to have their patient-facing technologies be certified, my fear would be you would stifle development."

**Barriers to Consideration of Health Literacy in Design Decisions.** Developers mentioned the lack of commonly accepted guidelines or sources of expertise for addressing health literacy. They also said that the lack of a specific, recognized, component of the cost to ensure that products address health literacy was a barrier, with one developer stating "It is hard to monetize."

Developers stated the following barriers to considering health literacy in the design of consumer health IT tools and resources:

- There is no universally accepted systematic approach to considering and addressing health literacy.

- Designers are not familiar with the cultural and language needs of the patient population being targeted.

- There is a celebration of new thinking and new priorities even when they are not necessarily better. This "innovation bias," as one developer called it, keeps developers from being able to address issues of literacy more generally.

- "Developing for limited health literacy audiences is seen as expensive, detailed, and not enjoyable or interesting."

- There is concern about legal issues that may arise when attempting to synthesize information if it is interpreted differently than intended.

- Determining the health literacy level of patients who developers are trying to target is difficult, even initially.

- Time is a barrier: developers are often working under quick timelines and do not want to delay getting a product to market by having to address health literacy.

- Developing for both low and high literacy levels is challenging and takes time.

## 3.2 Findings that Address Research Question 2: To what extent does the Health IT Literacy Guide aid purchasers in selecting health IT applications that are accessible to adults with different levels of health literacy?

**Familiarity with Health Literacy.** Purchasers reported limited familiarity with the concept of health literacy and how health IT should support it, inconsistent sources of information about it, mixed ideas about who was ultimately responsible for ensuring that products supported it, few tools for measuring product performance, and the belief that market demand was weak for products that served those with limited health literacy.

Participants were asked to define health literacy as it applies to their work as developers or purchasers. Overall, participants had many descriptions and definitions of health literacy and pointed out that there is no universally accepted definition of health literacy. Purchasers were less familiar with the concept of health literacy than developers. The following are examples of purchasers' descriptions of health literacy:

- "less emphasis on education and communication and more on goal-oriented action";

- "the degree to which patients have the capacity to understand and have the information they need to make medical decisions for themselves and their family";

- "to provide or identify someone in public health that a person can ask or have that information provided. To know who they can ask"; and

- "isn't it just the ability to read?"

**Awareness of the Health IT Literacy Guide.** A majority of focus group participants stated that they were not aware of the Health Literacy Guide nor did they believe other purchasers were familiar with it. Of the 26 participants in the purchaser focus groups, only 2 were aware that the Guide existed. As for participants' familiarity with AHRQ itself, one purchaser commented that researchers may be more aware of AHRQ, but many medical providers are less familiar with AHRQ and the resources they provide. Another purchaser commented that most purchasers of health IT products do not look to the government for health literacy resources, but rather rely heavily on vendors of health IT products to incorporate any health literacy guidelines into their products.

**Main Focus of the Health IT Literacy Guide.** Focus group participants were first asked their thoughts on the main point of the Guide. Purchasers agreed with developers that the Guide provided resources and guidelines that providers should use when creating health IT materials or when evaluating health IT products from vendors.

**Usefulness of the Health IT Literacy Guide.** Focus group participants were next asked how useful they thought the Guide was for helping developers and purchasers to evaluate health IT products.

Purchasers felt the Guide "covered the basics" of health IT design and health literacy principles. They agreed that the Guide would be useful for evaluating health IT products to ensure that they are accessible to all the populations they serve or to use when updating products in house, such as updating their Web site. Purchasers tended to agree with developers that the Guide would be most useful as a starting point or for those who are new to health IT and felt it

would be more beneficial for users starting from scratch or not very far along in adopting EHR systems.

The findings from the focus groups echoed those from the environmental scan. The scan identified 9 tools and resources, 22 best practices manuscripts, and 30 examples of health IT products (see *Appendix G*) that support the notion that the Guide is out of date.

**Health IT Literacy Guide Appendix Checklist.** When participants were asked specifically about the checklist located in the appendix of the Health IT Literacy Guide, a majority felt it was the most useful part of the Guide.

Although purchasers mostly agreed with developers that the checklist would be useful for evaluating health IT products, some purchasers felt that the checklist would be more useful for developers and found some of the questions difficult to answer as a purchaser of health IT products. Another purchaser mentioned that a short checklist is a great resource but might be useful only for a limited time because of rapid changes in technologies.

**AHRQ as the Source of the Health IT Literacy Guide and Literacy Information.** When asked their thoughts on whether the information in the Guide was believable, purchasers felt the information was straightforward and easy to use. As the source of the Guide, AHRQ was seen as more credible and less biased than a guide created by a vendor. Purchasers felt this information was needed when buying systems and products and when creating materials for consumers and patients. Although most purchasers felt the information in this Guide was believable, some purchasers mentioned that deciding what health IT products to buy is more of a financial decision and less about whether patients understand patient-related materials. Other purchasers mentioned that if an individual physician practice is already contractually committed to purchasing specific health IT products, addressing concerns about health literacy will not be a priority until a new contract is considered.

**Use of the Health IT Literacy Guide.** Similar to developers, purchasers felt that the checklist seemed to be the most useful part of the Guide. Purchasers anticipated that they would use the Guide or checklist to evaluate health IT products and vendors to ensure that they meet the recommended health literacy guidelines. Most purchasers agreed that they could use the Guide as a way to know what they should be looking for when purchasing certain technologies and health IT products. The Guide could prove helpful in the beginning of the process to help narrow down vendors by evaluating their products. Some purchasers also commented that the Guide could be used again toward the middle of the process once the materials have been created or products have been bought; they could use the Guide to check that the materials or products they are receiving and giving to patients are staying true to the guidelines presented in the Guide. A few purchasers noted that buying health IT products is largely a financial decision and if they are already tied to a contract for health IT systems or products, purchasers most likely will not evaluate potential products for health literacy.

**Audiences.** When asked for whom the Guide was written, purchaser focus group participants agreed with developers that the Guide was written to provide guidance for purchasers, such as health providers and practices, when evaluating health IT products for purchase. They also felt it gave purchasers information on what they should be searching for when buying health IT products.

Some purchasers felt that the Guide would not be very useful to them because it was up to the vendors, not the purchasers, to know this information and to make sure their products meet these guidelines. On the other hand, some purchasers felt that most health IT vendors and programmers do not have an adequate understanding of health literacy and could benefit the most from this Guide.

Focus group participants felt that medical practice personnel, including health care executives, physicians, and nurses, would also benefit from knowing this information.

**Sources of Information on Health Literacy.** When asked where they learned about health literacy, focus group participants mentioned various sources. Some purchasers said that they learned about health literacy from experts, studies, journal articles, or professional colleagues (clinicians). Some purchasers who were clinicians, social workers, or public health workers said that they learned about health literacy in medical or graduate school. Some purchasers learned about health literacy from colleagues who helped them to select products and from committees set up at their institutions to ensure that products and materials can be read and understood by those with varying levels of literacy. Two purchasers pointed out that they leave issues of health literacy to the vendors who supply their health education materials; one purchaser said, "We are hoping that the content is at the right level, but we don't always have control of it."

Purchasers were asked for resources they have used and found helpful that address health literacy specifically. Purchasers had more experience than developers with tools and resources that address health literacy in selecting products for their institutions. Although some purchasers said that they are directed to specific resources by their vendors or health IT groups, others mentioned the following sources of information on health literacy:

- CDC (Centers for Disease Control and Prevention),

- AHRQ,

- Healthit.gov,

- the Health Resources and Services Administration, and

- patient-centered care groups.

**Purchasers and Health Literacy.** Only 2 of 25 purchaser participants reported that they evaluate potential products for health literacy before purchasing. Others said that they rely on the third-party vendors who provide the products to ensure that health literacy is addressed. One participant reported that he had never had a request from his organization to address health literacy, but if he did receive a request, he would work with the vendor to address it.

Several purchasers said that the responsibility for ensuring that purchased tools and resources address health literacy lies with the head administrators or chief executives in their organizations. Those participants who use third-party vendors stated that they often write into an RFP or ask that vendors consider issues of literacy and health literacy. Some purchasers felt that they were not able to ensure that products they buy could be used by those with varied levels of health literacy. One purchaser said, "As a purchaser, I don't really know where to go to say [i.e., determine] if these vendors have even looked at this or if this has been tested."

**Barriers to Consideration of Health Literacy in Design and Purchase Decisions.** Both developers and purchasers mentioned the lack of commonly accepted guidelines or sources of expertise for addressing health literacy.

Purchasers of consumer health IT products identified a number of barriers to consideration of health literacy in purchase decisions, including language and culture differences among expected users as well as legal concerns (leading to very long documents not likely to be read and understood). Other barriers identified by purchasers included the following:

- The number of products to check for health literacy can be a barrier if a company has a large number of education materials.

- Poorly trained developers who do not understand that addressing limited health literacy is not the same as simply rewriting for the lowest level reader.

- Primary care practices are limited by having an EHR that limits or defines the educational materials and patient portal. Even if purchasers want to address health literacy, they may not be able to do so.

- Most providers do not think that health literacy is an issue. They assume that patients can read and understand because they ask questions. There can be a lack of understanding of the value of considering health literacy and evaluating health literacy of already existing materials.

## 3.3 Findings that Address Research Questions 3 and 4: In what ways can the Health IT Literacy Guide be improved or updated to be more timely, relevant, and useful to developers in designing health IT applications and purchasers in selecting health IT applications that are accessible to adults with different levels of health literacy?

**Definition of Health Literacy.** Through discussions with both developers and purchasers, it was found that no single, universally accepted definition of health literacy seems to exist, and both groups have varied thoughts on health literacy. Definitions of health literacy from both groups were not always accurate, and some found it difficult to differentiate health literacy from general literacy. Both developers and purchasers felt that the Guide could use some improvement in the introduction of the Guide (Section I) by providing a proper definition of limited literacy.

**Intended Audience of the Guide.** Developer and purchaser focus group participants often had conflicting views of who is accountable if health IT products do not address the needs of users with limited health literacy. Purchasers often felt that the responsibility lies with the vendors of the products and assumed it was being addressed, whereas developers themselves had mixed opinions as to who is accountable, with many saying the market should drive consideration of health literacy. Both groups recommended making it clear in the introduction of the Guide (Section 1) who the Guide's intended audience is and who should be using the Guide.

**Update on Guidelines for Specific Health IT.** A specific area of the Guide that both developers and purchasers agreed needed to be updated was the section on guidelines for specific health IT (Section III). Developers recommended adding specific guidelines for tablets because they are being used in medical practices and hospitals to obtain health information. Both groups also recommended revising the section on Mobile Phone, BlackBerry, and personal digital assistants (PDAs) by adding guidelines for smartphones and tablets, and deleting the information on PDAs. Developers also thought it would be helpful to have information on patient portals included in the Guide and checklist because they are becoming more prominent in medical

practice and Meaningful Use requirements. Purchasers also felt the use of home-monitoring devices by patients will increase in the near future and suggested that this section be updated and improved.

Findings from Part 2 of the environmental scan support the thoughts of focus group participants on updated specific health IT and indicate that the evolution of hardware and software capabilities since the Guide was released necessitates updated guidelines for specific forms of health IT products. For example, although guidelines for computer kiosks in the original Guide continue to apply whenever kiosks are used, this particular type of technology may be less widely used than newer portable touchscreen tablets or mobile devices such as smartphones. Similarly, the rise in telehealth technologies requires new guidelines to be introduced. This section provides examples of emerging best practices as newer technologies become more commonplace. Most of these best practices identified in the environmental scan follow what are increasingly becoming normalized design standards when it comes to the user interface of IT products. Overall, the shifts in technology access and online activities have increased expectations about what type of characteristics make consumer IT products helpful for users.

Environmental scan findings also support updated on smartphones and other mobile devices. As mentioned in the introduction of this report, mobile device adoption has greatly increased since the release of the Guide, with mobile devices providing primary Internet access to certain populations affected by the digital divide (Smith, 2011). Moreover, the introduction of smartphones allows users to interact with various types of applications, or "apps," that can serve as data collection and data retrieval mechanisms. As such, findings from the environmental scan indicate that *mobile applications need to consider unique data, interface, and memory issues.*

Best practices from published research identified in Part 2 of the environmental scan include the following:

- Ensure minimal memory usage to keep the application quick enough for a variety of resource-restricted devices (Kailas et al., 2010).

- Account for limited battery availability when incorporating biosensor data collection mechanisms (Kailas et al., 2010).

- Ensure the security and reliability of data collection mechanisms (Kailas et al., 2010).

As seen from the focus group findings, home monitoring devices were seen as another type of health IT where updated information was needed in the Guide. Findings from the environmental scan on health IT product evaluations include more specific guidance to support the fact that *health IT vendors need to be flexible in integrating home monitoring devices based on consumer needs.*

Best practices from published research identified in Part 2 of the environmental scan include the following:

- Find and match usable devices for specific population needs (e.g., a spirometer, which is easy to use for those with arthritis, and touch screen technologies, which have been shown to work well with limited-literacy populations) (Zayas-Cabán and Dixon, 2010)

**Business Case for Accessible Health IT.** Developer focus group participants recommended including some information in the Guide on the financial benefits that can occur from developing or purchasing health IT products that are accessible to limited literacy patients. By building a

business case for using these guidelines, developers felt it might get more attention because the cost of developing and providing materials is typically a major factor when choosing to develop or provide health IT products to patients. A number of focus group participants felt that since purchase of health IT products is largely influenced by cost and business drivers. Purchaser focus group participants felt the scope of the Guide should be expanded to include users and business or financial personnel who may contribute to the decision to develop or purchase health IT products.

**Use of User Testing for Evaluation of Health IT products.** Adding information on user testing for developing and evaluating health IT products was also mentioned by both developers and purchasers focus group participants. Both groups emphasized the importance of getting feedback from patients/users continuously throughout the development and evaluation process because they are the targeted audience for many of the health IT products. Participants agreed that the Guide should address how to involve patients/users in the health IT development or evaluation process so their feedback on how they would use the health IT products would be obtained. Purchaser focus group participants felt this Guide should also include more information or guidelines to consider when developing or providing health IT products for different cultural groups, and how to tailor the system/materials around specific cultural populations of relevance to certain geographic areas.

**Health IT Literacy Guide Appendix Checklist.** Both developer and purchaser focus group participants perceived the checklist to be the most useful part of the Guide and felt it could serve as a valuable resource for evaluating health IT products. To improve the checklist, both developers and purchasers recommended that the checklist should be expanded to include additional IT platforms, such as tablets and smartphones. Another recommendation from both developers and purchasers was to make the checklist more interactive by adding a ranking or scoring system to the checklist may be beneficial to purchasers so they can assess how they are doing when creating materials or when evaluating different products in making purchasing decisions. One purchaser also recommended that, in the section on iterative testing and revision, it would be beneficial to add information on gathering feedback from patients or users of the health IT products, including focus groups or usability testing.

As Web sites become more interactive, as recommended for the Guide by focus group participants, additional guidelines need to be considered, including *providing clear directions for how users can enter personal information.*

Best practices from published research identified in Part 2 of the environmental scan include the following:

- Place limited information-gathering requests at one time on-screen (Peters et al., 2009).

- Provide confirmation of data entry to minimize confusion for users (Peters et al., 2009).

- Use branching logic to minimize user cognitive overload (Peters et al., 2009).

- Allow users to enter detailed information immediately after entering initial data related to details (to minimize navigation overload) (Peters et al., 2009).

- Color-code user-selected responses (Wolpin and Stewart, 2011).

- Implement portability for future access to PHI from multiple access points (Hernandez, 2009).

- Make privacy and information use policies clear and easy to understand (Grossman et al., 2009).

- Provide attribution so the source of information is made visible (Grossman et al., 2009).

In addition, as more users have access to the Internet via mobile devices, Web site developers need to ensure sites load quickly on mobile devices and are easy to use on smaller screens (Kailas et al., 2010).

**Dissemination of the Health IT Literacy Guide**. Focus group participants were asked where they might expect to see this Guide. Both developers and purchasers indicated that although AHRQ was a good resource for researchers, few clinicians or developers of health IT products are aware of AHRQ or would ever think to look to AHRQ for this type of Guide. Making this Guide available through professional organizations was the most frequent response from both groups (Table 12).

**Table 12. Professional organizations mentioned by developers and purchasers**

| Developers | Purchasers |
|---|---|
| • HIMSS<br>• AMIA<br>• American Health Information Management Association<br>• American Hospital Association<br>• American Medical Management Association<br>• American Telehealth Association<br>• American Nurses Association<br>• Association of Medical Directors of Information Systems | • American Academy of Family Physicians<br>• Society for Participatory Medicine<br>• American Academy of Pediatrics<br>• National Association of Community Health Clinics<br>• American College of Healthcare Executives<br>• American Society for Training and Development |

Focus group participants also said they might expect to see this Guide published on other government agency Web sites and certification organizations, including the CDC, Substance Abuse and Mental Health Services Administration (SAMHSA), ONC or HealthIT.gov, NIST, The Joint Commission, CCHIT, and the Health Information Technology Regional Extension Centers. Participants also named grant-sponsoring organizations, such as Robert Wood Johnson Foundation and the Henry J. Kaiser Family Foundation, and public health organizations for places they might expect to find the Guide.

Lastly, a few participants recommended renaming the Guide to make it easier to find via a Web search. Developers mentioned that they would expect to locate the Guide using any common Web search engine, such as Google, employing search terms like "development design."

Participants were asked how AHRQ should try to reach developers and purchasers with the Guide. Developers and purchasers agreed that promotion of this Guide through various health IT newsletters and listservs, and improving search result optimization, would make it more accessible to the intended audience. Developers noted that the Guide should be incorporated into developer education as part of health IT design training. Purchasers noted that the Guide might be useful in educational settings, such as public health, medical, and nursing schools, in teaching the importance of these health literacy guidelines to future medical professionals.

Again, most developers agreed that sending the Guide to various professional organizations, such as those listed previously, would be most beneficial to reach developers and purchasers and publicize the Guide. They mentioned HIMSS most often as a useful way to disseminate the Guide. Several participants suggested using the HIMSS Annual Conference to showcase the Guide and to help disseminate the Guide to both developers and purchasers.

## 3.4    Summary of Findings Related to the Health IT Literacy Guide

The table below summarizes the main findings from the focus groups with developers and purchasers described above in detail. These findings are organized according to the Guide sections for which they apply.

**Table 13. Summarizing findings related to the Health IT Literacy Guide**

| Section Objective | Key Findings |
|---|---|
| **Section I: Introduction**<br>To provide definitions of "literacy," examples of health IT applications used by populations with limited literacy, and benefits of limited literacy accessible, health IT design. | • Participants from both developer and purchaser groups thought the Guide was written to provide guidance for purchasers, such as health providers and practices, when evaluating health IT products for purchase.<br>• Participants had many descriptions and definitions of health literacy and pointed out that there is no universally accepted definition of health literacy. Developers were more familiar with the concept of health literacy than purchasers.<br>• Both developers and purchasers reported limited familiarity with the concept of health literacy and how health IT should support it, inconsistent sources of information about health literacy, and few tools for measuring product performance.<br>• Purchasers had more experience than developers with tools and resources that address health literacy because they select products for their institutions. Often the tools and resources are suggested and chosen by outside vendors. |
| **Section II: Overview of Health IT for Limited Literacy Populations**<br>To provide advantages offered by health IT for limited literacy users and examples of predominant health IT applications used by consumers | • Both developers and purchasers reported that market demand was weak for products that served those with limited health literacy.<br>• Both developers and purchasers mentioned the lack of commonly accepted guidelines or sources of expertise for addressing health literacy. They also said that the lack of a well-defined cost of making sure products address health literacy was a barrier to consideration. |
| **Section III: Principles of Accessible and Usable Health IT**<br>To provide the importance of universal design and a description of universal design principles and to provide accessibility guidelines for general health IT and recommendations for specific health IT | • When asked about best practices for developing applications designed for those with limited health literacy, participants pointed to user-centered design or usability testing with the intended audience as best practices.<br>• Participants felt that the acceleration of health IT acquisition and adoption by providers has had an uneven impact on provider awareness of consumer use of health IT systems and issues related to health literacy.<br>• Participants were more aware of general guidelines for all health IT, such as plain language, relevant content, and cultural awareness. They were less aware of basic universal design principles. |

(continued)

**Table 13. Summarizing findings related to the Health IT Literacy Guide (continued)**

| Section Objective | Key Findings |
|---|---|
| **Section IV: Additional Resources**<br><br>To provide articles, Web sites, and other resources on the topics covered in the Guide | • Participants were unfamiliar with the Guide and had not seen many of the additional resources presented. They pointed out that they were out of date and should be updated. |
| **Appendix: Checklist**<br><br>To provide accessibility guidelines for general health IT and specific health IT in the form of a checklist | • Most participants found the checklist to be the most useful part of the Guide. They would use the checklist, especially if it were updated (to include mobile technology such as tablets) and interactive (such as giving a "score"). |

## 3.4.1 Findings from the Expert Interviews Related to Tools and Resources that can Aid Purchasers and Developers of Health IT

**Tools and Resources for Developers.** Expert Interview participants were asked which tools or resources they found most useful in helping developers to design health IT applications that are accessible to consumers with low health literacy. Although some participants had no specific input (because they did not use tools and resources), others named the following as useful tools that should be considered for inclusion in Section IV of the Guide:

- **The Plain Language Widget and Application** (http://www.lib.umich.edu/plain-language-dictionary). One health literacy expert described this tool as a dictionary that translates technical terms to more layperson terms.

- **The Harvard School of Public Health Literacy Web site** (http://www.hsph.harvard.edu/healthliteracy/practice/innovative-actions/index.html).This Web site was cited as helpful because it contains several tools and resources to use to ensure that language used is "plain" and written at an appropriate grade level.

- **The Suitability Assessment of Materials (SAM) Instrument** (http://aspiruslibrary.org/literacy/SAM.pdf). This instrument was originally developed for print materials but was modified for Web tools by the health literacy participant, who uses it at all phases of design.

- **The Usability.gov Web site** (http://www.usability.gov). A health literacy expert said, "We've used it to assess different parameters of Web sites…it gives us very tangible items to work on." An HCI developer said "It's a good resource for some basics."

- *Don't Make Me Think*, **by Steve Krug** (http://www.amazon.com/Dont-Make-Me-Think-Usability/dp/0321344758). This book "introduces usability concepts in a common sense way for Web design," and was mentioned by an HCI expert.

- **Jakob Nielsen's Web site** (http://www.useit.com/papers/heuristic/). This was described as a resource on accessibility that contains good "general principles for designing usable software that can be extrapolated to those with limited health literacy."

**Tools and Applications for Purchasers.** Experts were asked for specific tools and resources they have found to be useful in helping purchasers of health IT applications to ensure that the

tools they buy are accessible to consumers with low health literacy. Seven of nine experts (three health literacy, two consumer health IT, two HCI) felt that they did not have the expertise to answer this series of questions. The two usability experts who did answer these questions recommended usability testing as an important and useful tool for purchasers. One said, "If it's a bid purchase at an institution, when the decision is narrowed down to the final three, run a usability test with the [end] user. Use that data to help in the final decision." In addition, one usability expert mentioned using questionnaires as a way to determine whether a product is accessible for those with limited health literacy, specifically The Questionnaire for User Interaction Satisfaction (QUIS) developed by Ben Shneiderman and Kent Norman at the University of Maryland (http://lap.umd.edu/quis) (Chin et al., 1988). A number of usability-related questionnaires are found at this Web site and should be considered for inclusion as additional resources in Section IV of the Guide.

**Related Findings from Experts.** When asked about tools and resources that were not helpful to developers, two experts said that readability formulas are not helpful. As one usability expert said, "[Readability formulas] are the wrong way to go. I don't think that writing to a grade level is the right way to go." One health literacy expert said, "Any basic readability stuff is the kiss of death because designers then do not consider how to represent the data that is written at a certain grade level…They just stop designing and turn it over to the readability police." When asked what resources or tools are not helpful for purchasers of health IT applications—to ensure that the tools they buy are accessible to consumers with low health literacy—one usability testing expert said, "I think that just watching a demo from a salesman is a terrible way to decide."

According to one health literacy and one HCI participant, many health IT developers lack basic IT development and design skills in general, including user interface design and user testing experience. Creating linkages between health IT developers and "really good" general IT developers and creative IT teams is another way to ensure that accessibility for low-health literacy populations is addressed. One health literacy expert said, "Most of the health IT people I've come across don't have the background in the broader, more innovative fundamental IT design."

Two usability experts and one consumer health IT expert suggested that usability testing is a critical step in the development process. Conducting this testing with the specific intended audience (i.e., both individuals with limited literacy and limited health literacy) at several points in the development process is crucial to ensuring that health IT applications are successful and accessible. Including information on usability testing in the Guide was also supported by focus group findings. One HCI expert suggested that developers of health IT applications should be limited to "writing the code for which they've been trained" and be linked up with designers who know how to design accessible software. "History has shown that you'll never succeed in…making people understand two different disciplines," he said.

## 3.4.2  Findings from Expert Interviews and Environmental Scan Related to Designing Accessible Health IT Products

Since the Guide was released, evaluations of health IT products have led to new best practices in health IT. Many of these practices operationalize the principles that were introduced in the Guide. This section provides examples of best practices and examples from experts that can provide specific guidance for health IT developers and purchasers. These best practices have been shown to increase consumer interest in health IT products by (1) providing a user

experience that is tailored more specifically to user needs and (2) allowing users to interact with the content easily and to the extent they are interested in more in-depth information.

**Trends and Best Practices in Health IT Development.** When asked about recent trends in health IT development for those with limited health literacy, most experts suggested that trends for those with limited health literacy would also apply for those with limited literacy and consumers in general. As one usability expert said, "There is a substantial amount of research that shows when you help low literacy people you help the high literacy people too…When you help [people with] low literacy, you help everyone."

A total of four experts from all segments mentioned mobile health as a recent trend that affects health IT development for those with low health literacy. They pointed out that although not everyone has access to a computer, almost everyone, regardless of literacy level (health or otherwise), has a cellphone or smartphone. This technology has encouraged the design and development of texting and smartphone apps. Updating guidelines included in the Guide on mobile technologies was also supported by focus group findings.

A usability expert also mentioned to the importance of considering all methods that learners use, such as text, video, podcasts, gaming, question-and-answer quizzes, avatars, and talking to virtual health care providers.

Increased use of video on health topics by consumers was mentioned as an important trend. Using videos ensures that consumers do not have to read and only have to click on a video to get the information they need. Two important considerations are making sure that videos are short and to the point and that the consumer is informed at the beginning how long the video will last. A usability expert mentioned that one challenge with video is the lack of privacy at work. One expert stated that "people who don't want [other] people at work to know that they're pregnant but [they're on a Web site] and everyone is wondering why you're listening to pregnancy videos."

When asked about important considerations and factors that should be kept in mind when developing tools and resources for those with limited health literacy and should be considered for updating the Guide, experts pointed out that design methods for limited literacy consumers were often similar to design approaches for *any* consumer:

- Get to know the audience. As one HCI expert said, "Developers have to go out and spend time with the people they're designing for. That would improve the development immensely. There is no substitute for having people in direct observation and participation."

- Create "personas" as part of the predevelopment process to understand who will be using the site or resource. This persona is a composite figure with individual characteristics that match a targeted end-user.

- Organize directions correctly. Directions should be placed throughout the site or application, not just at the beginning. One health literacy expert said, "On some Web pages they give you all the instructions at once and you have to go back and refer to them to figure out what you need to do. People need a step-by-step process."

- Pay attention to specific design factors: Organize sites correctly with no scrolling; use "breadcrumbs" to ensure that the user can easily get back to previous pages; design a

search function to have automatic fill-in capability in case consumers do not know the spelling of a term; remove text heaviness; and use appropriate font, size, rollovers, etc.

When asked about best practices for development of applications designed for those with limited health literacy, seven of eight experts pointed to user-centered design or usability testing with the intended audience as best practices. A health literacy expert said, "One of the best practices is [to] pull in the group you are going to target with that application. If you are going to target American Indians, you should pull them in." Experts felt strongly that users should be involved in all phases, beginning before development and continuing through design. Iterative usability testing at all phases with the end-user and validation testing were also seen as crucial.

**Best Practices for Purchasers.** Both usability testing experts agreed that a best practice in helping purchasers is to conduct usability testing. One said, "Have all the people who are going to use it to try it out. In large organizations, the people who buy software are different than the people who use it. Consider the entire product in its context—how patients would actually use it; not just how it is shown in its demo use." Information on usability testing has previously been recommended for inclusion in Section III of the Guide.

**Advancements in Consumer Health IT.** Experts were asked how rapid advancements in technology and the Internet use have changed the development of consumer health IT and how these advancements have affected consumers. Overall, although experts agreed that some rapid advancement has occurred, especially in the increased availability of smartphones and other mobile technologies, they disagreed on whether these advancements have had much effect on consumers.

According to one health literacy expert, rapid technological advancements have brought the importance of health literacy to the forefront: "When I first started, limited health literacy skills were not addressed. Hospitals and drug companies (anyone who gives patient education) are now having to think about it. That's the way things are moving."

A health literacy expert said that these rapid advancements have been positive because they make consumers "feel more empowered that they can manage their health conditions. [It improves their] self-efficacy." However, a usability expert said that the effect these rapid advancements have had is negative: "[It's] opened up some consumers to greater stress and worry because they don't understand information because it's for health care providers, like the files that come to the EMR from labs—that data is in 'doctor speak' and consumers have to interpret that data themselves."

Experts felt that the acceleration of health IT acquisition and adoption by providers has had an uneven impact on provider awareness of consumer use of health IT systems and issues related to health literacy. Some providers have been slow to adapt to use of health IT systems. An HCI expert said, "Adoption by providers is uneven and they are uneasy. The majority are still struggling with getting the right script to the pharmacist, not getting the information to the patient." One usability expert who reported going on site visits to provider offices said that "clinicians are getting more opportunity to push educational materials to consumers and [are] more sensitive to language, but I don't see health care providers looking for low health literacy information."

Some providers have adopted new technology and are aware of health literacy but have a difficult time understanding that patients have also adopted new technologies and are often eager

for change. A health literacy expert explained, "I think that providers are becoming aware that consumers are a little more savvy about their health. In some situations I have seen some providers feel intimidated." Another health literacy expert said, "There is still a misperception that the public hasn't adopted the same technology. In big urban centers there is still a bias against the great unwashed and poor underserved."

The incorporation of consumer health vocabularies into health IT applications was seen as very important. As one health literacy expert put it, "We need to be more concerned with the words and terms that patients use. [This can get done by getting] rid of the lawyers and head scientists. It's both elitism and very ingrained tradition. The common language has never been considered the scientific one."

Some suggestions from experts that should be considered when updating the Guide included the following:

- Incorporate the common misspellings used by consumers on search engines with auto-fill options.

- Incorporate the common terms that consumers use such as "sugar" instead of "diabetes." "This also takes into account different cultures and how they use words" said one health literacy expert. Have "interest and understanding" of popular language and discourse.

- Ensure that consumers are able to verbally pronounce the condition if they do not know how to spell it. Have an audio button on the Web page that pronounces more technical terms.

In addition to the content included in Section III of the Guide, health IT product evaluations have shown that it is important to account for consumer health vocabularies in developing consumer health informatics products.

Best practices from published research identified in the environmental scan that should be considered for updating Section III of the Guide include the following:

- Use simple medical language instead of medical jargon (e.g., "flu" vs. "influenza") (Peters et al., 2009; Sox et al., 2010).

- Use consumer health vocabulary tools in designing consumer health informatics applications (e.g., the PlaneTree Classification System) (Keselman et al., 2008).

- Test various ways of presenting complex health information (e.g., graphical representation of information) and offer multiple and tailored presentations when possible (Keselman et al., 2008).

There are additional general best practices (Kramer-Jackman and Popkess-Vawter, 2011) that have surfaced since the Health IT Literacy Guide was released that address broad consumer health IT issues related to the increased interactivity of consumer health IT products and increased availability of products such as PHRs (Peters et al., 2009). The implementation of these best practices has been shown to improve the consumer experience by providing users with an increased sense of trust in the products they are using through user control of their information, increased user communication capabilities, external educational and clinician support systems, and general interface accessibility (Cruickshank et al., 2012).

According to findings from the environmental scan, consumer health IT users want health IT products to allow them to communicate with their providers, share health information with them, and connect with others that share their health-related experiences.

Communication best practices from published research identified in Part 2 of the environmental scan that should be considered for updating Section III of the Guide include the following:

- Allow patients to prepare for appointments by sending information to providers electronically ahead of time (Weitzman et al., 2009).

- Allow user feedback, flagging, or reciprocal notification to amend information (Weitzman et al., 2009).

- Include timely message checks by providers to ensure that users receive a timely response (Reti et al., 2010; Walker et al., 2009).

- Allow users to use their PHI as a conduit to connect to patients with similar conditions (Halamka et al., 2008).

Findings from Part 2 of the environmental scan also suggest that health IT consumers find products most helpful when they improve their health care experience directly (e.g., when they see clinicians using information they added to their PHR or when they have educational assistance and technical support available to them outside of the health IT application).

Best practices from published research identified in Part 2 of the environmental scan that should be considered for updating Section III of the Guide include the following:

- Take advantage of ancillary staff positions to support consumer education, including health coaches and technology/information system navigators (Keselman et al., 2008; Weitzman et al., 2009).

- Provide an easy set of audio/video instructions (Whitten et al., 2011).

- Partner with libraries and community-based organizations to increase users' computer skills (Hernandez, 2009; Whitten et al., 2011).

- Have clinicians reassert instructions for consumer health IT products during appointments or explicitly refer to data collection uses (Hernandez, 2009).

- Integrate monitoring device data with patient–provider communication workflow (Ball et al., 2007).

**The Importance of Tailoring.** All participants thought that personalized and tailored content for low-health literacy consumers was crucial. One health literacy expert said, "I don't think generic information helps people with low health literacy. The more tailored, the more likelihood of the individual being more treatment compliant."

Participants were asked their thoughts on ways to further personalize the user experience by customizing health information while addressing health literacy. Many experts said that the same best practices for health literacy and good design and development should still apply, even with more personalization. One health literacy expert suggested gearing information toward a consumer's particular condition. Another health literacy expert recommended addressing someone in the first person during login, using the first name of the user, and putting content in

the second person (e.g., "you need…") to "speak directly to the reader." A usability expert suggested, "One of the things is to build in flexibility—the ability to show or hide information. Show me only the first two things I need to look at; not everything at once." One HCI expert suggested that the "industry needs to borrow from social networking approaches [around] engagement. Let users personalize their portals, network with others with their condition, have a live news feed, [so that the site can be] adopted as a daily part of their lives." Another HCI expert suggested that it was essential to have a home page that allows a user to select who he or she is (patient, caregiver) and tailor information accordingly.

Since the release of the Guide, the ability to provide users with personalized information online has greatly increased, and published research on health IT products often identifies integrating customized health information to personalize the user experience as a best practice.

Best practices from published research identified in the environmental scan that should be considered for updating Section III of the Guide include the following:

- Use a patient's medical conditions and PHI to present information about new drugs, treatments, clinical trials, and other resources that may be relevant (Wolpin and Stewart, 2011).

- Use patient medication lists from PHRs to trigger drug interaction warnings (Peters et al., 2009).

- Incorporating tailored health dashboards to increase medical situational awareness of users based on the conditions they are managing, or their individual risk factors (Ball et al., 2007)

- Suggest ways to help patients manage their own care by integrating PHI and biomedical technologies (Ball et al., 2007).

**Access for Nonpatients.** Although all participants agreed that health IT applications (such as a patient portal) should explicitly provide access for nonpatients—such as providers, family members, and caregivers—most participants mentioned that access should be limited to those who "need" the information. Providing this access was seen as an important way to ensure coordination of care for patients who have caregivers, such as the elderly and others who may have low literacy and receive assistance from others. However, the number one concern and barrier to access expressed by participants was privacy. There was a sense that existing HIPAA laws were not adequately addressing the new technologies, such as patient portals, and that further consideration and agreement nationwide (instead of state by state) are needed regarding privacy and access issues.

In expressing concern about access to nonpatients, one health literacy expert said, "It can be very scary for someone who feels vulnerable. There are caregivers who take advantage of people who are very sick." A usability expert said, "[It is] absolutely important to provide access to everyone [who needs it]. This doesn't mean everyone should [have access]."

Findings from the environmental scan indicate that users want to be able to allow or restrict access to health information stored in the health IT products they use based on their preferences.

Best practices from published research identified in Part 2 of the environmental scan that should be considered for updating Section III of the Guide include the following:

- Allow users to share access to their PHR or PHI via proxies using clear and easy-to-use consent mechanisms (Ball et al., 2007; Halamka et al., 2008; Weitzman et al., 2009).

- Allow users to store health information in a PHR for more than one individual (Peters et al., 2009; Reti et al., 2010).

- Assess needs of family members, caregivers, and other alternate users in product design (Keselman et al., 2008).

- Allow users to restrict access to providers and entities they trust and limit the type of information each type of user can see (e.g., by tethering provider-based medical records with a PHR) (Moreno et al., 2007).

- Develop clear and understandable privacy policies that specify who can access patient data and how data will and will not be used (Grossman et al., 2009).

**Learning Supports.** Experts in instructional design describe certain kinds of instructor guidance provided to learners as "scaffolding." Participants were asked their thoughts about information scaffolding after being read the following definition: "Information scaffolding provides support that allows users to move from one concept or screen to another, building on previous knowledge. For IT, it is used for multiple navigation opportunities for users—so they can go back and read about something they are not sure of or skip a screen/information that they already know. It could also be used to help with word pronunciations and definitions."

Most participants agreed that information scaffolding was important, but several pointed out that it was already a standard part of good design and therefore not a new concept or one important only for low literacy or low health literacy audiences.

One health literacy expert said, "As you begin to do research on an issue, you get taken in different directions. You need to be taken back to your original screen and that is true for more than just low health literacy people." Another health literacy expert pointed out that "good information is not linear."

Findings from the environmental scan show that information representation has evolved since the release of the Guide, with an increased integration and visualization of datasets across disciplines made easier by using open-source software and accessible data sources. In addition, health IT product evaluations have shown that users prefer multiple ways of obtaining information on an interface, so purchasers and developers should provide easy-to-use information scaffolding opportunities in the user experience (Keselman et al., 2008; Peters et al., 2011; Weitzman et al., 2009). Information scaffolding refers to support that allows users to move from one concept or screen to another, building on previous knowledge.

Best practices to increase reading and comprehension from published research that should be considered for updating Section III of the Guide include the following:

- Provide "mouse-over" explanations of medications and definitions of medical conditions (Ball et al., 2007; Weitzman et al., 2009).

- Provide "drill-down" capabilities for treatments and summaries of research findings using hyperlinks (Weitzman et al., 2009).

- Provide multiple ways to search for information, including alphabetical lists, and autocomplete enabled search boxes (Weitzman et al., 2009).

- Use innovative visualizations to present data to allow data mining by users (Goldberg et al., 2011).

- Organize content to optimize behavior change (e.g., content organization should be informed by user needs and context, determinants of health, and behavior change theory) (Goldberg et al., 2011).

- Use systems designed to support localization—different languages, different literacy or numeracy levels, different visual approaches—for presenting the same health information (see http://www.pgsi.com/ for a product example).

**Existing Accessibility Guidelines (Section 508 Compliance).** Overall, participants felt that the current Section 508 Web site accessibility regulations are, as one health literacy expert said, "a start." Two participants (health literacy and usability) felt that, because of expense and time, most developers and designers were not following the current regulations: "This is the very *least* anyone can do. On the other hand, research shows people are not doing even this."

One usability expert suggested that current Section 508 regulations should be used as a proxy for yet-to-be-developed guidelines for audiences with low health literacy. Developing new regulations that take into account low health literacy will, according to one health literacy expert, take time and rigorous testing.

Information on Section 508 regulations should be considered when updating Section III of the Guide.

## 3.5   Discussion

This evaluation of the Health IT Literacy Guide surfaced a noticeable gap between the focus group findings in which the collective experience of purchasers and developers of health IT showed little attention on limited literacy user requirements when designing or purchasing health IT, and the findings from expert interviews and the environmental scan, which identified evidence that literacy barriers in the health context are creating real difficulties for patients and providers, and can be addressed through resources such as Web sites, best practices guides, and product examples in which limited literacy user needs are a specific focus.

The finding of limited Web site activity for the Guide is consistent with focus group discussions with developers and purchasers, indicating that few were aware that the Guide existed or had accessed the Guide. A number of focus group participants reviewed a copy of the Guide before attending the focus group. Thus, focus group findings are best understood in the context of individuals who recently had (in many cases) their initial exposure to the Guide. In large part due to limited use, the Guide has had a minimal impact on developers who design health IT applications or purchasers who select health IT applications accessible to adults with different levels of health literacy.

Developers and purchasers indicated that there would be value in having a succinct resource, particularly one with a checklist or similar tool, to help familiarize or remind them of the important principles of universal design identified in Section 3 of the Guide, and how to recognize their use. In this way, they endorsed the Guide as being valuable, an affirmative finding for research questions 1 and 2 described in detail in Chapter 3.

A number of improvements to make the Guide more current and more useful to developers and purchasers are suggested in Chapter 4—primarily through updating different areas of the Guide content, enhancing the checklist, and updating helpful resources for further reading.

The request from some participants for the creation of an interactive checklist was intended to help improve and streamline their process for assessing and introducing universal design principles, especially those that address limited literacy users, into the design and purchase of health IT. If an interactive tool is developed, it should (itself) follow universal design principles and leverage techniques such as heuristic analysis, user testing, and prototyping to increase the likelihood that the tool will be valued and useful to its targeted audience.

None of the resources identified in the environmental scan was a direct substitute of the Health IT Literacy Guide, and the scan did not identify an analogue to the checklist found in the Guide. For this reason, the primary recommendations are to: (1) update the Guide, (2) develop the Guide's checklist, (3) disseminate the Guide and expand the intended audience of the Guide to include developers, purchasers, users, and business decisionmakers in management or executive roles.

## 3.6 Limitations of the Findings

Given the qualitative methods of research and limited number of participants, results from the expert interviews and focus groups do not represent a statistically valid sample of developers and purchasers of health IT from the broader population. However, since a cross-section of the target audience for the Guide was included, feedback received can be used as input from these key audiences.

# Chapter 4. Recommendations

Given the importance of health literacy and the generally favorable view of the Guide by focus group participants, the evaluation team recommends updating the Guide to make it more current and developing a dissemination strategy for the Guide to reach a broader audience of developers, purchasers, and stakeholders of health IT products.

Thirteen recommendations are described in detail below, including their importance (high, medium, or low), level of effort (LOE) (high, medium, or low), and type of subject matter expertise (SME) required. The *importance* rating reflects the anticipated contribution the item makes to a user's understanding of the Guide or ability to use the Guide. The *LOE* rating reflects the anticipated relative work effort of completing the recommendation using one full-time equivalent (FTE), from low (a few days) to medium (a few weeks) to high (a few months or more).

Types of expertise are included in Table 14, such as *content* expertise (for many areas of the Guide) and *Web tool design* expertise (for the checklist). Several kinds of content expertise are desirable since the Guide presents content for practical use by purchasers, developers, and business stakeholders. Content areas include literacy, health literacy, usability, software design, software development, consumer health IT, and human computer interaction. Web tool design expertise includes skills in Web page prototyping, design, development, heuristic evaluation, and user testing.

Although several dimensions could be used to rank-order these recommendations, those classified as having high importance and low effort offer the highest value. Next to be considered should be recommendations of high importance and high effort followed by the remaining recommendations deemed of medium importance and with low effort.

## 4.1 Recommendations for Improving the Health IT Literacy Guide

The Guide should be improved and updated to be more timely, relevant, and useful to developers and purchasers in designing health IT applications that are accessible to adults with varying levels of health literacy. The organization of the sections below is based on the structure of the Health IT Literacy Guide.

### 4.1.1 Recommendations for Changes to the Introduction and Overview of the Guide

To improve and update Section I (Introduction) and Section II (Overview) of the Health IT Literacy Guide, several changes should be made to make it more timely, relevant, and useful to developers in designing and purchasers in selecting health IT applications that are accessible to adults with different levels of health literacy.

**The Guide should include a clear definition of health literacy in the introduction.** Based on the evaluation, further discussion of the concepts of usability and accessibility, and how they relate to literacy and health literacy, would be helpful. Defining health literacy and related concepts at the beginning of the Guide will help to avoid any confusion on the focus of the Guide. The definition of literacy used in Healthy People 2020 (HealthyPeople.gov, 2012) is suggested. This recommendation is categorized as being of high importance and of low effort.

The Guide should clarify in the introduction not only who the intended audience is for the Guide, but also the role of this audience in addressing health literacy among consumers and patients. It would be beneficial to include in the introduction of the Guide a more detailed description of the Guide's intended audience and their roles for ensuring that health IT products are accessible for populations with limited literacy. The introduction or overview should identify activities and processes during system purchase, design, and development that impact user understanding of health concepts downstream, especially if the impact is indirect or complex. This recommendation is seen as being of high importance and of low effort.

The Guide should include some information on the business case and financial aspects (cost savings, product marketability, regulatory compliance, or other benefits) that may accrue from developing or purchasing health IT products that are accessible to limited literacy patients. The intended audience of the Guide should be expanded to include business or financial personnel who may contribute to the decision to develop or purchase health IT products. Since purchase of health IT products is largely influenced by cost and business drivers, addressing the business case and financial aspects for following recommendations in the Guide would be more likely to influence decisionmakers since the cost of developing and providing systems is typically a major factor when choosing to develop or provide health IT products to patients. This work would likely entail conducting a literature review and possibly interviewing subject matter experts in order to describe or develop the business case for supporting limited health literacy among health IT users. This recommendation is deemed as being of high importance and of moderate effort.

The Guide should describe how a socio-technical framework can be used to understand how patients/consumers with limited literacy benefit from accessible health IT. Research has highlighted the role of health IT in supporting patient understanding not only through technology accessibility, but also by supporting improved cognitive reinforcement, communication, social interaction, and learning. As consumer use of technology continues to grow, the role of health IT in supporting patient learning and understanding is likely to expand. Assessing and improving the effectiveness of health IT to support limited literacy users is facilitated by consideration of the interactions among users, activities, and technology within physical, social, community, and policy contexts (National Academies, 2011). Applying a socio-technical perspective can be valuable in helping developers, purchasers, and other stakeholders consider the many factors that singly and jointly influence the user experience and the value a technology brings. This recommendation is categorized as being of medium importance and of medium effort.

## 4.1.2 Recommendations for Changes to Principles of Accessible and Usable Health IT

Changes to Section III (Principles of Accessible and Usable Health IT) of the Guide will make it more timely, relevant, and useful to developers and purchasers.

The content of the Guide should be updated with more current examples. Updated (1) tools and resources that can aid developers and purchasers of health IT, (2) best practices from the literature pertaining to developing accessible health IT products (including universal design principles), and (3) examples of recent health IT products that have been found to be effective with populations with limited literacy skills or limited experience with technology are discussed in detail in *Appendix G*. These were identified during the environmental scan.

**The Guide should include information on technologies that have emerged and expanded since the publication of the Guide in 2007.** Health IT platforms such as tablet computers and smartphones, applications such as patient portals on a desktop or mobile device, and devices for mobile tracking and remote sensing are being used more commonly. It is recommended to include information about tablets because medical practices and hospitals are using tablets more often in office settings and with patients. Smartphones are another expanding technology that should be addressed in the Guide, especially given that 45% of Americans now own a smartphone with the capability to access health information through the Internet (Rainie, 2012). Guidelines for smartphones should contain information on apps that consider unique data, interface, and memory issues. It is also recommended to add information on patient portals because they are becoming more commonly available through medical practices striving to meet advancing meaningful use requirements. Lastly, it is recommended to avoid the use of the term "personal digital assistant" or PDA since this term is no longer favored. Detailed information that can assist AHRQ in implementing this recommendation obtained from the environmental scan is reported in *Appendix G*. This recommendation is seen as being of high importance and of low effort.

**The Guide should include information about significant features that impact the ease of use of health IT for patients and members of the care team.** Specifically, additional guidelines are needed for user controls that allow or restrict access to health information; appropriate navigation and linking within PHRs and patient portals; and inclusion of multidirectional communication capabilities. The Guide should also address the role of consumer health vocabularies in developing consumer health informatics products and the importance of integrating customized health information to personalize the user experience. In addition, the universal design section of the Guide should be expanded and integrate key terminology and principles throughout. This information may resonate with health IT developers, aid future dissemination of the Guide, help establish a common language between health literacy advocates and IT developers, and promote important development practices that improve usability for the patient. This recommendation is deemed as being of high importance and of low effort.

**The section in the Guide on home-monitoring devices should be updated because patients' use of these devices has increased, and this will undoubtedly continue.** This update should include information on how project vendors need to be flexible in integrating these devices based on consumer needs. This recommendation is seen as being of medium importance and of low effort.

**The section in the Guide on Web sites should be updated to include clear guidance about the use of personal information collected from users.** The environmental scan of best practices from published research suggests that limiting and simplifying information requests as well as ensuring that privacy and information use policies are clear will both minimize user confusion and allay privacy concerns. This recommendation is considered to be of low importance and of low effort.

**The Guide should reference additional information on user testing for developing and evaluating health IT products.** It is recommended that the Guide address how to involve patients/users in the health IT development and evaluation processes so their feedback can be used to improve health IT products. In addition, it is recommended to reference information on user testing in which developers of health IT products present the user with alternative design options to gauge which content and formats are preferred (Christian, 2012). A useful reference

focusing on consumer health IT design, *Designing Consumer Health IT: A Guide for Developers and Systems Designers (2012)* includes a number of good references that highlight the role of user testing. Culturally specific user testing is particularly useful when developing or providing health IT products for different populations or geographic areas. This recommendation is categorized as being of medium importance and of low effort.

### 4.1.3 Recommendations for Changes to the Checklist

**The Checklist (in the appendix) of the Guide should be updated and moved into the body of the Guide.**

**Make the checklist a more prominent focus of the Guide and adding a scoring system, if possible, to make it more useful for developers in designing and testing products and for purchasers in evaluating products.** It is also recommended to update the checklist to reflect improvements included in the body of the Guide, such as information on tablets and smartphones, gathering feedback from patients or users of the health IT products through focus groups and usability testing. Updates to the Guide should consider whether separate checklists for developers and purchasers are warranted, whether scenarios should be included in the Guide for ease of use, and whether external references should be included in the checklist for quick access. This recommendation is considered being of high importance and requiring a high level of effort.

### 4.1.4 Recommendations for Dissemination of the Guide

**Develop a dissemination strategy so the updated Guide can reach more developers and purchasers of health IT products than are currently being reached.** It is believed this dissemination strategy should include distributing the updated Guide to several professional organizations related to health informatics and health care provider organizations. HIMSS is one specific professional organization that was found to be the most influential for both developers and purchasers of health IT products. Not only does it seem beneficial to distribute the Guide to HIMSS to disseminate to its members, but the HIMSS Annual Conference could also be used to showcase the Guide and disseminate it directly to both developers and purchasers of health IT products. It is also recommended to include other organizations in the dissemination plan, such as CDC and ONC, as well as certification organizations and grant-sponsoring organizations.

It is also recommended that the Guide should be promoted through various health IT newsletters and listservs to make it more accessible to the intended audience. Some promotion strategies include improving the search result optimization of this Guide to make it easier to find on the Internet using common Web search engines like Google and employing search terms like "development design." The Guide might also be renamed to make it easier to find via a Web search, thereby reaching more developers and purchasers of health IT products.

In addition, it is recommended to use Webinars and other presentation venues to teach about using the Guide to support health IT selection, design, and development. The same approach could be used to solicit ideas for ongoing improvement of the checklists and the Guide. Additional recommendations related to the dissemination of the Guide include the following:

- Ask other Web sites/agencies to add the Guide as a key reference link from their Web site or resources.

- Consider search engine optimization (SEO) approaches to making the Guide easier to locate.

- Consider promoting the Guide at conferences, gatherings, and on the AHRQ Web site.

- Invite experts—from NIST, CDC, Institute of Healthcare Improvement, ONC, HIMSS, AMIA, vendors, other industry groups—to periodically review and update the Guide.

- Observe the use of checklists during purchase, design, and development activities to determine their utility.

Lastly, as part of the dissemination plan, it is recommended that the Guide be used in educational settings such as public health, medical, and nursing schools in order to teach future medical professionals of the importance of health literacy considerations in health IT products. Similarly, it is recommended to incorporate the Guide into developer education as part of health IT design and usability training to give designers a more in-depth understanding of health literacy principles and how best to design products with these principles in mind. The dissemination plan recommendations are categorized as being of high importance and of medium effort.

## 4.2 Recommendations for How Often the Guide Should Be Updated, Where the Guide Should Be Located, and How the Recommendations Should Be Implemented

To serve the needs of developers, purchasers, and business decisionmakers, it is believed that content areas of the Guide will need updates at different frequencies. For example, specific technologies that are commonplace today may be outdated in a few years. Also, new resources providing guidance in the design of health IT for limited literacy users are likely to evolve more quickly than in the past, given intensified interest in this area. Static documents in formats such as PDF are more likely to become outdated than Internet-based Web pages that can be updated more easily, especially when, like a dynamic Web site, changes can be introduced easily or automatically (according to established policies). Perhaps future updates can be scheduled like maintenance activities on a Web site, providing a chance to check and update links to resources, add autogenerated content from webcrawlers, and provide an archive and history of tracked changes, such as a Wiki.

Wherever the Guide is located, it must be easily found to have an impact. Its searchability and ease of retrieval should be tested and adjusted periodically (using common search engines and common search terms) to optimize dissemination. Cross-links that leverage key health IT Web sites sponsored by AHRQ, ONC, CMS, VHA, and many others can improve retrieval and dissemination. Locating the Guide on the health IT tools and resources page seems appropriate.

When implementing the recommendations for updating the Health IT Literacy Guide, a number of areas should be addressed.

- Content updates for information provided in the Guide should be performed approximately every 2 years to keep information from being out of date. A Web page referenced in the Guide but separate from it, containing lists of resources, would permit simple and more frequent updates as needed.

- The checklist should be developed as an interactive tool that is separate from the content portion of the Guide. Creating an effective tool for stakeholders who make or influence

development or purchase decisions for health IT will require the development of user requirements, product design concepts, a working product prototype, usability testing and user feedback on the prototype, and development of the tool. Once available in production, tracking of interactive tool use and routine collection of user feedback will provide important input for future improvements to the tool.

- Dissemination-related activities should be planned in advance to position the updated Guide and interactive tool for maximal impact. Even if dissemination is anticipated to be a later effort or part of another project, early dissemination planning could help to refine the overall product concept and design. Dissemination activities might include Webinars, blogs, news stories, SEO, case studies, technology, or health IT conferences, and activities sponsored by other federal agencies or nongovernmental organizations.

## 4.3 General Guidance on How to Develop Similar Tools or Resources

A number of findings and recommendations from this project may have general relevance to future tools or resources developed or guided by AHRQ in a future project.

- Future tools or resources should specifically identify the target audience or audiences for the tool or resource, since understanding and meeting the specific needs of each audience will help to identify the requirements of the tool or resource, impacting the downstream work.

- The future project should identify the functional requirements of the tool or resource in development, anticipating the possibility that the end-product might be a static document, an interactive tool, a video, or in some other type of format.

- The project should address user testing and monitoring of product use to maximize its impact; for an interactive tool or static document, usability testing appropriate to the tool or resource should be planned and performed.

- Coordination of new or updated tools or resources with preexisting related tools or resources should be addressed in the project.

- The project should encourage consideration of a broad set of stakeholders, including business stakeholders, since they often influence or mediate decisionmaking and resources for a downstream project.

- A dissemination strategy should be developed from the beginning of the project, even if it is not carried out until a later project.

- If appropriate, the project should consider a socio-technical approach to planning, designing, and assessing the tool or resource being considered, since many influences play a role in adoption and use of tools and resources. The socio-technical approach draws attention to the people, technologies, and actions that interact when a tool or resource is used in a real-world setting, and how those interactions may be influenced by the physical, social, community, or policy environment. This perspective is also introduced in *Section 4.1* of this report.

## 4.4　Recommendations Summary

Overall, based on findings from this evaluation, four high-level recommendations emerged: (1) keep the Guide; (2) expand dissemination of the Guide; (3) enhance the utility of the Guide and the audience it addresses; and (4) update the Guide's content.

Keeping the Guide is important because this evaluation found sustained interest in the content of the Guide among purchasers and developers of health IT, as well as a significant gap in knowledge about how health IT can support limited literacy patients and consumers. Increased dissemination of the Guide is critical for gaps in knowledge to be addressed, not only because limited dissemination leads to limited impact, but because broader use will increase the likelihood that improvements in the Guide will be surfaced. Participants in the focus groups, in particular, voiced strong interest in having a *checklist* tool they could access when making software purchasing decisions, for example. They also thought that business decisionmakers— especially those responsible for system selection, maintenance, and design decisions—were important stakeholders in ensuring that health IT would meet the needs of limited literacy users, and should be explicitly identified as part of the intended audience. Finally, the Guide's content, while still providing some useful information, has numerous areas that are outdated or incomplete. Updates to the Guide's content, leveraging findings from this report and the use of content experts, are anticipated to increase the value brought by the Guide to its intended audience and align it with advances in the industry.

**Table 14. Summary of recommendations by Guide section**

| Guide Section | Section Objective | Key Findings | Recommendations | Level of Importance | Level of Effort | Source or Justification |
|---|---|---|---|---|---|---|
| Section I: Introduction | To provide definitions of "literacy," examples of health IT applications used by populations with limited literacy, and benefits of limited literacy accessible health IT design | • Participants from both developer and purchaser groups thought the Guide was written to provide guidance for purchasers, such as health providers and practices, when evaluating health IT products for purchase.<br>• Participants had many descriptions and definitions of health literacy and pointed out that there is no universally accepted definition of health literacy. Developers were more familiar with the concept of health literacy than purchasers.<br>• Both developers and purchasers reported limited familiarity with the concept of health literacy and how health IT should support it; there were inconsistent sources of information about health literacy and few tools for measuring product performance.<br>• Purchasers had more experience than developers with tools and resources that address health literacy because they select products for their institutions. Often, the tools and resources were suggested and chosen by outside vendors. | *Content expertise* in literacy and health literacy; usability, software design and development; consumer health IT; and human computer interaction is needed to implement the recommendations that follow.<br>• Provide and prominently feature a clear and consistent definition of health literacy.<br>• Clarify who the intended audience is, key roles, and important processes (that affect health literacy).<br>• Include discussion of business drivers and business value associated with health literacy. Expand the intended audience to include business or financial personnel who contribute to decisions to purchase or develop health IT.<br>• Describe and define related concepts (e.g., usability) and how they relate.<br>• Guide should reflect a socio-technical approach to supporting patient/consumer understanding of health concepts. | High<br><br>High<br><br>High<br><br><br>Medium<br><br>Medium | Low<br><br>Low<br><br>Low<br><br><br>Low<br><br>Low | • Expert interviews and focus groups: lack of clarity of meaning<br>• Expert interviews and focus groups: lack of clarity of meaning<br>• Focus groups: importance of making health literacy cost effective, targeting resources to those who make business decisions |
| Section II: Overview of Health IT for Limited Literacy Populations | To provide advantages offered by health IT for limited literacy users and examples of predominant health IT used by consumers | • Both developers and purchasers reported that market demand was weak for products that served those with limited health literacy.<br>• Both developers and purchasers mentioned the lack of commonly accepted guidelines or sources of expertise for addressing health literacy. They also said that the lack of a cost was a barrier to consideration of health literacy. | (see Section 1 recommendations) | High | Low | — |

(continued)

**Table 14. Summary of recommendations by Guide section (continued)**

| Guide Section | Section Objective | Key Findings | Recommendations | Level of Importance | Level of Effort | Source or Justification |
|---|---|---|---|---|---|---|
| Section II: Overview of Health IT for Limited Literacy Populations | To provide advantages offered by health IT for limited literacy users and examples of predominant health IT used by consumers | • Both developers and purchasers reported that market demand was weak for products that served those with limited health literacy.<br>• Both developers and purchasers mentioned the lack of commonly accepted guidelines or sources of expertise for addressing health literacy. They also said that the lack of a cost was a barrier to consideration of health literacy. | (see Section 1 recommendations) | High | Low | — |
| Section III: Principles of Accessible and Usable Health IT | To provide the importance of universal design and a description of universal design principles. To provide accessibility guidelines for general health IT and recommendations for specific health IT | • When asked about best practices for developing applications designed for those with limited health literacy, participants pointed to user-centered design or usability testing with the intended audience as best practices.<br>• Participants felt that the acceleration of health IT acquisition and adoption by providers has had an uneven impact on provider awareness of consumer use of health IT systems and issues related to health literacy.<br>• Participants were more aware of general guidelines for all health IT, such as plain language, relevant content, and cultural awareness. They were less aware of basic universal design principles. | *Content expertise* in usability, software design and development; consumer health IT; and human computer interaction is needed to implement the recommendations that follow.<br>• Address current and emerging technologies such as smartphones, tablets, tracking devices, and patient portals.<br>• Remove references to personal digital assistants (PDAs). | High<br><br><br>High | Low<br><br><br>Low | • Expert interviews and focus groups: Guide is out of date and does not contain new and emerging technology<br>• Environmental scan: there are tools and resources available that utilize universal design principles and could be good models for an updated Guide |
| Section IV: Additional Resources | To provide articles, Web sites, and other resources on the topics covered in the Guide | • Participants were unfamiliar with the Guide and had not seen many of the additional resources presented. They pointed out that they were out of date and should be updated.<br>• Since the publication of the Guide, there have been several resources and tools developed that would be useful to include in this section. | See 3.3.1 for a listing of resources to be considered. | Medium | Low | • Environmental scan: more updated resources exist and would be useful to include |

(continued)

**Table 14. Summary of recommendations by Guide section (continued)**

| Guide Section | Section Objective | Key Findings | Recommendations | Level of Importance | Level of Effort | Source or Justification |
|---|---|---|---|---|---|---|
| Appendix: Checklist | To provide accessibility guidelines for general health IT and specific health IT in the form of a checklist | • Most participants found the checklist to be the most useful part of the Guide. They would use the checklist, especially if it were updated (to include mobile technology such as tablets) and interactive (such as giving a "score"). | *Technical expertise* in Web tool design, including Web page prototyping, design, and development; heuristic evaluation; and user testing is needed to implement the recommendations that follow. | | | • Expert interviews and focus groups: checklist was most useful section of the Guide and would be used by many participants, especially if it was interactive |
| | | | • Make the checklist more prominent as a section in the Guide as a tool for evaluating health IT (for purchasers) and as a tool for designing and testing health IT (for developers). | High | High | |
| | | | • Consider whether separate checklists are warranted. | High | High | |
| | | | • Consider including Web links and references in the checklist. | High | High | |
| | | | • Determine how the checklist would be used. | High | High | |
| | | | • Consider research to develop and test new versions of the checklist, and check usability. | High | High | |

# References

Agency for Healthcare Research and Quality. Designing Consumer Health IT: A Guide for Developers and Systems Designers; 2012. http://healthit.ahrq.gov/sites/default/files/docs/page/Designing%20Consumer%20Health%20IT%20A%20Guide%20for%20Developers%20and%20Systems%20Designers_0.pdf. Accessed June 20, 2013.

Agency for Healthcare Research and Quality. Special emphasis notice: AHRQ announces interest in career development (K01, K02, K08) and dissertation (R36) grants focused on health information technology (IT). Wired [Internet]: Agency for Healthcare Research and Quality; 2008. http://grants.nih.gov/grants/guide/notice-files/NOT-HS-08-014.html. Accessed on February 1 2013.

Agency for Healthcare Research and Quality. Health information technology: best practices transforming quality, safety, and efficiency. Wired [Internet]: Agency for Healthcare Research and Quality; 2013. http://healthit.ahrq.gov/portal/server.pt?open=514&objID=5554&mode=2&holderDisplayURL=http://wci-pubcontent/publish/communities/k_o/knowledge_library/key_topics/consumer_health_it/consumer_health_it_applications.html. Accessed on February 1 2013.

AHRQ. National action plan to improve health literacy. Wired [Internet]: Agency of Healthcare Research and Policy; 2010. http://psnet.ahrq.gov/resource.aspx?resourceID=18329. Accessed on February 22 2013.

AHRQ. AHRQ Health IT Bibliography. Wired [Internet]; 2011. http://healthit.ahrq.gov/bibliography. Accessed on February 27 2013.

American Medical Association. Health literacy: report of the Council on Scientific Affairs. J Am Med Assoc. 1999;28(6):552-7.

Baker DW. The meaning and the measure of health literacy. J Gen Intern Med. 2006;21(8):878-83.

Ball MJ, Smith C, Bakalar RS. Personal health records: empowering consumers. J Healthc Inf Manag. 2007;21(1):76-86. PMID: 17299929.

Berkman ND, Sheridan SL, Donahue KE, et al. Health literacy interventions and outcomes: An updated systematic review. 2011.

Center for Universal Design. The principles of universal design. Wired (Internet): NC State University; 2011. http://www.ncsu.edu/project/design-projects/udi/center-for-universal-design/the-principles-of-universal-design/. Accessed on February 1 2013.

Chin J, Diehl V, Norman K. Development of an Instrument Measuring User Satisfaction of the Human-Computer Interface. .  Proceedings of SIGCHI '88; 1988 New York. ACM/SIGCHI; pp. 213-8.

Christian B. Test everything: notes on the A/B revolution. Wired [Internet]; 2012. http://www.wired.com/wiredenterprise/2012/05/test-everything/. Accessed on February 1 2013.

Cruickshank J, Packman C, Paxman J. Personal Health Records: Putting patients in control? 2020health Report; 2012. http://www.2020health.org/2020health/Publications/publications-2012/Public-Health-Records.html2013.

DeWalt DA, Broucksou KA, Hawk V, et al. Developing and testing the health literacy universal precautions toolkit. Nurs Outlook. 2011 Mar-Apr;59(2):85-94. PMID: 21402204.

Eichner J, Dullabh P. Accessible health information technology (Health IT) for populations with limited literacy: a guide for developers and purchasers of health IT Prepared by the National Opinion Research Center for the National Resource Center for Health IT. Rockville, MD: Agency for Healthcare Research and Quality; 2007.

Goldberg L, Lide B, Lowry S, et al. Usability and accessibility in consumer health informatics current trends and future challenges. Am J Prev Med. 2011;40(5 Suppl 2):S187-97. PMID: 21521594.

Grossman JM, Zayas-Cabán T, Kemper N. Information gap: can health insurer personal health records meet patients' and physicians' needs? Health Affairs. 2009;28(2):377-89.

Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. Journal of the American Medical Informatics Association. 2008;15(1):1-7.

HealthyPeople.gov. Healthy People 2020 objective topic areas. Wired [Internet]; 2012. http://www.healthypeople.gov/2020/topicsobjectives2020/pdfs/HP2020objectives.pdf. Accessed on February 27 2013.

Hernandez LM. Health literacy, eHealth, and communication: putting the consumer first: workshop summary. Washington, DC: National Academy Press; 2009.

IOM. Health literacy – a prescription to end confusion. Institute of Medicine, National Academy of Sciences; 2004. http://www.iom.edu/Reports/2004/Health-Literacy-A-Prescription-to-End-Confusion.aspx. Accessed on February 22 2013.

John Hopkins University. Web Accessibility. Wired (Internet): John Hopkins University; 2013. http://webaccessibility.jhu.edu/what-is-accessibility/index.html. Accessed on April 15 2013.

Kailas A, Chong CC, Watanabe F. From mobile phones to personal wellness dashboards. IEEE Pulse. 2010;1(1):57-63. PMID: 20875965.

Keselman A, Logan R, Smith CA, et al. Developing informatics tools and strategies for consumer-centered health communication. J Am Med Inform Assoc. 2008;15(4):473-83. PMID: 18436895.

Koh HK, Berwick DM, Clancy CM, et al. New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. Health Aff (Millwood). 2012;31(2):434-43. PMID: 22262723.

Koh HK, Brach C, Harris LM, et al. A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care. Health Affairs. 2013;32(2):357-67.

Kramer-Jackman KL, Popkess-Vawter S. Method for technology-delivered healthcare measures. Comput Inform Nurs. 2011 Dec;29(12):730-40. PMID: 21694585.

Lee SY, Arozullah AM, Cho YI. Health literacy, social support, and health: a research agenda. Soc Sci Med. 2004;58(7):1309-21.

Mancuso JM. Health literacy: A concept/dimensional analysis. Nursing & Health Sciences. 2008;10(3):248-55.

Manganello JA. Health literacy and adolescents: a framework and agenda for future research. Health Educ Res. 2008;23(5):840-7.

McCormack L, Bann C, Squiers L, et al. Measuring health literacy: a pilot study of a new skills-based instrument. J Health Commun. 2010;15(S2):51-71.

Miles MB, Huberman AM. Qualitative data analysis: An expanded sourcebook: Sage Publications, Incorporated; 1994.

Moreno L, Peterson S, Bagchi A, et al. Personal Health records: What Do underserved Consumers Want?: Mathematica Policy Research, Incorporated; 2007.

National Academies. Health care comes home: the human factors. Wired (Internet): Committee on the Role of Human Factors in Home Health Care; 2011. http://sites.nationalacademies.org/dbasse/bohsi/health_care_comes_home/. Accessed on February 22 2013.

Nutbeam D. Health promotion glossary. Health Promotion International: V 0113. no. 4: Oxford University Press; 1998.

Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promot Intl. 2000;15:259-67.

Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. Am J Health Behav. 2007;31(Suppl 1):S19-26.

Peters K, Niebling M, Slimmer C, et al. Usability guidance for improving the user interface and adoption of online personal health records.  2009.

plainlanguage.gov. Improving communication from the federal government to the public. 2011. http://www.plainlanguage.gov/. Accessed on February 22 2013.

Rainie L. Two-thirds of young adults and those with higher income are smartphone owners. Pew Research Center's Internet & American Life Project; 2012. http://pewinternet.org/Reports/2012/Smartphone-Update-Sept-2012.aspx. Accessed on September 30 2012.

Ratzan SC, Parker RM. National library of medicine current bibliographies in medicine: health literacy. In: Selden CR, Zorn M, Ratzan SC, eds. Bethesda, MD: National Institutes of Health, U.S.Department of Health and Human Services; 2000.

ReadabilityFormulas.com. Readability formulas. 2013. http://www.readabilityformulas.com/. Accessed on February 22 2013.

Reti SR, Feldman HJ, Ross SE, et al. Improving personal health records for patient-centered care. Journal of the American Medical Informatics Association. 2010;17(2):192-5.

Rootman I. Health literacy and health promotion. Ontario Health Promotion E-Bulletin; 2002. http://www.ohpe.ca/node/175. Accessed on February 1, 2013.

Schillinger D. Improving the quality of chronic disease management for populations with low functional health literacy: a call to action. Dis Manage. 2001;4:103-9.

Smith A. 35% of American Adults Own a Smartphone. Washington, DC: Pew Internet and American Life Project; 2011. http://pewinternet.org/Reports/2011/Smartphones/Summary.aspx Accessed on October 13 2011.

Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health. 2012;12(1):80-.

Sox CM, Gribbons WM, Loring BA, et al. Patient-centered design of an information management module for a personally controlled health record. Journal of medical Internet research. 2010;12(3).

Speros C. Health literacy: concept analysis. J Adv Nurs. 2005 Jun;50(6):633-40. PMID: 15926968.

U.S. Department of Health and Human Services. National action plan to improve health literacy. Washington, DC: U.S. Department of Health and Human Services; 2010.

U.S. Department of Health and Human Services. Your guide for developing usable & useful Web sites. Wired (Internet): U.S. Department of Health and Human Services; 2013. www.usability.gov. Accessed on February 1 2013.

Usability Professionals' Association. Resources: about usability. Wired (Internet): User Experience Professionals Association; 2013. http://www.upassoc.org/usability_resources/about_usability/what_is_ucd.html. Accessed on February 1 2013.

von Wagner C, Steptoe A, Wolf MS, et al. Health literacy and health actions: a review and a framework from health psychology. Health Educ Behav. 2009 Oct;36(5):860-77. PMID: 18728119.

Walker J, Ahern DK, Le LX, et al. Insights for internists: "I want the computer to know who I am". J Gen Intern Med. 2009 Jun;24(6):727-32. PMID: 19412641.

Weitzman ER, Kaci L, Mandl KD. Acceptability of a personally controlled health record in a community-based setting: implications for policy and design. Journal of medical Internet research. 2009;11(2).

Whitten P, Holtz B, Cornacchione J, et al. An evaluation of telehealth websites for design, literacy, information and content. J Telemed Telecare. 2011;17(1):31-5. PMID: 21075801.

Wolpin S, Stewart M. A deliberate and rigorous approach to development of patient-centered technologies. Semin Oncol Nurs. 2011 Aug;27(3):183-91. PMID: 21783009.

Zayas-Cabán T, Dixon BE. Considerations for the design of safe and effective consumer health IT applications in the home. Quality and Safety in Health Care. 2010;19(Suppl 3):i61-i7.

# Appendix A
# Accessible Health Information Technology (IT) for Populations with Limited Literacy: A Guide for Developers and Purchasers of Health IT

**Accessible Health Information Technology (IT) for Populations with Limited Literacy:**

**A Guide for Developers and Purchasers of Health IT**

**Prepared for:**
National Resource Center for Health IT
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
540 Gaither Road
Rockville, MD 20850
www.ahrq.gov

**Prepared by**:
June Eichner and Prashila Dullabh
NORC at the University of Chicago

**AHRQ Publication No. 08-0010-EF**
**October 2007**



The Guide can be accessed at
http://healthit.ahrq.gov/sites/default/files/docs/page/LiteracyGuide_0.pdf

# Appendix B
# List of Key Words

The following is a list of keywords used in the Web search and literature search components of the environmental scan:

- accessible
- accessibility
- accessible design
- application
- application design
- application development
- accessible health technology
- apps
- articles
- best practices
- checklist
- considerations
- consumer
- consumer health informatics tool
- decision aid
- design
- design considerations
- design principles
- developer
- developer of health IT
- development
- development considerations
- development principles
- ease of use
- e-health
- EHR literacy
- EHR design
- fitness
- electronic health record
- electronic medical record
- gadget
- guidance documents
- guide
- guiding principles
- health
- health applications
- health data
- health informatics design
- health information exchange
- health information technology
- health IT literacy
- health IT UX
- health literacy
- health products
- health technology
- health website
- interactive
- interactive design
- interactive health technologies
- interactive design guidelines
- interactive development guidelines
- IT materials
- limited literacy skills
- literacy
- literacy technology
- low literacy
- medical informatics
- mobile applications
- mobile literacy design
- online
- patient guidance informatics
- patient portal
- patient technology
- personal health records
- products
- public health
- purchasers of health IT
- reports
- resources
- standards
- system
- systems architecture
- technical assistance
- technical standards
- technology
- telehealth design
- testing
- tips
- tools
- universal design
- usability
- user-centered design
- user design
- user experience
- user testing
- UX
- wellness

# Appendix C
# AHRQ Health IT Literacy:
# Consent for Participation

**Phone Interview**
**11.15.2011**

**Introduction and Purpose:**

You have been asked to be interviewed as part of this study. RTI International, a non-profit company in North Carolina is conducting a series of interviews. The interviews are sponsored by the Agency for Healthcare Research and Quality (AHRQ), part of the U.S. Department of Health and Human Services. AHRQ is a government agency charged with improving the quality, safety, efficiency, and effectiveness of health care for all Americans.

AHRQ is conducting a needs assessment to understand participants' perceptions of the types of tools and key issues in health literacy that need to be considered if developers and purchasers of health IT are to improve how they address health literacy and, in turn, ensure that consumer health IT is accessible and understandable regardless of literacy level.

**Procedures:**

You will be asked to participate in an individual phone interview asking for your opinions and reactions to specific materials. The interview will be audiotaped to make sure that your responses are captured accurately and to help us write a report summarizing the results of the interviews. The interview is expected to last no more than one hour. For your time and effort, you will receive $150; therefore, your mailing address will be requested at the time of the interview.

**Risk/Discomforts:**

There is no known physical risk to you from being in this study. You can decline to talk about any topic for any reason. You can also stop being in the interview at any time.

**Benefits:**

There is no direct benefit to you for being in this interview. What we learn from the interviews will help AHRQ to develop and deliver health care information resources to various groups.

**Confidentiality:**

We will be audio recording the interview. The audio files will be destroyed at the end of the project. Notes will be made of the recordings. You will only be referred to as "health literacy expert" "usability expert" "consumer health IT expert" or "human-computer interaction expert" in the notes. Your comments will be kept private to the extent allowable by law. The notes will be kept on a password-protected computer. Only authorized project staff will be able to see them. Any forms related to the project that have your name or information that could identify you will be kept in a locked file cabinet. These forms will be destroyed once the project ends. However, there is still a small risk that your privacy could be broken.

**Payment:**

You will be sent $150 for your time and effort.

**Right to Refuse or Withdraw:**

It is your choice to be in this interview. You can choose not to talk about any topic. You can stop being in the interview at any time.

**Persons to Contact:**

If you have questions about the interview you can call Jennifer Alexander at (301) 770-8219. She can be reached between 9 AM and 5 PM Eastern Standard Time Monday - Friday. If you have questions about your rights as a participant, you can call RTI's Office of Research Protection toll-free at 1-866-214-2043.

# Appendix D
# AHRQ Health IT Questions for Expert Interviews

**FINAL 11.15.2011**

[NOTE: Participants will have previously been emailed the questions and consent form to read over before the call]

Thank you for your time today. I'm _____ and I'm from RTI, a non-profit research organization. I am conducting a series of interviews for the Agency for Health Care Research and Quality (AHRQ), an agency of the U.S. Department of Health and Human Services.

AHRQ is conducting a needs assessment to understand participants' perceptions of the types of tools and key issues in health literacy that need to be considered if developers and purchasers of health IT are to improve how they address health literacy and, in turn, ensure that consumer health IT is accessible and understandable regardless of literacy level. Your insights are very important to us in this process, and your time today is appreciated. Our discussion will last about 60 minutes.

Before we begin, I want to review a few things:

- Did you have a chance to read over the consent form that we sent you? [If not, read out loud to participant]. Do you have any questions about it? Do you agree to participate at this time?

    If Yes – continue
    If No – thank and end

- Just to review, your participation is voluntary.

- Everything we discuss today will be kept private to the extent allowable by law, including AHRQ's confidentiality statute, 42 USC 299c-3 (c). Your name and contact information, which only the study staff knows, will not be given to anyone else and no one will contact you after this interview is over.

- I will be audio recording our conversation today. The recordings will be used to help me write a summary report and will be kept in a secure location then destroyed at the conclusion of the study. I want to stress that no names will be mentioned in the final report created from these interviews.

- If at any time you are uncomfortable with my questions, you can choose not to answer. Just let me know that you prefer not to answer.

- Most importantly, there are no right or wrong answers. I want to know your opinions. I am not an AHRQ staff member, so don't hold back on giving me your honest opinions.

- Do you have any questions before we begin?

I'd like to start with a definition. We will be discussing consumers throughout our call and I want to make sure we are both working with the same meaning: [**Read and refer back if**

**necessary**] A consumer can be anyone with a health concern including a patient or a caregiver. Consumers do not include health care providers.

I. **Development tools and resources**

1. What are some tools and/or resources that you have found most useful in helping developers to design health IT applications that will be accessible to consumers with low health literacy? [For each listed] What makes this useful?

2. Are there some specific tools or resources (or types of tools and resources) that address development of consumer health IT applications for low health literacy that you have found to be particularly **unhelpful**? Why?

3. What are some trends in health IT development that would positively impact consumers with limited health literacy skills?

4. How about trends in health IT development that would positively impact all consumers, regardless of literacy skills? [PROBE on universal design, usability]

5. What are some considerations to ensure that technologies are accessible and understandable regardless of a consumer's literacy level?

6. What are some of the most important factors that system developers and designers should consider when developing health IT resources and applications that will be accessible to consumers with low health literacy?

7. Are there any 'best practices' that you have encountered regarding **development** of applications that are accessible for those with low health literacy? If so, what are they and what makes them best practices?

8. Are there other ways in which you think that developers and others can take health literacy into account as they design health IT applications that will be used by consumers with low literacy?

II. **Purchasing tools and applications**

9. What are some tools and/or resources that you have found most useful in helping purchasers of health IT applications to ensure they are accessible to consumers with low health literacy? [For each listed] What makes this useful?

10. Are there some specific tools or resources (or types of tools and resources) that are intended to help purchasers of health IT applications for consumers with low health literacy that you have found to be particularly **unhelpful**? Why?

11. What are some of the most important factors to consider when purchasing health IT applications that will be accessible to consumers with low health literacy?

12. Are there any 'best practices' that you have encountered to help purchasers of applications ensure that they will be accessible for those with low health literacy? If so, what are they and what makes them best practices?

13. Are there other ways in which you think that purchasers and others can take health literacy into account when selecting applications?

### III. Consumer Health IT

14. How have rapid advancements in technology and Internet use changed the development of consumer health IT?

15. How have these advancements affected consumers?

16. How is the acceleration of health IT acquisition and adoption by providers impacting provider awareness of consumer use of health IT systems and issues related to health literacy?

17. How can consumer health vocabularies be incorporated into new health IT applications to improve access among consumers with limited literacy?

18. What are some ways in which the user experience can be further personalized by customizing health information while addressing health literacy?

19. How important is it for health IT applications (such as a patient portal) to explicitly provide access for non-patients such as providers, family members, and caregivers? What are some barriers to providing this access? What are some facilitators to providing this access?

20. Do you think that it is important that health IT applications include multidirectional capabilities that enable information to communicated to multiple parties? Why or why not?

21. Next, I'd like to ask about your thoughts on the potential impact of 3 **different factors that promote** consumer health IT applications usable by individuals with limited health literacy.

    a. Personalized and tailored health information or content
    b. Information scaffolding [READ if needed: *Information scaffolding provides support that allows users to move from one concept or screen to another, building on previous knowledge. For IT, it is used for multiple navigation opportunities for users - so they can go back and read about something they are not sure of or skip a screen/information that they already know. It could also be used to help with word pronunciations and definitions.*]
    c. Existing accessibility guidelines

### IV. Conclusion

22. Is there anything else you would like to say about any of the topics we've discussed or about the materials we looked over?

I would like to thank you for your time and opinions today. Your feedback was very useful and will be very helpful to AHRQ.

**IF PARTICIPANT WILL BE GETTING INCENTIVE, PLEASE ASK FOR MAILING ADDRESS:**
**NAME:**
**ADDRESS:**
**CITY, STATE, ZIP**:

# Appendix E
# Focus Group Consent Form

**Introduction and Purpose:**

You have been asked to be in a focus group as part of this study. The purpose of this study is to hear your opinions about tools and materials that can be used by health IT developers and purchasers. RTI International, a non-profit company in North Carolina, is conducting a series of focus groups. The focus groups are sponsored by the Agency for Healthcare Research and Quality (AHRQ), part of the U.S. Department of Health and Human Services.

**Procedures:**

A focus group is when about 6-10 people get together to talk about a topic and share their opinions. During the group, we will ask you to tell us your feedback on tools and materials. The group will take about 90 minutes.

We will be doing seven groups with a total of about 56 health IT developers and purchasers, either in-person or by telephone.

A moderator will be there to guide the discussion. Some of the people working on the project may observe the discussion and take notes through a one-way mirror (for in-person meetings) or listen to the discussion and take notes (by phone).

**Risk/Discomforts:**

There is no known physical risk to you from being in this study. You can decline to talk about any topic for any reason. You can also stop being in the group at any time.

**Benefits:**

There is no direct benefit to you for being in this focus group. What we learn from the group will help AHRQ to develop and deliver health IT information resources to various groups.

**Confidentiality:**

We will be audio recording the group discussion. The audio files will be destroyed at the end of the project. Notes will be made of the recordings. We will only refer to first names in the notes. Your comments will be kept private to the extent allowable by law. The notes will be kept on a password-protected computer. Only authorized project staff will be able to see them. Any forms related to the project that have your name or information that could identify you will be kept in a locked file cabinet. These forms will be destroyed once the project ends. However, there is still a small risk that your privacy could be broken.

**Payment:**

We will provide you with payment of $150 for your time, effort and travel expenses.

**Right to Refuse or Withdraw:**

It is your choice to be in this group. You can choose not to talk about any topic. You can stop being in the group at any time.

**Persons to Contact:**

If you have questions about the focus group you can call RTI Project Director Dr. Jonathan Wald at 781-370-4019. He can be reached between 9 AM and 5 PM Eastern Standard Time Monday - Friday. If you have questions about your rights as a participant, you can call RTI's Office of Research Protection toll-free at 1-866-214-2043.

**Your Consent:**

I have read this consent form. I had a chance to ask questions and my questions were answered. I was given a copy of this consent form.

Do you consent to participate in the group now?

 __Yes
 __No

# Appendix F
# Attachment A – Focus Group Moderator Guide

**FINAL 9.26.11**

[**NOTE**: This guide is to be used for both developer and purchaser focus groups. For developers, please focus on design and for purchasers, please focus on selection.]

Thank you for your time today. I'm _____ and I'm from RTI, a non-profit research organization. I am conducting these interviews for the Agency for Healthcare Research and Quality (AHRQ), an agency of the U.S. Department of Health and Human Services.

The purpose of our discussion today is to learn about how you consider health literacy in the design/selection of health IT for consumers and what tools and resources you use to help you with this. We would also like to get your feedback on a resource on health literacy designed for developers and purchasers of health IT. The results of today's discussion will be used to help AHRQ improve the content and format of current and future health literacy materials for developers and purchasers of health IT, as well as other audiences. Your insights are very important to us in this process, and your time today is appreciated. Our discussion will last about 90 minutes.

Before we begin, I want to review a few things:

- [**if online**] Did you have a chance to read over the consent form that we sent you? [**NOTE**: If not, read out loud to participants.] Do you have any questions about it? Do you agree to participate at this time?

  If Yes – continue
  If No – thank and end

- Your participation is voluntary and you have the right to not answer any question or withdraw from the discussion at any time.

- Everything we discuss today will be kept private to the extent allowable by law. Your name and contact information, which only the study staff knows, will not be given to anyone else and no one will contact you after this discussion is over.

- We will be audio recording the discussion today and I have some coworkers observing.

- If at any time you are uncomfortable with my questions, you can choose not to answer. Just let me know that you prefer not to answer.

- Most importantly, there are no right or wrong answers. I want to know your opinions. I did not create these materials, so don't hold back on giving me your honest opinions.

## I. Introduction

I'd like to go around the table and, when we get to you, please tell us:

- Your first name

- Where you work or the type of organization (for example, university, health system, industry, non-profit, etc.)

- Your main role at your organization

## II. Familiarity with and Consideration of Health Literacy (15 minutes)

1. How do you define health literacy? What does that term mean to you?

2. How do you define and what do you know about the following [ask about each]:
   a. Accessibility?
   b. User experience?
   c. Usability?
   d. Human-computer interaction?

3. How have you learned about health literacy? [Probes: training, course, informal]

4. How often do you take health literacy into consideration when designing/selecting consumer health IT tools? In what ways do you consider it?

5. What are some of the barriers to considering health literacy when designing/selecting consumer health IT tools? How do you address these barriers?

6. What are your primary sources of information about designing/selecting consumer health IT tools?

7. What resources and materials are helpful to you when you consider health literacy in designing/selecting consumer health IT tools? Why have they been helpful?

8. What resources are you familiar with designed for use by developers/purchasers of health IT that deal **specifically** with health literacy? Have these resources been helpful or not? Why or why not?

9. How do you look for information about health literacy? Online? Journals? Industry representatives?

**FOR DEVELOPERS:**

10. Do you currently test your products for health literacy? What resources do you use to do that?

11. At what point in the design process do you think about issues such as ensuring that products are available to all patients and health literacy? [Probes: requirements, design, specification, coding, testing, go-live]

12. Who is, or should be, accountable to make sure that product design addresses the needs of limited health literacy users?

**FOR PURCHASERS:**

13. Do you currently evaluate the health literacy requirements of consumer health IT tools you recommend for consumers?

14. When in the process of selecting products do you think about issues such as patient accessibility and health literacy? [Probes: selection, purchase, installation, training, use]

15. Who is, or should be, accountable to make sure that selected products will adequately address limited health literacy users?

## III. Quality of the Health IT Literacy Guide (30 minutes)

I have shared with you an example of a health literacy resource designed for developers and purchasers of health IT that is currently available on the AHRQ National Resource Center for Health IT Web site. I'd like you to take a few minutes and look through the guide including the checklist at the end.

[NOTE: Give participants some time to review the guide – they don't have to read the entire guide, just skim through it to get the general idea.]

16. Have you ever used this guide? If not, were you familiar with it?

17. Do you think other developers/purchasers are familiar with this guide or know it exists?

18. What do you think is the main point of this guide?

19. How useful do you think the guide is in helping developers/purchasers to evaluate health IT products?

20. How easy or difficult do you think the guide would be for you and your colleagues to use?

21. Is the information in the guide believable? Why or why not?

22. Do you think developers/purchasers of health IT would be able to use the guide for its intended purpose?

23. Would you use this guide? If so, how? If not, why not?

24. In what steps of the software design process (for developers) or system selection process (for purchasers) would you use the guide?

25. What do you think about the checklist at the end? Have you seen a similar resource?

26. Would you use a checklist like this? If so, how and when? If not, why not?

27. Is there anything missing from this guide or from the checklist? What would you add?

28. Is there anything you would change in this guide or in the checklist? If yes, what would you change and why? If not, why not?

29. What other types of tools and resources would be useful to developers/purchasers of consumer health IT when addressing health literacy?

30. How does the guide compare to other resources on health literacy that you are familiar with?

31. Do you have any other comments on how the guide or the checklist can be improved to make it more useful to purchasers and developers of health IT?

## IV. Audiences and Dissemination (15 minutes)

32. Who do you think this guide was written for? Who are the audiences?

33. Are there any other audiences that the guide should target?

34. Where would you expect to see/find the guide? [Probe: online, AHRQ site, org site, other]

35. If AHRQ wanted to reach developers/purchasers like you with this guide, how should they do so?

## V. Conclusion (5 minutes)

36. Is there anything else you would like to say about any of the topics we've discussed or about the guide?

I would like to thank you for your time and opinions today. Your feedback was very useful and will be very helpful to AHRQ.

# Appendix G
# Environmental Scan Results

## Environmental Scan Part 1: Examples of Resources (9)

### Health IT Organizations & Websites: 2 resources

| Organization | Resource Title | Resource Link |
|---|---|---|
| AMIA | *DRAFT: Policies and Practices to look for from Organizations that Collect Your Personal Health Information: A Consumer Checklist* | http://www.amia.org/sites/amia.org/files/2007-Policy-Meeting-draft-consumer-checklist.pdf |
| AHRQ | *Consumer Health Information Technology in the Home: A Guide for Human Factors Design Considerations* | http://www.nap.edu/openbook.php?record_id=13205&page=1 |

### Web Search: 7 resources

| Source | Resource Title | Resource Link |
|---|---|---|
| AAFP | "How to Select an Electronic Health Record System" | http://www.aafp.org/fpm/2005/0200/p55.html |
| AHIMA | *Web-Based Systems for Dissemination of Health-Related Data: A Guide for Public Health Agencies Developing, Adopting, or Purchasing Interactive Web-Based Data Dissemination Systems* | http://library.ahima.org/xpedio/groups/public/documents/government/bok1_024248.pdf |
| CHF | *Electronic Medical Records: A Buyer's Guide for Small Physician Practices* | http://www.chcf.org/publications/2003/10/electronic-medical-records-a-buyers-guide-for-small-physician-practices |
| Microsoft | *Connected Health Framework Architecture And Design Blueprint* | http://www.microsoft.com/health/ww/ict/Pages/Connected-Health-Framework.aspx |
| NIA/NIH | *Making Your Website Senior Friendly* | http://www.nia.nih.gov/health/publication/making-your-website-senior-friendly |
| Interactions Magazine | *User Experience Design Guidelines for Telecare (e-health) services* | http://dl.acm.org/citation.cfm?doid=1288515.1288537 |
| U.S. DHHS | *Guide to Writing and Designing Easy-to-Use Health Websites* | http://www.health.gov/healthliteracyonline/ |

**Discussion**

The following is further description of new resources identified in Part 1 of the environmental scan that could be added to the next iteration of the Guide's "*Additional Materials*" section.

- **Health Literacy Online Guidance**
  *Health Literacy Online: A Guide to Writing and Designing Easy-to-Use Health Web Sites*
  http://www.health.gov/healthliteracyonline/

This is a research-based how-to guide for creating health Web sites and Web content for the millions of Americans with limited literacy skills and limited experience using the Web. It is geared to Web designers, content developers, and other public health and communication professionals. Some of the research that informs this guide was also used to inform the Health IT Literacy Guide. This is the only other guide that is specifically focused on health literacy.

- **Older Adults Web Guidance**
  *Making Your Website Senior Friendly*
  http://www.nia.nih.gov/health/publication/making-your-website-senior-friendly
  This is a research-based tip sheet that provides guidelines that can help designers and developers create Web sites that work well for older adults. It includes specific tips, examples, and references. It also provides clear references and tips related to literacy, cognitive processing, and usability.

- **Guidelines for Home Care Health IT Products**
  *Consumer Health Information Technology in the Home*
  http://www.nap.edu/catalog.php?record_id=13205
  This guide is for purchasers and developers of health IT to develop and purchase home health IT applications that will be easy for consumers to use in a wide range of home environments. It provides insights and recommendations on choosing and developing applications that take into account users' cognitive, physical, and sensory abilities. In terms of tools, the document provides some consideration charts and a design checklist.

- **Consumer Education Support Materials for Providers**
  *Optimization Strategies for Client Education and Report Cards*
  http://www.stratishealth.org/documents/HITToolkitHH/2.Utilize/2.2Effective%20Use/2.2Optimze_Ed_Report_Cards.doc
  This tool discusses some ways to evaluate client or patient education components of EMR systems to assess tailored versus generic information.

# Environmental Scan Part 2: Examples of Best Practices (22)

**AHRQ Health IT Bibliography Review: 3 resources**

Ball M, Smith C, et al. Personal Health Records: empowering consumers. J Healthc Inf Manag 2007 Winter;21 (1):76-86.

Halamka J, Mandl KD, Tang P. Early Experiences with Personal Health Records J Am Med Inform Assoc 2007. Oct 18.

Young, AS., Shoai, R., et al. Information technology to support improved care for chronic illness. J Gen Intern Med. 2007 Dec; Suppl 3:425-30.

**Literature Search: 19 resources**

Fensli R, Oleshchuk V, et al. Design Requirements for Patient Administered Personal Electronic Health Records Biomedical Engineering Trends in Electronics, Communications and Software 2011.

Grossman J, Zayas-Caban T, et al. Information Gap: Can Health Insurer Personal Health Records Meet Patients' and Physicians' Needs? Health Affairs 2009;28 (2):377-389.

Goldberg, L., Lide, B., et al. Am J Prev Med. Usability and accessibility in consumer health informatics current trends and future challenges. 2011 May;40 (5 Suppl 2):S187-97.

Hernandez L. Health Literacy, eHealth, and Communication: Putting the Consumer First: Workshop Summary 2009. http://www.ncbi.nlm.nih.gov/books/NBK36296/pdf/TOC.pdf

Kailas, A., Chong, C., et al. From Mobile Phones to Personal Wellness Dashboards. IEEE Pulse. 2010 Jul/Aug;1 (1):57-63.

Keselman A, Logan R, Smith CA, et al. Developing informatics tools and strategies for consumer-centered health communication. J Am Med Inform Assoc 2008;15:473–83.

Kramer-Jackman, KL., Popkess-Vawter, S. Method for Technology-Delivered Healthcare Measures. Comput Inform Nurs. 2011 Jun 21. Epub ahead of print.

Lerouge, C., Ma, J., et al. User profiles and personas in the design and development of consumer health technologies. Int J Med Inform. 2011 April 8. Epub ahead of print.

Moreno L, Peterson S, et al. Personal Health Records: What do Underserved Consumers Want? Mathematica Policy Research Inc May 2007;4.

Peters K, Niebling M, Slimmer C, et al. Usability guidance for improving the user interface and adoption of online personal health records [Internet], 2009. Accessed 9/14/2011.

Reti SR, Feldman HJ, et al. Improving personal health records for patient-centered care. J Am Med Inform Assoc 2010;17:192–5.

Rodriguez M, Casper G, et al. Patient-centered Design: The Potential of User-Centered Design in Personal Health Records

Schnipper, JL., Gandhi, TK., et al. Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. Inform Prim Care. 2008;16 (2):147-55.

Sox CM, Gribbons WM, Loring BA, Mandl KD, Batista R, Porter SC. Patient-Centered Design of an Information Management Module for a Personally Controlled Health Record. J Med Internet Res 2010;12 (3):e36.

Walker J, Ahern DK, Le LX, et al. Insights for internists: "I want the computer to know who I am". J Gen Intern Med 2009;24:727–32.

Weitzman ER, Kaci L, Mandl KD. Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy and Design. J Med Internet Res 2009;11 (2):e14.

Whitten, P., Holtz, B., et al. An evaluation of telehealth websites for design, literacy, information and content. J Telemed Telecare. 2011;17 (1):31-5. Epub 2010 Nov 12.

Wolpin, S., Stwart, M. A Deliberate and Rigorous Approach to Development of Patient-Centered Technologies. Semin Oncol Nurs. 2011 Aug;27 (3):183-91.

Zayas-Cabán T, Dixon BE. Considerations for the design of safe and effective consumer health IT applications in the home. Qual Saf Health Care 2010;19 (Suppl 3):i61–7

## Environmental Scan Part 3: Examples of Health IT Products (30)

### Web Search: 19 resources

| Product | Type | Resource Link |
| --- | --- | --- |
| Adaptiv | Provider health IT | http://getadaptiv.com/ Accessed in November 2011. |
| BodyBugg | Popular consumer health IT | http://www.bodybugg.com/ |
| Daily Burn | Popular consumer health IT | https://dailyburn.com/ |
| Fit Friendzy | Popular consumer health IT | http://itunes.apple.com/us/app/fit-friendzy-exercise-challenges/id445749821?mt=8 |
| FitBit | Popular consumer health IT | http://www.fitbit.com/ |
| Fooducate | Popular consumer health IT | http://www.fooducate.com/ |
| Health Wise | Consumer health site targeting limited literacy audience | http://www.healthwise-aberdeen.com/index.shtml |
| HealthMap | Popular consumer health IT | http://healthmap.org/en/ |
| Kids Health - Parent Resources | Consumer health site targeting limited literacy audience | http://kidshealth.org/parent/ |
| Lose It | Popular consumer health IT | http://itunes.apple.com/us/app/lose-it!/id297368629?mt=8 |
| Map My Run | Popular consumer health IT | http://itunes.apple.com/us/app/imapmyrun-running-run-jogging/id291890420?mt=8 |
| Microsoft Amalga | Provider health IT | http://www.youtube.com/watch?v=Zyp9xQUIzkA |
| Moody Me | Popular consumer health IT | http://itunes.apple.com/us/app/moody-me-mood-diary-tracker/id411567371?mt=8 |
| Morsel | Popular consumer health IT | http://itunes.apple.com/us/app/morsel-2.0/id378392735?mt=8 |
| My Net Diary | Popular consumer health IT | http://www.mynetdiary.com/ |
| Patients Like Me | Popular consumer health IT | http://www.patientslikeme.com/ |

(continued)

## Web Search: 19 resources (continued)

| Product | Type | Resource Link |
|---|---|---|
| Ringful Health | Popular consumer health IT | http://www.ringful.com/apps/hospital/ |
| Run Keeper | Popular consumer health IT | http://itunes.apple.com/us/app/runkeeper/id300235330?mt=8 |
| Sleep On It | Popular consumer health IT | http://itunes.apple.com/us/app/sleep-on-it-sleep-tracker/id393927199?mt=8 |

## Literature Search: 11 resources

| Product | Type | Citation |
|---|---|---|
| Google Health | PHR | Weitzman ER, Kaci L, Mandl KD. Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy and Design. J Med Internet Res 2009;11 (2):e14. |
| Indivo | PHR | Halamka J, Mandl KD, Tang P. Early Experiences with Personal Health Records J Am Med Inform Assoc 2007. Oct 18. |
| Lifelines2 | EHR | Wang, TD., Wongsuphasawat, K., et al. Extracting Insights from Electronic Health Records: Case Studies, a Visual Analytics Process Model, and Design Recommendations. Journal of Medical Systems 2011; May 4. |
| MedWISE | EHR | Senathirajah, Y., Kaufman, D., et al. Cognitive Analysis of a Highly Configurable Web 2.0 EHR Interface. AMIA Annu Symp Pro 2010; 2010: 732-736. |
| Microsoft Health Vault | PHR | Weitzman ER, Kaci L, Mandl KD. Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy and Design. J Med Internet Res 2009;11 (2):e14. |
| Mychart | PHR | Halamka J, Mandl KD, Tang P. Early Experiences with Personal Health Records J Am Med Inform Assoc 2007. Oct 18. |
| MyMedicalRecords | PHR | Peters K, Niebling M, Slimmer C, et al. Usability guidance for improving the user interface and adoption of online personal health records [Internet], 2009. Accessed 9/14/2011. |
| PatientSite | PHR | Halamka J, Mandl KD, Tang P. Early Experiences with Personal Health Records J Am Med Inform Assoc 2007. Oct 18. |
| Patient Gateway | EHR, consumer informatics | Schnipper, JL., Gandhi, TK., et al. Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. Inform Prim Care. 2008;16 (2):147-55. |
| Talking Touchscreen | Consumer health informatics | Yost, KJ., Webster, K., et al. Acceptability of the talking touchscreen for health literacy assessment. J Health Commun. 2010;15 Suppl 2:80-92. |
| VA EHR | EHR | Russ, AL., Saleem, JJ., et al. Electronic health information in use: Characteristics that support employee workflow and patient care. Health Informatics J. 2010 Dec; 16 (4):287-305. |

**Discussion**

The following are a few examples of health IT products that model best practices pertaining to the development of health IT products.

- Microsoft HealthVault's online health tracking tools are examples of existing products that provide personalized health content such as specific guidance and tailored behavior change suggestions (Peters et al., 2009): http://www.microsoft.com/en-us/healthvault/tools-devices/tools.aspx.

- Hospital Compare by the startup ringfulHealth is a mobile device application that helps consumers choose the best provider in their area based on ratings and location. Users can search for providers in a variety of ways and are presented with the results as both a list and a map: http://www.ringful.com/apps/hospital/.

- PatientsLikeMe is a social networking site that connects users to others with similar symptoms and medical conditions. It also allows users to find clinical trials for which they might be eligible based on their PHI: http://www.patientslikeme.com/.

- Fooducate is a smartphone app that allows users to scan the barcode of food products at the grocery store to find out that food's nutritional value and health rating. The app also allows users to compare products: http://www.fooducate.com/.