

Following the Path of the Patient

Reaching
New Heights
in Patient
Powered Care



Evaluating
Technology-Enabled
Patient Education

Susan C. Hull MSN, RN-BC, NEA-BC
September 7, 2017

PART 2 slides

Lens 3: Health Literacy

PEMAT

Patient Education Materials Assessment Tool

The screenshot displays the PEMAT website interface. On the left is a navigation sidebar with categories: Clinicians & Providers, Education & Training, Hospitals & Health Systems, and Prevention & Chronic Care (highlighted). Under Prevention & Chronic Care, there are sub-items: Announcements, Healthier Pregnancy Provider Training, Evidence-Based Decisionmaking, Improving Primary Care Practice, Behavioral and Mental Health, Capacity Building, Care Coordination, Clinical-Community Linkages, and Health Care/System Redesign.

The main content area features the title "The Patient Education Materials Assessment Tool (PEMAT) and User's Guide" and a subtitle "An Instrument To Assess the Understandability and Actionability of Print and Audiovisual Patient Education Materials". Below the subtitle are buttons for "Next Page" and "Table of Contents". The version "Version 1.0" is noted.

The description states: "The Patient Education Materials Assessment Tool (PEMAT) is a systematic method to evaluate and compare the *understandability* and *actionability* of patient education materials. It is designed as a guide to help determine whether patients will be able to understand and act on information. Separate tools are available for use with print and"

On the right side, there are social media icons (Facebook, Twitter, Email, RSS, and a plus sign) and the publication number "14-0002-EF". Below this is a section titled "ALTERNATE FORMATS" with a dropdown arrow, containing a list of downloadable resources: "PEMAT User Guide [3.17MB]", "Tool for Printable Materials [489.62KB]", "Tool for Audiovisual Materials [378.42KB]", and "PEMAT Auto-Scoring Form [235KB]". At the bottom right, there is a thumbnail image of the PEMAT User Guide cover, which shows two women looking at a document together.

Designing Health Literate Mobile Apps

Jordan Broderick, Theresa Devine, Ellen Langhans, Andrew J. Lemerise,
Silje Lier, and Linda Harris*

January 28, 2014

**Participants in the activities of the IOM Roundtable on Health Literacy's Collaborative on New Technologies*

INSTITUTE OF MEDICINE
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Advising the nation • Improving health

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<https://health.gov/communication/lite/BPH-HealthLiterateApps.pdf>

National Library of Medicine (NLM)



Center for Health Literacy Promotion

Action research for effective use of health info & services

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[Health Literacy Library](#)

[Health Literacy Definitions](#)

[Health Literacy Resources](#)

[CHLP Blog](#)

[Free Training](#)

[Beginnings Guides](#)

[WUN Collaboration](#)

[Events](#)

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Promoting Health Literacy with Free Information & Cool Tools from Your National Library of Medicine

These videos and accompanying materials may be used freely for educational purposes only as long as no changes are made, attributions are retained, and no part is sold or used for any commercial purpose.

This three-part video training series is designed for social and health services providers and programs with limited time and money for training and materials. The brief videos (8-10 minutes) are intended for independent or small group learning and for use in staff meetings, trainings and other scheduled activities. For details on the presenters, producer, and funder see the [Facilitator's Guide](#).



Session 1 (8 min) introduces the two part challenge of promoting health literacy. Then Gail Kouame of the National Network of Libraries of Medicine takes viewers on a tour of the free, evidence-based information resources of the National Library of Medicine. She demonstrates how to access [MedlinePlus](#), [Genetics Home Reference](#) and

[ClinicalTrials.gov](#) from any computer. Gail's tour models how to introduce the resources to families and so accomplish the first challenge - to empower a person to obtain information that is reliable, understandable, actionable, and free.

Session 1: [Pre-test Post-test Handout View Video #1](#)

Beginnings Guides



It matters what a mother knows and what a mother does.

Beginnings Guides are designed to complement counseling during office and home visits for prenatal and parent education and family support. The Guides are both teaching & learning materials for promoting [health literacy](#), reflective function, and other essential life skills for parents.

In English & Spanish Easy to read. Rigorously tested in Early Head Start, Healthy Start, Healthy Families, Strengthening Families, First Five, Families First, Parents as Teachers, teens ... Complements [Ages & Stages](#). Companion to the [Life Skills Progression](#) instrument.

Beginnings Pregnancy Guide translates the health promotion content of prenatal care into easy-to-read practical guidance for a healthy pregnancy. Now in its 8th edition. 6 booklets (96 pages) referenced by gestational age. Over 310,000 families served [FAQ Pregnancy Guide](#)
Karu Marudain

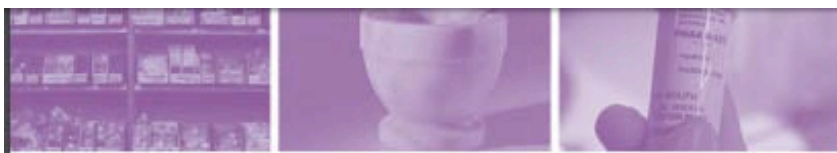
<http://www.healthliteracypromotion.com/Beginnings-Guides.html>

AHRQ

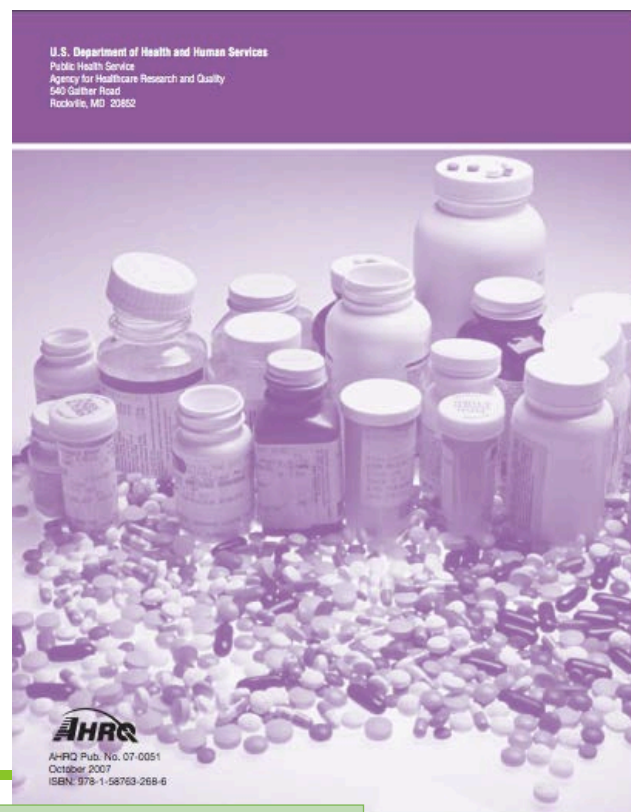
Health Literacy Tools for Use in Pharmacies

The Agency for Healthcare Research and Quality (AHRQ) has developed six health literacy tools for pharmacy:

- Pharmacy Health Literacy Assessment Tool & User's Guide.
 - Training Program for Pharmacy Staff on Communication.
 - Guide on How To Create a Pill Card.
 - Telephone Reminder Tool To Help Refill Medicines On Time.
 - Explicit and Standardized Prescription Medicine Instructions.
 - How to Conduct a Postdischarge Followup Phone Call
 - Health literacy tools to improve communication for providers of medication therapy management
- Want to learn more about these tools? Go to: [AHRQ Tools](#)
-



Is Our Pharmacy Meeting Patients' Needs? A Pharmacy Health Literacy Assessment Tool User's Guide



<https://www.ahrq.gov/sites/default/files/publications/files/pharmlit.pdf>

Health Literacy

Health Literacy	
Health Literacy Basics	+
Find Training	+
Create a Health Literacy Plan	+
Collaborate	+
Guidelines, Laws, & Standards	
Develop & Test Materials	+
Health Literacy Research	-
Federally Funded Research	
Sharing Health Literacy Research	
Evidence Reviews & Research Summaries	
Evaluate Skills & Programs	+

[CDC](#) > [Health Literacy](#) > [Health Literacy Research](#)

Evidence Reviews & Research Summaries



Here you will find the most recent evidence report on health literacy interventions and outcomes and brief research summaries on health literacy topics.

Health Literacy Evidence Reviews

[Health Literacy Interventions and Outcomes: An Updated Systematic Review](#) . The Agency for Healthcare Research and Quality (AHRQ) summarizes the evidence on health literacy and outcomes in a systematic review.

Research Summaries on Health Literacy Topics

CDC is committed to applying and sharing research to improve health literacy. In our Research Summaries section we present findings from recent published studies focused on specific health literacy topics. See our Science Bites for very brief summaries of select findings and recommendations for practice. Use these summaries to improve the effectiveness of your communication and program activities.

- > **Numeracy affects decision-making about health risks**
- > **Limited health literacy can affect self-care abilities, readmission, and early death for people diagnosed with heart disease**

Visual Communication Resources

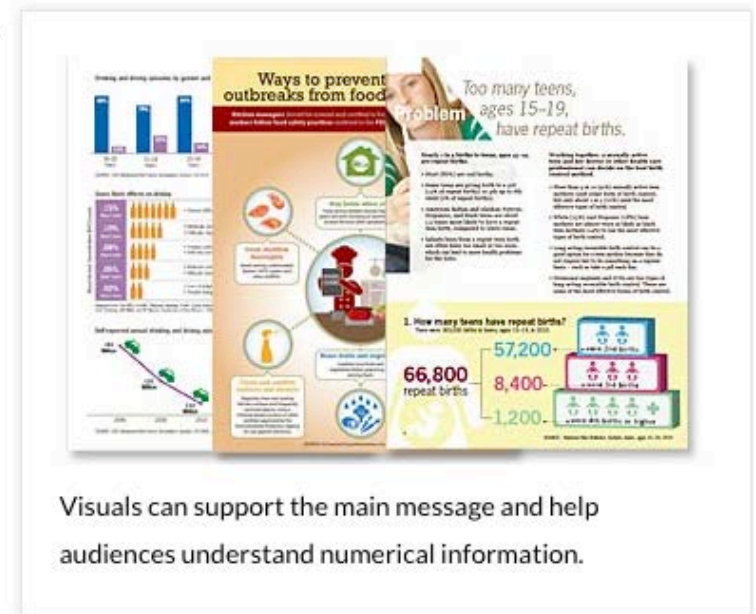


Visuals, such as pictures, drawings, charts, graphs and diagrams, can be effective tools for communicating health information. Visuals can make the presentation of complex information easier to comprehend, more attractive, and can also reinforce written or spoken health messages.

Visual communication can benefit all audiences, but can be especially helpful to individuals with lower literacy and numeracy skills. Remember, though, that visuals can't speak for themselves. People can interpret visuals, just as they do words, in different ways. Choose visuals that support the main message and have clear headings, labels, and captions.

Below are several resources for public domain health pictures, as well as resources that will help you make decisions about choosing images that effectively communicate your message and graphic displays your audience will understand.

- [Public Health Image Library \(Centers for Disease Control and Prevention 2008\)](#)
- [Visuals Online \(NIH National Cancer Institute\)](#) [↗](#)
- [Making Data Talk](#)  [2 MB, 52 page] [↗](#) (NIH National Cancer Institute)
- [Visualizing Health](#) [↗](#) (University of Michigan)
- [Icon Array](#) [↗](#) (University of Michigan)



Visuals can support the main message and help audiences understand numerical information.

VISUALIZING HEALTH

A Scientifically Vetted Style Guide for Communicating Health Data

[About](#)

[The Wizard](#)

[Browse the Gallery](#)

[Using Visualizing Health](#)

What & Why

Data can help people make better decisions about their health. But it's not always clear what sort of presentation will make the most sense to the most people. ... [READ MORE](#)

How

Visualizing Health contains graphic displays of health information that we've validated through research among the general public. ... [READ MORE](#)

Who

Visualizing Health was developed by the University of Michigan, with funding from the Robert Wood Johnson Foundation. ... [READ MORE](#)



Support
provided by



Robert Wood Johnson
Foundation

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<http://www.vizhealth.org/>

Using Visualizing Health

Using Visualizing Health

VizHealth Adventures

Risk Calculator

Icon Array Generator

How to Choose an Image

How to Adapt an Image

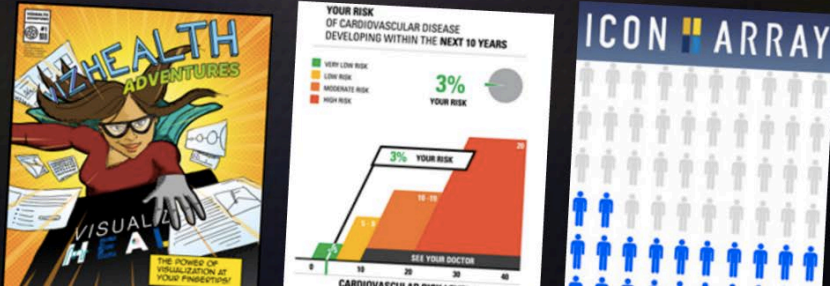
How to Attribute Use

How to Provide Feedback

Visualizing Health is a style guide that is intended to serve as both inspiration and instruction to health professionals and others seeking to communicate health risk information to the public.

The graphic visualizations on this site are more than just attractive designs: they have been scientifically tested with real users. Our hope is for this information to be used far and wide, and that what we've learned will help make it a little easier for health professionals to explain complicated concepts to those people who need to understand it.

Visualizing Health contains a lot of good ideas about how to present health data – but this site is only a start. We encourage researchers, designers, and other professionals to continue building on what we've learned. One clear lesson from this project is that when it comes to presenting health information, there is no single “best” graphic. Different goals require different designs, and graphics that performed well in our testing may not always be the best choice to accomplish the things that matter most to you.



My goal

- Classifying risks
- Raise or lower concern
- Awareness of risk
- Differences in likelihood
- Risk tradeoffs



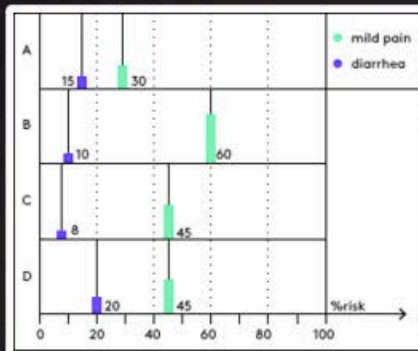
Details or gist?

- Verbatim recall
- Gist understanding



Data I have

- Benefit estimate
- Risk over time
- Case counts
- Population risks
- Risk disparity

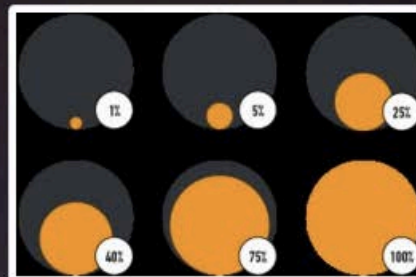


(35) Tables of side effect risks

...MORE LIKE THIS

- Risk tradeoffs
- Differences in likelihood

ALL TAGS



(87) Icons to show likelihood of side effects

...MORE LIKE THIS

- Differences in likelihood
- Classifying risks

ALL TAGS

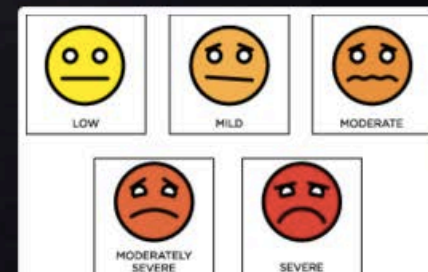
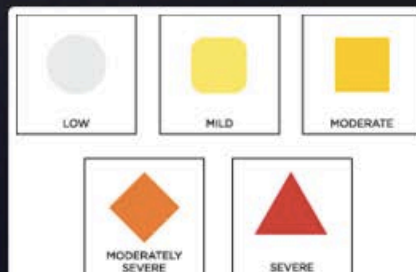
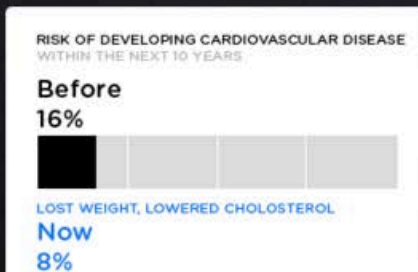


(68) Visualizing very small risks

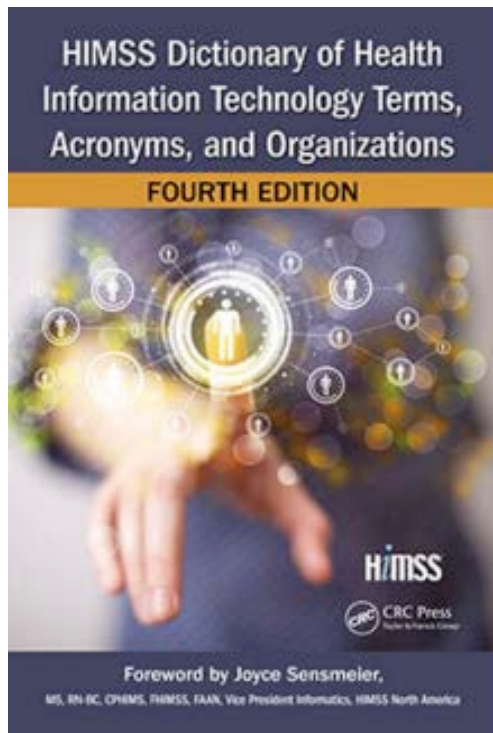
...MORE LIKE THIS

- Raise or lower concern
- Awareness of risk

ALL TAGS



Lens 4: Interoperability and Usability



More than 3000 definitions

Interoperability means the ability of health information systems to work together within and across organizational boundaries in order to advance the effective delivery of healthcare for individuals and communities.

- **“Foundational”** interoperability allows:
 - data exchange from one information technology system to be received by another and does not require the ability for the receiving information technology system to interpret the data
- **“Structural”** interoperability is:
 - An intermediate level that defines the structure or format of data exchange (message format standards)
 - To ensure uniform movement of healthcare data from one system to another such that the clinical or operational purpose and meaning of the data is preserved and unaltered
 - Defines the syntax of the data exchange
 - Ensures that data exchanges between information technology systems can be interpreted at the data field level
- **“Semantic”** interoperability provides:
 - Highest level interoperability, which is the ability of two or more systems or elements to exchange information and to use the information that has been exchanged
 - Takes advantage of both the structuring of the data exchange and the codification of the data including vocabulary so that the receiving information technology systems can interpret the data
 - This level of interoperability supports the electronic exchange of patient summary information among caregivers and other authorized parties via potentially disparate electronic health record (EHR) systems and other systems to improve quality, safety, efficiency, and efficacy of healthcare delivery

Emerging HL7 mHealth Standards

1. mFHAST

- Mobile Framework for Healthcare Adoption of Short-Message Technologies standard
- transport, structure and content

2. MH2F

- Mobile Health Functional Framework Standard
 - Consumer Mobile Health Application Functional Framework

3. FHIRframe

- Fast Healthcare Interoperability Resources for mobile devices open API standard

4. Meds-on-FHIR

- Patient Medication Administration IG using FHIR profile

Usability, Design, Interoperability

Recent Research

- Georgsson, Mattias., Stagers, Nancy . “An evaluation of patients’ experienced usability of a diabetes mHealth system using a multi-method approach,” Journal of Biomedical Informatics. Volume 59, February 2016, Pages 115-129. Retrievable at:
<http://www.sciencedirect.com/science/article/pii/S1532046415002762>
 - Ashurst, Emily J. and Jones, Ray B. “Is the Health App Challenge approach of patient-led application conception, development, and review worthwhile?” Health Policy and Technology (2017) 6, 83–92. Retrievable at:
<http://www.sciencedirect.com/science/article/pii/S2211883716300909#t0020>
 - “Challenges in Assessing Mobile Health App Quality: A Systematic Review of Prevalent and Innovative Methods,” American Journal of Preventive Medicine, Volume 51, Issue 6, December 2016, Pages 1051-1059. Retrievable at:
<http://www.sciencedirect.com/science/article/pii/S0749379716302574>
 - Schnall, Rebecca., Bakken, Sue., et. al. “Usability Evaluation of a Prototype Mobile App for Health Management for Persons Living with HIV, ” Student Health Technology Informatics, 2016, 225: 481-5.
-

Usability, Design, Interoperability

Recent Research, 2

- Schnall, Rebecca., Rojas, Marlene., Bakken, Suzanne., Brown, William., Carballo-Diequez, Alex., Carry, Monique., Deborah Gelauded, Deborah., Patterson Mosley, Jocelyn., and Travers, Jasmine. “A user-centered model for designing consumer mobile health (mHealth) applications (apps),” *Journal of Biomedical Informatics*, Volume 60, April 2016, Pages 243-251. Retrievable at:
<http://www.sciencedirect.com/science/article/pii/S1532046416000241>
 - McMillan, Brian., Hickey, Eamonn., Patelb, Mahendra G., and Mitchell, Caroline. “Quality assessment of a sample of mobile app-based health behavior change interventions using a tool based on the National Institute of Health and Care Excellence behavior change guidance,” *Patient Education and Counseling*. Vol.99 Issue 3, March 2016, pp429-435.
<https://doi.org/10.1016/j.pec.2015.10.023> Retrievable at:
<http://eprints.whiterose.ac.uk/91906/3/Quality%20assessment.pdf>
 - Brown III, William., Yen, Po-Yin., Rojas, Marlene., Schnall, Rebecca d”Assessment of the Health IT Usability Evaluation Model (Health-ITUEM) for evaluating mobile health (mHealth) technology,” *Journal of Biomedical Informatics*. 2013 Dec; 46(6):1080-7. doi: 10.1016/j.jbi.2013.08.001. Epub 2013 Aug 23. Retrievable at:
<https://www.ncbi.nlm.nih.gov/pubmed/23973872>
-

Usability Testing

with Think Aloud Protocol

Think Aloud is a usability assessment method commonly employed to determine users' thoughts and opinions while they perform a list of specified tasks with a system.

- Originated in 1984 in psychology (Simon and Ericsson); Rev in 1993, well established within the Human Factors field.

Asks users to talk aloud during their interactions, to express their reactions and thinking and to explain what they are doing as they perform specific, representative tasks.

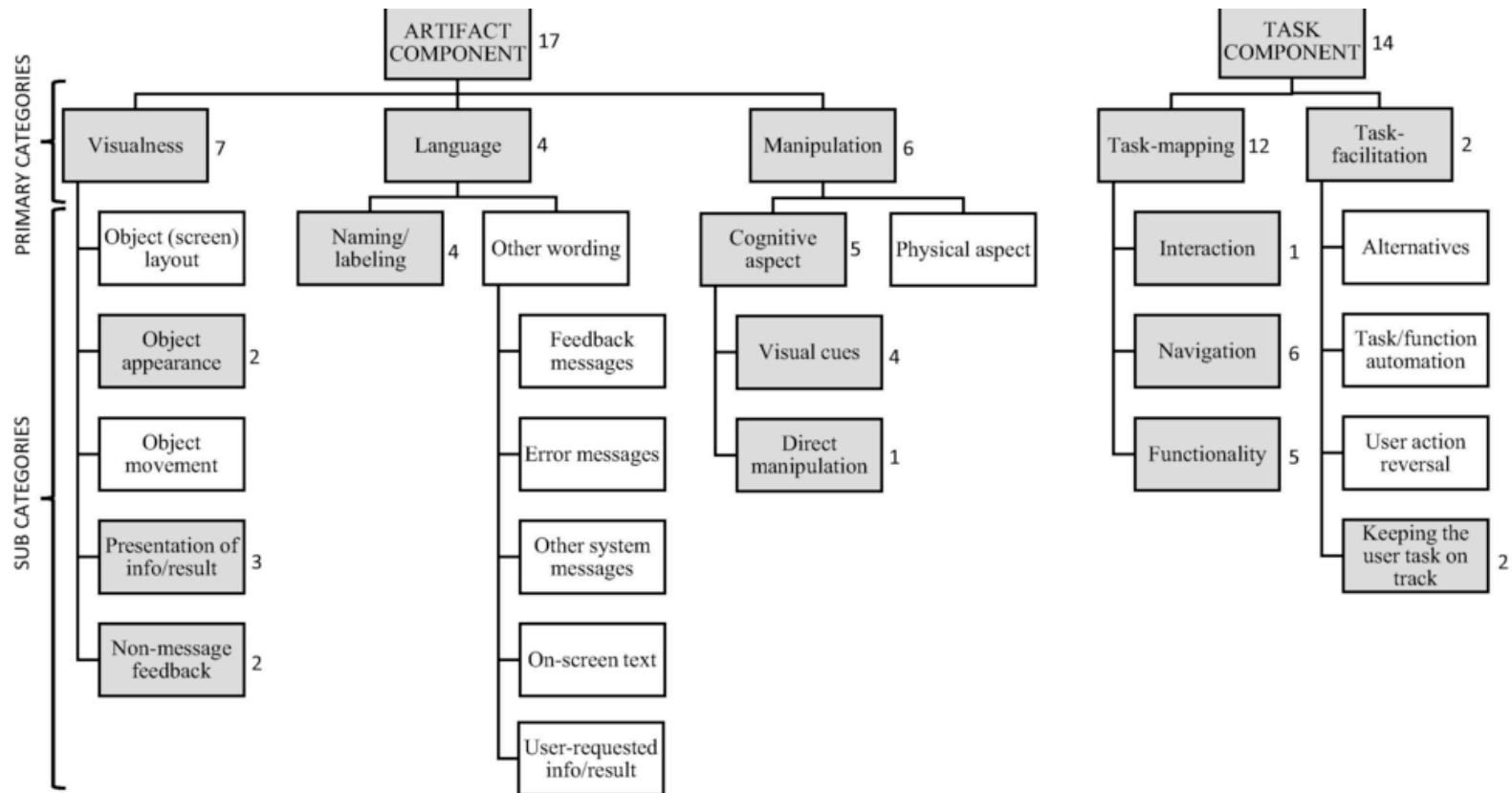
- Data is audio- and/or video-recorded and/or an observer takes thorough, written notes
- Minimal intervention from the tester assures users' thought processes are not interrupted except to remind them to keep talking.
- The focus is on understanding users' decision making processes and on how users experience the system in their own words
- Because the method provides extensive, detailed data, only a small sample of five to eight users is needed in usability testing to detect 80–85% of usability problems, to gain a thorough understanding of task behavior and to identify the main usability problems

Testing recommendations:

- Representative tasks for the specific domain are also essential, and they should be as realistic as possible
- Conduct in the actual user's context or one as close to the natural environment as possible

Georgsson, Mattias., Stagers, Nancy . "An evaluation of patients' experienced usability of a diabetes mHealth system using a multi-method approach," *Journal of Biomedical Informatics*. Volume 59, February 2016, Pages 115-129.

Think Aloud Protocol



Georgsson, Mattias., Stagers, Nancy . "An evaluation of patients' experienced usability of a diabetes mHealth system using a multi-method approach," *Journal of Biomedical Informatics*. Volume 59, February 2016, Pages 115-129.

A Review and Analysis of Existing Mobile Phone Applications for HAI Prevention

Rebecca Schnall, RN, MPH, PhD, Assistant Professor* and Sarah Iribarren, RN, PhD, Postdoctoral Research Fellow*

[Author information](#) ► [Copyright and License information](#) ►

The publisher's final edited version of this article is available at [Am J Infect Control](#)

See other articles in PMC that [cite](#) the published article.

Abstract

Go to: 

Background

The expanding number of mobile health applications (apps) holds tremendous potential to reduce and eliminate healthcare associated infections (HAIs) in clinical practice. The purpose of this review was to identify and provide an overview of the apps available to support prevention of HAIs and to assess their functionality and potential uses in clinical care.

Methods

We searched three online mobile app stores using the following terms: infection prevention, prevention, hand hygiene, hand washing, and specific HAI terms (catheter-associated urinary tract infection (CAUTI), central line-associated bloodstream infections (CLABSI), surgical site infection, and ventilator associated pneumonia (VAP)).

Results

Search queries yielded a total of 2,646 potentially relevant apps, of which 17 met our final inclusion criteria. The areas of focus were: CAUTI (n=1, 5.9%), VAP (n=1, 5.9%), environmental monitoring (n=2, 11.8%), hand hygiene (n=2, 11.8%), and the remainder (n=11, 64.7%) were focused on more than one area (e.g., multiple infection prevention bundles or infection prevention guidelines).

Conclusion

Mobile apps may help reduce HAI by providing easy access to guidelines, hand hygiene monitoring support, or step-by-step procedures aimed at reducing infections at the point of clinical care. Given the dearth of available apps, and the lack of functionality with those that are available, there is a need for further development of mobile apps for HAI prevention at the point of care.

Keywords: mobile apps, healthcare associated infections, mHealth technology

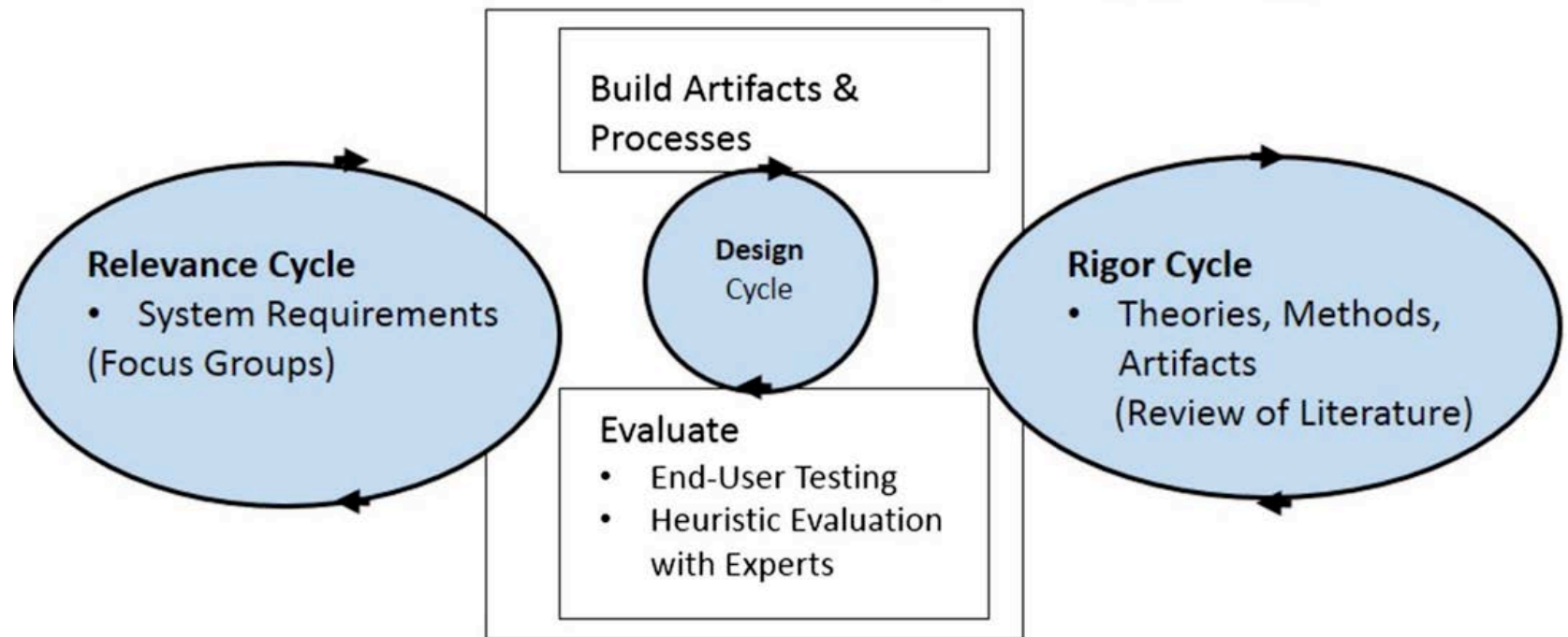
17 m-health apps (out of 2646) met inclusion criteria for mHealth apps for HAI prevention

Given the dearth of available apps, the lack of functionality within the apps, there is a need for further development of apps for HAI prevention at the point of care.

Schnall, et. al

A user-centered model for designing consumer mobile health (mHealth) applications (apps)

A User Centered Model for Mobile Health (mHealth) App Design



Schnall, Rebecca., Rojas, Marlene., Bakken, Suzanne., Brown, William., Carballo-Diequez, Alex., Carry, Monique., Deborah Gelauded, Deborah., Patterson Mosley, Jocelyn., and Travers, Jasmine. "A user-centered model for designing consumer mobile health (mHealth) applications (apps)," *Journal of Biomedical Informatics*, Volume 60, April 2016, Pages 243-251

NICE Behavior Change Guidance

NICE health behavior change guidance can be adapted to quality assess mobile apps.

- 9 themes relevant to app quality assessment were identified from the NICE guidance:
 1. Purpose of the app
 2. Planning and development
 3. Usability
 4. Initial assessment and tailoring
 5. Behavior change techniques (BCT)
 6. Behavioral maintenance and relapse prevention
 7. Evaluation
 8. Documentation
 9. Data protection
 - The purpose of the mobile health behavior change apps sampled was clear overall.
 - There was poor evidence for user and professional input, usability, and tailoring.
 - This tool lays the groundwork for a mobile app quality assessment framework.
-

Table 2

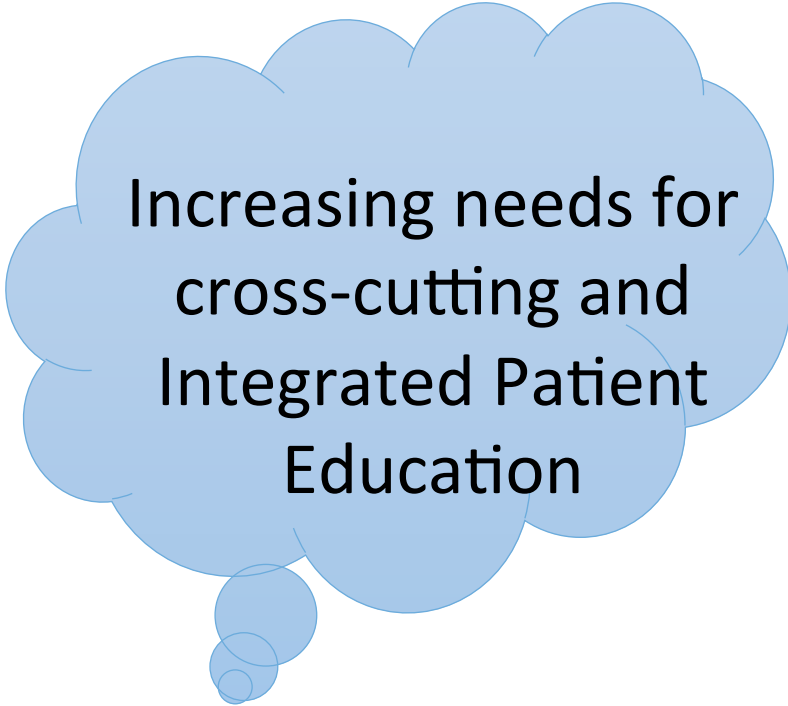
Health-ITUEM concepts and representative quotes from the exemplars.

Error prevention	System offers error management, such as error messages as feedback, error correction through undo function, or error prevention, such as instructions or reminders, to assist users performing tasks	R: Oh no. When the phone first came to me, I did not know how to turn it off. I took out the battery and put it back in, and still said emergency, and I thought it was something wrong with the phone. So, I pushed the reset and it just restarted everything M: It erased everything that was on there. R: Yes. (Exemplar 2)
Completeness	System is able to assist users to successfully complete tasks. This is usually measured objectively by system log files for completion rate	R: Did you guys put an app of books; like that you could look up books? R: I saw that R: Yes, when I first... M: It was already on there for the phone, yes R: That came in handy M: The books, the list of books? R: Yes. I was reading a lot M: Really? R: Yes. (Exemplar 2) M: You forgot about your diet or you forgot about the app? R: Both. (Exemplar 2)
Memorability	Users can remember easily how to perform tasks through the system	M: And now do you find those answers on your phone? R: Well, simply type in the answer. They have like the Yahoo answer. And I can see if anybody else is going through the same problems I am. (Exemplar 1)
Information needs	The information content offered by the system for basic task performance, or to improve task performance ^{26,27}	"Voice to text," is an important feature (Exemplar 1)
Flexibility/Customizability	System provides more than one way to accomplish tasks, which allows users to operate system as preferred	M: So, did anyone look at any of the apps or some of the information online and just not understand what it was saying? Like the obesity app, was it confusing? R: No (Exemplar 2)
Learnability	Users are able to easily learn how to operate the system	M: Okay, so what do you use it for? R: Facebook and (inaudible), mostly. Also check my email there because I do not feel like going on a computer to check the mail. (Exemplar 1)
Performance speed	Users are able use the system efficiently	So like it depends on if you feel you can trust it, or if it matches up with what's going on with you. (Exemplar 1)
Competency	Users are confident in their ability to perform tasks using the system, based on Social Cognitive Theory ^{28,29}	R: If I have any health-related problems I usually just go on Google and it takes to me some doctor website, where real doctors answer the questions (Exemplar 2)
Other outcomes	Other system-specific expected outcomes representing higher level of expectations.	

Lens 5: Connected Health + Care

Integrating Care across Settings 2.0

- Face to face traditional care
- Virtual Visits
 - E-mail
 - Video
 - Combination
- Remote Patient Monitoring (RPM)
- Tele-health
- Tele-therapies
- Avatars
- Virtual Reality, Augmented Reality
- Amazon Echo
- Individual, Group, Family, Neighborhood Visits and Tools



Increasing needs for
cross-cutting and
Integrated Patient
Education

One example: RPM With Vivify Health



Vivify Health

Kit Contents



4-G Wireless Tablet



Weight Scale



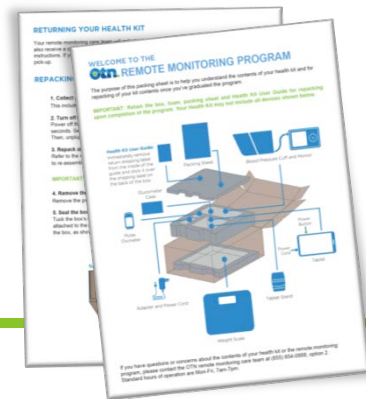
Blood Pressure Monitor



Pulse Oximeter



Quick Start Guide



Patient User Guide



Tablet Stand
Power Cord & Adapter



Glucometer &
Glucose Meter Adapter



Thermometer



Objective 4

Share best practices in your settings to deepen partnership with others -- including patients, communities & HIT partners.

Deepening Partnership with Patients, Communities & HIT Partners

Small Group Exercise: Circle in groups of 3-4

Round One:

Describe a recent technology-enabled development experience where you successfully partnered with your HIT colleagues to bring the voice of patients and patient communities to the patient education table?

- What facilitated success? What barriers/hurdles need to be overcome?

Round Two:

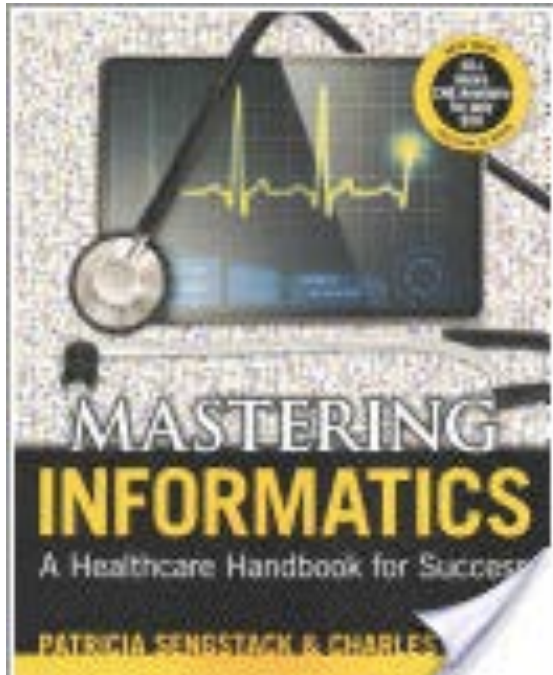
Share a recent success with a technology-enabled patient education evaluation.

- Which lenses were included? Which were most helpful?
 - Traditional m-health, Co-production, Patient Activation, Health Literacy, Usability and Interoperability, Connected Health – Connected Care, and Others?
 - What key learnings you will take forward to other efforts?
-

Objective 5

Anticipate future trends to guide capacity building within this community.

Are We Prepared?



“The future of mobile, smart and connected health innovations are predicted to come sooner than our ecosystem of care, infrastructure and health policy can prepare for.”

Susan C. Hull, Chapter 17, p.

Circa Late 90'S

P4 Medicine

- Leroy Hood (2010), well known as the inventor of the first automated DNA-sequencing machine and founder of the Biology Systems Institute at University of Washington, and for his work with the Ohio State University Idea Studio, is credited for his definition in the late 1990s of **P4 Medicine**

Prediction:

Using two new sources of health-related diagnostic data—genetic makeup and protein biomarkers—care providers can generate comprehensive predictions about a patient's health future, including the current effects of any abnormal genes and the current reactions to any environmental toxins or infectious pathogens.

Personalization:

Understanding each individual's genetic makeup and differences is supporting new approaches to personalization of care. On average, each human differs from another by less than 1% of his or her genetic makeup. These genetic differences give rise to our physical differences, including our potential predisposition to various diseases.

Prevention:

Approaches based on each individual's genetic makeup and current blood protein markers will help us determine the probability of an individual contracting certain diseases, as well as reveal how an individual may respond to various treatments, thereby providing guidance for developing customized therapeutic drugs and other prevention strategies.

Participation:

Because of prediction, personalization, and prevention, Hood predicted that patients will more actively **participate** in their health and well-being.

However, participatory medicine will require the development of powerful new approaches for securely handling enormous amounts of personal information, including that generated from mHealth solutions, and for educating patients, physicians, nurses, and the entire collaborative care team.

Circa 2000

“Consumer Informatics Supporting Patients as Co-Producers of Quality” at the AMIA Spring 2000 Congress

Key themes:

1. Changes in roles of consumers and providers
2. Support for a patient–provider–information technology partnership
3. Virtual, not physical, structure for health care and health care information delivery
4. Health care as an integrated part of each person's life



[J Am Med Inform Assoc](#). 2001 Jul-Aug; 8(4): 309–316.

PMCID: PMC130075

Consumer Informatics Supporting Patients as Co-Producers of Quality

[Bonnie Kaplan](#), PhD and [Patricia Flatley Brennan](#), RN, PhD

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Congress Recommendations:

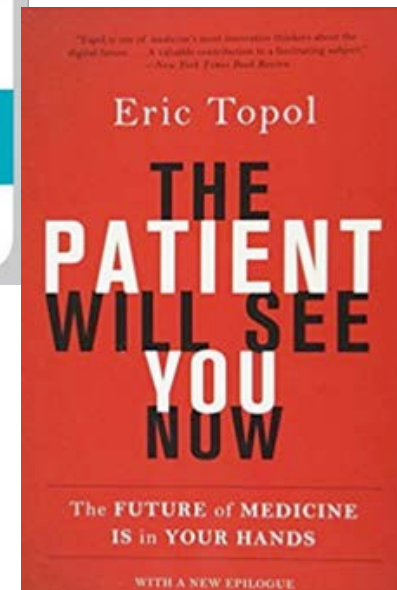
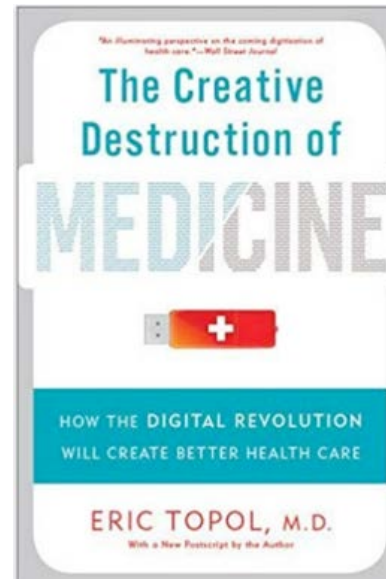
1. AMIA take an active leadership role in consumer health informatics.
2. Specific recommendations were made concerning research, new patient record systems, provider support, information access and evaluation, and policy and regulation.

Circa 2012

Re-Classifying Health and Patient Education

Topol (2012, p. 229) predicted that:

- “the entire classification system of medical conditions and diagnosis is about to be rewritten.”
- Advances in understanding systems biology, genetics, and genomics are bringing new tools into the health domain of providers and patients; these will combine in powerful ways, enabled by mHealth innovation.
- There is a need and opportunity for nursing and patient educators expertise to join and develop this emerging field.



Codifying the Individualome

Omics and the Science of Individuality (Topol 2012)

- Today's healthcare is rather impersonalized
 - “We use only a few measurements to diagnose disease and are generally unable to make fine distinctions among individuals' values, beliefs, preferences, health behaviors, and determinants of health, or between subtle variations of the same disease.”
 - The convergence of digital health tools that map individual differences in the epigenomic markings, bringing a window into understanding how every organ system responds with the environment.
 - Many of these scientific breakthroughs are being established in the field labeled the “-omics”
 - **Proteome**: for proteins, their structures, and functions
 - **Transcriptome**: for the genetic material transcribed into RNA
 - **Metabolome**: for molecules and how they are metabolized in our bodies, such as hormones
 - **Glycome**: for sugars
 - **Lipidome**: for lipids
 - **Interactome**: for how proteins relate to one another
 - **Exposome**: for how an individual's environment influences their health
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December 2016

Why APIs?

Making digital health data useful to patients is a national priority—and application program interface technologies, or APIs, are needed to realize this goal.

- API technologies, adopted widely in banking and retail, make it possible to move information easily between computer systems or programs.
- APIs are used to let ATMs connect to banks and airline systems to connect to travel portals.
- APIs have the potential to remove many barriers to the sharing of health information between providers, patients, and others but they are fairly new to health care.

APIs are starting to enter the EHR market because of the U.S. government's Health IT Certification Program authorized under three federal laws:

- the Health Information Technology for Economic and Clinical Health (HITECH) Act,
- the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA)
- The 21st Century Cures Act.

The certification program incentivizes:

- The exchange of interoperable information between EHRs and other health IT systems such as apps, pharmacy systems, or laboratories.
- APIs for EHRs must include features such as identity authentication and must enable secure exchange of digital health data in a form that can be read and used by other computers the way a shopping order from one computer can be verified by another.

Because there are a variety of distinct EHRs and other health data systems that must communicate to mobilize health data, **APIs are key to advancing health record interoperability.**



What's Trending: ACA Marketplace Stability



Publications » To the Point » Making Health Data Useful...

Making Health Data Useful to Patients Through Open APIs

Wednesday, December 7, 2016



By Judah Thornehill, Bob Estepay, M.D., Eric C. Schneider, M.D., Aneesh Chopra and William Yasniuff

APIs and Consumer-Directed Health Information Exchange

- Unlike provider to provider health information exchange, provider to consumer health information exchange is mandated under the law therefore helping to expedite interoperability
 - Consumer-directed exchange is outside of HIPAA and therefore not subject to the same privacy and security rules as traditional provider to provider health information exchange
 - Consumers have a right to access their health information any time and for any reason.
 - *Any* barriers for consumers to access their data (technical, business, cultural, policy specific, workflow-related) and send that data to *any* third-party application of their choosing should be defined as **information blocking** under the 21st Century Cures Act
-

2017 Directions for HHS ONC

Implementing the 21st Century Cures Act

- Three use cases related and the development of a common agreement / trust framework:
 1. Patients can access their health information electronically **without any special effort**
 2. Providers and organizations accountable for managing the health of populations can receive necessary and appropriate information on a group of individuals without having to access one record at a time (bulk accountability)
 3. The health information technology (health IT) community should have open and accessible application programming interfaces (APIs) to encourage entrepreneurial, user-focused innovation to make health information more accessible and to improve electronic health record (EHR) usability
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AHIMA Releases Standardized Patient Request for Information Form

Home

homepage-featured

AHIMA Releases Standardized Patient Request for Information Form

Posted By Mary Butler on Jul 20, 2017

Requesting one's health information is among the most confusing medical endeavors for consumers, since laws can vary by state and even trained release of information (ROI) professionals may not be aware of the latest government guidance. AHIMA has been working on a way to streamline this process and reduce uncertainty for health information management (HIM) professionals and consumers. The result of that work was unveiled this week with the release of AHIMA's [Patient Request for Health Information Form](#).

The model form is intended to help providers streamline patient health information request processes and ensure they are compliant with the Office for Civil Rights' (OCR) guidance on an individual's right of access under the



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PATIENTS' ACCESS RIGHTS

CLICK HERE to learn more about AHIMA's model Patient Request for Health Information form, available free.



Popular Post: All time

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- ▶ [How to Request Your Medical Records](#)
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- ▶ [Who Has Rights to a Deceased Patient's Records?](#)
- ▶ [Physician Query Examples](#)
- ▶ [Californian Sentenced to Prison for HIPAA Violation](#)

<http://journal.ahima.org/2017/07/20/ahima-releases-standardized-patient-request-for-information-form/>

AHIMA Recommendations

- Recommendations for using the Patient Request for Health Information Model Form include:
 - Organizations should edit the form based on system capabilities as well as operational needs.
 - Organizations should read and understand the OCR guidance, 45 CFR 164.524(c)(3), to ensure compliance.
 - Organizations are not precluded from developing their own internal policies that comply with the OCR guidance as long as they do not create barriers to patient access. For example, if a patient requests health information be transmitted through unsecured e-mail, the provider should comply.
 - Logo, barcode, and address may be added to the form at the organization's discretion.
 - OCR guidance and state laws should be consulted when developing an organization's fee structure.
 - For more information and to download a copy of the form visit: <http://www.ahima.org/modelform>.
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Some Predictions – In Next Decade...

We are well poised to advance technology-enabled patient education:

1. Follow the path of the patient
 2. Catalyze coproduction with patients, families and communities
 3. Adopt disruptive and big data technologies to personalize and mass customize precision care and education
 4. Advance care continuity and collaborative care
 5. Visualize descriptive, predictive and prescriptive analytics
 6. Experience wisdom – from data, information & knowledge
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Reaching New Heights in Patient Powered Care



Thank You!

Closing Conversation

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