Annotated List of Recommended Reading

For this year’s AMIA Policy Invitational, we asked AAAS Health, Education, and Human Services Fellow Dr. Shifali Aurora to provide an introductory perspective on some of the publications around patient-centered care, collaboration, communication and coordination. Here is an annotated list of her top ten recommended readings. Those marked with an asterisk were larger and more comprehensive than could be easily summarized in a brief document. Where available, we have provided links to the resources.


- The goal was to characterize consumers attitudes regarding perceived benefits of electronic health information exchange as well as potential privacy and security concerns
- 1847 respondents (participated in a telephone survey)
- 82% were very or somewhat concerned about the security of the EHR. Consumers were concerned about security of HIE related to misuse of PHI for fraud, posting on internet, or discrimination. Also concerned about potential loss of their PHI
  - Those ages 40-64 were significantly more concerned about security
- 70% were very or somewhat concerned about the privacy of HIE. Specific concerns about being denied credit or employment, but majority wanted their physician involved in determining the privacy settings
- Concern about the information being linked to the wrong person
- 90% aware of the potential benefit to physicians which includes: helping with coordination of care, reducing duplicate medical tests, improving quality of care
- 75% felt benefits outweighed risks
- 50% willing to share all of their health information, but those who were more concerned about privacy or security were less likely to share their information
2) National Academies Press: Organizational Change to Improve Health Literacy-Workshop Summary
Rapporteurs: Melissa French and Lyla Hernandez
http://www.nap.edu/download.php?record_id=18378

- The goal of the workshop was to foster dialogue and discussion to advance the field of health literacy
- Health literacy is the product of the interaction between individuals capacities and the health literacy related demands and complexities of the health care system
- Ten attributes of a health literate health care organization:
  - Have leadership that makes health literacy integral to its mission, structure, and operations
  - Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement
  - Prepares the workforce to be health literate
  - Includes populations served in the design, implementation, and evaluation or health information and services
  - Meets the needs of populations with a range of health literacy skills while avoiding stigmatization
  - Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact
  - Provides easy access to health information and services and navigation assistance
  - Designs and distributes print, audiovisual, and social media content that is easy to understand and act on
  - Addresses health literacy in high-risk situations, including care transitions and communications about medicines
  - Communicates clearly what health plans cover and what individuals will have to pay for services
- Panel I: Implementing attributes of a health literate organization
  - The tone and style of interaction established at the beginning of an interaction can encourage patients to be receptive to the messages at the end of the visit. Knowing the patients living environment is key as well
- Segmenting a treatment plan into smaller components helps
  - Have patients explain back to the provider the treatment plan
- It may help for the patient to have an advocate at appointments (friend, family member) who can ask questions; set actionable goals
  - Panel II: Implementing attributes of a health literate organization
    - Make patient documents shorter and more succinct
    - Ongoing support of leadership of the hospital system is critical
    - Visual tools can be helpful to patients
    - Health literacy is key to patient safety as well
  - Panel III: Implementing attributes of a health literate organization
    - Messages that you portray need to be standardized
    - Have materials in multiple languages
    - Test beds for new ideas is important
    - There should be organized professional development in health literacy
    - A common and validated measure of health literacy is needed

3) AHRQ Personal Health Information Management and the Design of Consumer Health Information Technology *
Authors: Ritu Agarwal and Jiban Khuntia
http://healthit.ahrq.gov/sites/default/files/docs/citation/09-0075-EF.pdf
  - The goal was to show the importance of patient centered care and using health IT for delivery of care
  - Consumer health IT is a collection of tools, technologies, and artifacts that consumers use to support their health care management tasks
  - Patient empowerment depends on capturing/ managing PHI
  - Themes in literature
    - Personal Health information management is a special case of the activity of personal information management.
    - Personal information management includes the tasks that people perform in order to acquire, organize, maintain, and retrieve information to complete tasks to fulfill their roles
      - PHIM relates specifically to the management of health information
    - There is a variety of different types of information that constitute the full set of personal health information. They can come for multiple different sources
- Categories: personal identifiers, personal demographics, emergency and critical info, biomedical/clinical/genetic phi, mental/psychological phi, physical activity/BMI/nutrition, and insurance/financial info
- Sources: health care provider, health care insurer, individual social network, mass media, others
  - Users of PHIM vary: may go beyond the person themselves to family, physicians, payers, health providers
  - The process of PHI management can be supported thru infrastructure tools: tools for health monitoring, tools for storage/retrieval tools for health info search/seeking.
  - barriers to overcome to execute PHIM activities successfully: personal limitations, privacy
  - Approaches to study PHIM and PIM practices and tools are either naturalistic or lab-based inquiries
    - Gaps in literature: taxonomies of users/use activities/use contexts, PHIM practices of subpopulations that have not been studied, comparative effectiveness of PHIM practices, articulation of functional requirements of tools and design philosophies, details of design elements, rigorous evaluation of tools and technologies

4) Improving Consumer Health IT Application Development: lessons from other industries *


- The goal was to understand developmental methods from other industries to improve the design of consumer health IT
- Recommendations:
  - use methods that include high levels of user involvement and iteration
  - utilize one or more of the following design methods- top 5 underlined
  - Prototyping
  - Agile development
  - Heuristic evaluation
  - Top-down design
  - Lean product development
  - Engage human factors in the design team
  - Keep it simple
  - Pay careful attention to user characteristics
  - Use multiple design methods
• Use prototypes/consumer feedback based on their use of the prototype
  o Areas for continued research
    ▪ Systematic comparisons of alternative levels of user involvement and iteration for different types of consumer health IT applications
    ▪ Qualitative methods to document and isolate successful and unsuccessful design processes currently in use for consumer HIT apps
    ▪ Retrospective case studies documenting design processes and longitudinal studies documenting the evolution of market leaders of the four categories of consumer HIT applications discussed
    ▪ Investigate user response to products that are modular in nature.
  o One of the core 5 pillars to improve health care safety is engaging and educating consumers to better manage acute and chronic conditions
    ▪ Consumer health IT apps are targeted toward individuals who receive services from the health care system. Allows them to perform a variety of PHIM.
    ▪ As of Sept 2010, seven thousand health apps existed, but insufficient adoption and diffusion
      • This may because of barriers to use (poor design), lack of provider incentive for electronic interaction, inability for patients to populate consumer health IT apps, or limited systematic evaluation of tools available to show evidence of utility and effectiveness.
  o Extensibility of design approach findings to consumer HIT apps
    ▪ There is no universally accepted definition of such tools in the literature
    ▪ Interactive consumer HIT apps include: in home monitoring, online forums on health topics, electronic patient access to their med records and patient-physician messaging, interactive educational system, interactive training systems that monitor patient signals and provide feedback, and interactive and tailored reminder system
    ▪ 4 distinctive categories of tools: 1) health info storage, archival, and retrieval; 2) health status monitoring, 3) health info seeking and searching, 4) infrastructural tools and artifacts
    ▪ Recommend high user involvement and high levels of iteration

There is a need to bridge the gap between the access to information and information understanding.

There is a need to help consumers to understand health related web-based resources so that they can act upon it. Doing such will empower consumers.

Consumer health informatics aims at supporting consumers of health information to address their needs and changes by developing web-based apps with which consumers can efficiently obtain information.

There are significantly different ways in how health information consumers value, understand, and seek health related content.

- Especially in dimensions of degree of engagement in health enhancement and degree of independence in health decision making.

Those with chronic illnesses or facing significant barriers in accessing health care tend to seek information online.

- Finding relevant information and assessing the quality are the first building blocks to the empowerment of consumers.

Effective contextualization and personalization reduces communication complexity and makes it easier for the consumer to understand and trust information.

- Tailoring information to the consumer decreases demand on the consumer to transform and translate that information.
- Mutual understanding: one user understanding the other user needs to be measured. Contextualization and personalization play a role in either improving or decreasing mutual understanding.
- Those concepts should also be taken into account when we are creating web-based health applications.


Rapporteurs: Tracy Ludwig and Steve Olson


Goals of meeting

- Focus on adults who by virtue of an inherited/congenital condition, accident, or disease(s) become impaired in their ability to be as independent as possible.
• Provide an overview on how the independence, community integration, and well-being of these individuals can be improved through access to technology
• Examine existing and emerging technologies, with a focus on technologies most likely to be employed
• Discuss barriers to deployment and adoption of technologies and reasons for abandonment of technologies already in use

Disability it is thought to be the interaction of physical/mental limitations with social and environmental factors. That determines whether someone has a disability. Thus it is thought is that most disability is thus preventable
  ▪ An important aspect of these social and environmental factors is the technology that a person has access too
  ▪ This workshop was set up to discuss this concept further

Challenges to achieving independence:
  ▪ Complex technology is not necessarily the answer to every problem. Relatively simple technologies are needed to solve common but extremely complex problems
  ▪ Many excellent technologies are not widely used for a variety for reasons, including inadequate reimbursement, insufficient funding for translational research and technology, and a lack of collaboration and training among technology developers and providers
  ▪ Because families are smaller today than in the past, fewer children are present to care for parents, and many of them live farther away and have jobs
  ▪ Until technologies that are obvious, easy, relatively affordable, and sensible are widely available, the market will have failed the people who could benefit from those devices
  ▪ Interoperability and interconnectivity of different technologies, such as between health care systems and devices, are necessary to facilitate the exchange of information and to ensure the continuity of information

Teaching out of the laboratory: Joseph Coughlin
  ▪ Of the US population of 310 million: 110 million have one chronic disease, 60 million have two; 20 million have more than five
  ▪ If you provide good technology, it will apply to people’s needs automatically, but you need to get technology out of the lab and into the living room
  ▪ Another issue is that a lot of these technologies don’t come with someone to help set them up, answer ?s, etc. (like apple store or geek squad)
The people who come up with the best ideas are those that live in those communities or have those diseases

- Innovation is putting practical ideas into use
- Health care providers will need to be systems integrators

- The center for aging services technologies: Majd Alwan
  - CAST is a program that brings service providers together with tech companies and researchers
  - We need to remove barriers to the adoption of technologies at the federal, state, and local levels
  - Telehealth can help manage chronic conditions, stabilize newly diagnosed patients, and encourage self-management
  - The biggest problem with adoption of these technologies is the absence of business models that are conducive to their adoption

- Technologies to promote community integration
  - The design of a community can promote the integration and participation of all family members.
  - The four major areas of disability are mobility, hearing, vision, and intellectual. Addressing one may address others in the process
  - Abandonment of a technology is just one of several barriers to participation
  - Social connectedness is another way to promote community integration
  - Technology can promote community participation via cloud computing; you can stay connected to friends, church groups, work groups, etc.
  - The three motivational influences of behavioral change: autonomy, competence, and social relatedness


- Goal of a medical home is to address many of the failures and delivery gaps within the current primary care system
  - Goals include coordinating care, engaging patients and families, and improving population management
- They are team based, patient centered; EHR is central to the medical home
Implementation shows it reduces costs and lowers EHR usage and fewer hospitalizations

In the Geisinger model: the EHR is a building block for most of the efforts
  - Ex: the EHR would summarize the patients information before they are seen by the physician thus alerting providers to health maintenance needs, and chronic disease process deficiencies

7 domains in EHRs that need further development: clinical decision support, registries, team care, care transitions, personal health records, telehealth technologies, measurement capabilities

From the policy perspective barriers include external payment reform will be the key to enabling medical homes. I.e. Monetary incentives


Examines whether and how practices use EMRs to support coordination of tasks
  - Done thru semi-structured telephone interviews
  - Involved 52 physicians from 26 practices, CMO at 4 EHR vendors

6 themes
  - EMRs facilitate within-office care coordination, chiefly by providing access to data during patient encounters and through electronic messaging
  - EMRs are less able to support coordination between clinicians and settings, in part due to their design and a lack of standardization of key data elements required for information exchange
  - Managing information overflow from EMRs is a challenge for clinicians
  - Clinicians believe current EMRs cannot adequately capture the medical decision-making process and future care plans to support coordination
  - Realizing EMRs’ potential for facilitating coordination requires evolution of practice operational processes
  - Current fee-for-service reimbursement encourages EMR use for documentation of billable events (office visits, procedures) and not of care coordination (which is not a billable activity)

They felt that reform payment policy should include care coordination, this would encourage the evolution of EMR technologies (i.e. inter-practice data exchange)
9) IOM report: Patient charting the course: citizen engagement in the learning health system
   Editors: LeighAnne Olsen, Robert S. Sanders, and J Michael McGinnis

   - August 2010 workshop set out to identify and reflect on strategies advancing public understanding of a transformative, patient-centered LHS
   - Key areas to achieving LHS: clinical research, clinical data, information tech, financial incentives. Characterized by real time and continuous knowledge generation. Currently though data is scattered across the system in siloed repositories. Also need to focus on comparative effectiveness research- focuses on routine practice settings and real world populations
   - Common themes:
     - Listening: each patient-clinician interaction starts with uninterrupted attention to the patient’s voice on issues, perspectives, goals, and preferences. These should guide clinical decisions.
     - Participatory: health outcomes improve when patients are engaged in their own care. Patient adherence also improves
     - Reliable: each patient should expect proven best practice as the starting point in their care. Currently there is variability in medical practice. CDS tools may help with this. Incentives are needed to promote this
     - Personalized: with proven best practices as the starting point, science based tailoring is shaped by personal biological traits, genetics, circumstances, and preferences.
     - Seamless: care delivered by multiple providers in multiple setting should nonetheless be expected to be fully integrated and seamless; the concept of team based care
     - Efficient: patients, their families, and clinicians should expect care to be appropriate to need, resources, and time required
     - Accountable: all relevant aspects of the clinical experience, including pt perspectives, should be captured and routinely assessed against expectations
     - Transparent: info on the outcomes of care-both effectiveness and efficiency should be readily accessible and understandable to patients and their families
     - Trustworthy: patients should expect a strong and secure trust fabric on all dimensions- safety, quality, security, efficiency, accountability, and equity
     - Learning: in a learning health system, the patient is an active contributor to, and supporter of, the learning process
   - Other main concepts:
One component of patient engagement in healthcare is public confidence and trust in clinical research.

There is a lot of data out there (on the web, blogs, personal stories, etc) and patients must sort thru to see which is reliable and which is not.

The current informed consent process falls short of the goal of helping patients understand risks and benefits to make informed decisions; we should instead do shared decision making.

Barriers to implementation of a collaborative improvement model. 1) The culture of medicine is hierarchical. 2) Managers have limited appreciation of the components of a continuous learning environment, 3) Senior leaders must devise strategies and allocate resources to ensure that continuous learning.

10) Individuals access to their own health information: ONC Policy Brief: June 2012
Author: Jamie Skipper, R.N.Ph.D.

- Individuals who engage in their health care achieve better health outcomes and benefit from lower health care costs. ONC has been working to leverage current legislation and regulations to design health IT policies and programs that enhance individuals electronic access to their information.
- What has been done so far?
  - HIPAA privacy rule established a set of national standards for the protection of certain health information. Allows individuals the right to get a copy of their health information.
  - HITECH Act in 2009 required entities to provide patients their records in electronic format and that the patient can send a copy to an entity that they designate.
  - 2011 the national strategy for quality improvement in health care was released which focused on patient access to understandable information and decision support tools that help pts manage their health.
  - In 2010 CMS and ONC released the final rule pertaining to stage 1 of the electronic HR incentive program. This was to have providers show meaningful use of these ehr technologies (including health information upon request, discharge instructions, clinical care summary after a visit). Stage two will include a requirement that providers offer plus the ability to view, download, and transmit their information.
- Challenges were set forth in 2011 creating software that helped ensure safe transitions from hospital to home
- Blue button allows individuals to download their PHI from specific sources (VA is using this)
  - Issues that still exist
    - removing social barriers (ex: patient’s fear of asking their health care providers for a copy of their health information
    - Getting patients their health information in a reasonable time and reasonable level of readability
    - Most PHRs can’t download information from EHRs.
    - Portability of patients health information; privacy issues for PHRs
    - Granting proxy access to the individuals caregiver or another designee