Health IT Research Priorities to Support the Health Care Delivery System of the Future

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Health IT Research Priorities To Support the Health Care Delivery System of the Future

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Executive Summary

Introduction

The Agency for Healthcare Research and Quality (AHRQ) has been at the forefront of health information technology (IT) research for more than a decade. Since 2004, AHRQ has spent more than $300 million to identify effective ways to use health IT to improve health care quality. A significant proportion of that investment has been spent on the development of the evidence base for how health IT improves health care quality. In addition, the Agency has funded the creation of evidence-based tools and methods to support health care researchers working at the cutting edge to advance knowledge about the appropriate uses of health IT and to assist health care providers in putting that knowledge into practice.

The purpose of the Health IT Horizon Scanning project was to identify the trends that inform the future of health IT research and to develop research priorities based upon those trends. A panel of innovative thinkers was engaged to present their individual insights about trends that may impact the use of health IT to improve health care quality from the perspective of their individual area of expertise. These innovative presentations are referred to collectively as the Visionary Panel Series.

This report is a summary of the activities conducted for the Health IT Horizon Scanning project from 2012 to 2014. The report includes the goals and objectives of the project, the methodology and approach used to establish the Visionary Panel Series, the major factors driving change in health care, a vision of the future of health care, and the research questions raised by the presentations and discussions that followed.

Methodology

Framework for Developing Research Priorities

The design of the Visionary Panel Series was informed by a framework for establishing health research priorities developed by Viergever et al. (2010).[1] They proposed a checklist for health research priority setting that allowed for informed choices on different approaches and outlines nine common themes of good practice for setting research priorities. The project team adapted this framework to the Health IT Horizon Scanning project by mapping the nine checklist items to the steps needed to achieve the project's goals and objectives. The framework consists of three phases: preparation, priority setting, and post-priority setting. The preparation phase involves setting the context for the project, developing a comprehensive approach to gathering information, and ensuring that the process includes all stakeholders. The *Foresight to Insight to Action* model, developed by the Institute for the Future (IFTF), was used to gather information on emerging trends and indicators of change in fields of study related to health care and health IT and to gain insight through facilitated discussions. The IFTF's foresight-to-action cycle was designed to stimulate futures thinking in an effective, actionable way, as follows:

Foresight: The presentations by Visionary Panel members provided information on relevant trends and signals of change emerging in their own fields of expertise that may inform the future of health care delivery. The presentations identified trends that would inform the health IT research agenda in the next 5 to 10 years.

Insight: IFTF staff with expertise in the areas of technology innovation and health facilitated discussions with the Visionary Panel members following each presentation.

Action: The discussions were synthesized and the information will be used to inform the AHRQ Health IT Portfolio's research agenda.

Phase 2, priority setting, involved planning for implementation of research priorities, developing the criteria for deciding on the priorities, and determining methods for decisionmaking. Phase 3, post-priority setting, included evaluation of the process and ensuring transparency in the final reporting.

Vision of a Health IT-Enabled Health Care System

The Visionary Panel

The 12 Visionary Panel presenters included experts from academia, industry, and practice who are knowledgeable about trends impacting health and health care delivery. Each presenter provided a unique view of how the practice of health care and health care research will look in the future. Although each presenter discussed a different topic, all agreed that the current cost of health care is unsustainable and that advances in information technologies have the potential to transform the way that health care is delivered in the future. The topics presented included trends in: health care, technology, the business of health care, aging, big data and analytics, data visualization and comprehending multiple data streams, connected health and personalized preventive care, advances in mobile technology, patient-generated health information, social media in health care, digital health, and participatory health care and research.

Key Drivers Shaping the Future of Health Care

The Visionary Panel presented five key trends that will drive change in the current health care system: (1) the aging population, (2) consumer expectations for access to conveniently available care, (3) rapid innovation in IT, (4) the use of big data and advanced analytics to improve health care decisionmaking, and (**5)** recent regulatory actions that have created the opportunity for new health care business models to emerge by aligning incentives to reward quality, not quantity, of care. The interplay among these drivers has created an environment that supports the innovative changes to the health care system expected to occur over the next 5 to 10 years.

A Health IT-Enabled Health Care System

Presentations and facilitated discussions informed the creation of a vision of an ideal health IT-enabled health care system. The emphasis is on a system that is *data-driven*, *patient-centered*, and *continuously improving* as follows:

1. The future health care delivery system is one that is highly integrated and data-driven. Patients, caregivers, and providers have access to advanced decision support systems. Data sources include health information generated by individuals from medical and fitness devices, mobile applications, sensors, online health communities, and published literature.
2. The health care system is optimized for continuous improvement. Process outcomes are captured and used in continuous improvement activities.

3. Knowledge discovery is advanced by novel analytic methods and new sources of data. Knowledge sharing is open and transparent so that all stakeholders benefit.
4. Patient information is readily accessible to patients, caregivers, and providers on the device of their choice. The information is securely aggregated and remotely stored ("in the cloud") and includes self-generated health information, sensor data, clinical data including diagnoses and prescriptions, laboratory results, and other sources of data, and is accessible in real-time.
5. Patients and providers have access to visualization tools needed to quickly access the information, make accurate decisions, and communicate effectively.
6. Patients, clinicians, technology developers, data scientists, and visualization experts work collaboratively to design safe, efficient health IT that supports a data-driven health care system.
7. Access to care is expanded through innovative business models that provide streamlined care for common conditions and technologies designed to reach all patients, including vulnerable populations.
8. Health care is ubiquitous, convenient, personalized, and encompasses wellness and preventive care delivered in both traditional and nontraditional care settings. It emphasizes continuity of care and chronic care management.
9. Care teams, supported by health IT, manage a patient's conditions in a coordinated way rather than disjointed episodes of care.
10. Patients make decisions about health collaboratively with their interdisciplinary care team and family members. Decisions are informed by multiple sources of data and robust decision support systems.

Implications for Research

The future of an integrated, data-driven health care system presented by the Visionary Panel raises many research questions. The Visionary Panel also made a number of suggestions for the types of research needed to better understand the role of health IT in the new health care system. This section presents an overview of the research questions raised throughout the Horizon Scanning project. The research questions are presented in three subsections as follows: (1) questions that fall within the purview of the Health IT Portfolio; (2) questions that fall outside of the purview of the Health IT Portfolio but are relevant to AHRQ's mission; and (3) questions that are important but fall outside of AHRQ's purview.

Research Topics and Questions Relevant to the Health IT Portfolio

Health care datasets are large and growing rapidly, which presents both challenges and opportunities for health care delivery and health research. Challenges include the need to develop the tools and methods to manage and analyze large volumes of both structured and unstructured data and present it in ways that are meaningful to patients and their health care providers. Data quality is another challenge. Ensuring continuous access to accurate, human, and machine-understandable high-quality data will require experienced computer and data scientists to derive actionable information from vast quantities of data. Data visualization methods will be especially important for communicating information quickly, easily, and effectively.

Advanced Decision Support Tools. To stay current with the rapidly expanding body of clinical knowledge, providers and patients will increasingly rely on advanced decision support

systems to inform patient care decisions. Advanced decision support tools will employ intelligent logic and enable updates to decisional algorithms to accommodate new information, such as scientific discoveries and clinical evidence. The systems will operate in the background, often invisibly to users and will integrate seamlessly with standing health IT infrastructure, such as electronic health records (EHRs). Robust and workflow-friendly decision support systems will transform raw data into actionable information, improving overall quality, efficiency, and safety. Funding research that identifies how advanced decision support systems will perform consistently and transparently is critical.

Big Data Analytics. Advances in the aggregation of large volumes of data and powerful analytic tools create health IT research opportunities. Providing data-driven solutions in health care that will leverage big data will require a better understanding of the technical and methodological challenges to aggregating, analyzing, and presenting data to end users. As big data analytics find their way into clinical use, challenges will arise for how to incorporate new information flows into clinical workflows.

Using Health IT to Display and Communicate Health Information. Presenting clinical and health information in a meaningful way is critical for patients, caregivers, and providers. Advances in visualization science and health IT, both of which are quickly evolving and cross multiple disciplines, suggest a number of areas for future research. Scientific visualization techniques, in which spatial characteristics of an object, dataset, or signal are analyzed, may yield new and useful applications for organizing and presenting data collected from sensors and biometric devices. Information visualization techniques, in which nonspatial characteristics of an object, dataset, or signal are analyzed and presented graphically, may also help address the growing challenge of uncovering hidden associations in data, especially in very large datasets or in those containing disparate kinds of data. Data that combine both spatial and nonspatial dimensions and attributes present additional challenges. Research that brings cognitive science, data analytics, clinical workflow and decision-making experts, and visualization scientists together to tackle these problems could yield innovative solutions that improve workflow, understanding of uncertainty, diagnostic and treatment performance, and perhaps, cost containment.

Use of Health IT to Support Distributed Care Models. Distributed care models in which a variety of individuals in different roles participate in health- and care-related activities are a large part of the vision of the future. The design and development of appropriate IT to support distributed care models requires a thorough understanding of the services and information needs of the patient and each participant. Planning the technology to support the distributed delivery of health care also requires studying the structure of the care delivery components and multiple organizations' goals. Understanding and coordinating the optimal mix of services—ranging from workers who perform home-based custodial tasks, home health workers, nurses, nurse practitioners, physician assistants, physicians, medical specialists, dentists, social workers, psychologists, and psychiatrists—require translational research in a variety of areas.

The Use of Health IT to Improve Efficiency. Value-based care models reward providers who eliminate unnecessary or ineffective activities and work more efficiently. Shifting from a fee-for-service-based model that rewards volume to a value-based care model that rewards cost-effective, quality care will require providers to structure of their delivery networks to favor lower-resource care while maintaining high-quality care. This change will strongly favor the use of ambulatory and home care settings by patients whenever possible, and will rely on and accelerate the use of technology-enabled care models.

Evaluation studies of technology-enabled care models and interventions should be conducted to understand which models provide cost-effective solutions and operational efficiencies without sacrificing improvements in quality and safety. Coordination of data collected across care settings so it can be integrated, analyzed, and used to provide targeted feedback to patients and providers is essential for improved efficiency.

Health IT Safety Monitoring and Testing. Widespread reliance on the use of health IT and analytics in clinical practice will alter the way care is delivered. Automating minor or routine medical tasks can lead to unintended safely issues and may impact the patient-provider dynamic. Safety issues may also arise from heavy reliance on analytics and decision support for diagnosis and treatment decisions. In addition, new methods of using data in care delivery to support quality improvement initiatives and to develop new clinical guidelines for screening, diagnosis, and treatment of disease may also increase safety risks.

Linking datasets continues to raise privacy concerns that are heightened by the addition of genomic and other metabolic data. Synthetic datasets may be used to conduct analyses that test theoretical models and frameworks without compromising the confidentiality of the data.

Research Topics and Questions Relevant for AHRQ

Some research questions the Visionary Panel raised are important for researchers interested in better understanding how new sources of health information may be used to improve care delivery. Both data generated by patients as they interact in online health communities and data generated from wearable devices were discussed. It will be important to understand how patient-generated information from online communities can be used in conjunction with provider-generated data to create research networks to recruit patients into research studies, collect and validate data, match patient data across different sources, and coordinate research across multiple platforms and organizations. Identifying tools and policies that facilitate the use of information generated by patients in online health communities or social media for research purposes and in clinical care is important future work. Understanding how patients understand and use clinical terminology and how clinicians understand and use patient-generated information are both important. Lack of standards to define the phrases and terms patients use through a controlled vocabulary presents a challenge.

Visionary Panel presenters also raised the concept of patients as “experts” in their own experience and noted that patients and family members are highly motivated to understand everything that they can about their situation, including their condition in their personal context. These online conversations among patient experts provide a rich source of data for research.

Finally, Visionary Panel presenters discussed data generated by wearable devices as another important source of data for research. The challenge is to identify how these types of data may be aggregated for research. One solution would be to create an open-data platform where organizations could share the data with health care researchers. The cost of aggregating, curating, and analyzing data in an open-data platform presents a challenge. Developing self-sustaining mechanisms to monetize and use the data while maintaining appropriate privacy and security protections are important challenges to explore. Further work to develop and standardize data protection and sharing agreements is important for data generators and consumers to maintain trust that the systems that store, manage, and aggregate their data will be safe.

Research Topics and Questions Outside of AHRQ's Mission

A few questions were raised that are important to the future of health care but fall outside AHRQ's purview. These topics and questions are related to the development of the future health care workforce, use of genomic and other "–omics" data in health care decisionmaking, and the management and analysis of big data broadly defined.

Potential Mechanisms for Research Funding

The Visionary Panel presenters raised many topics for research; some are specific to health IT researchers and others are aimed at health services and other researchers working to improve health and health care in the United States. Health IT research involves a complex interplay between people, technology, and care delivery. The Visionary Panel suggested that significant change will occur in all three areas. Patients, caregivers, and providers will demand more convenience, technology is rapidly evolving, and the point of care is changing. Research into how health IT will facilitate change in health care delivery will require a multidisciplinary approach that includes social science and biomedical researchers, technology users and developers, computer scientists, computational biologists, device makers, and third-party aggregators. Funding for research should take into account new approaches to identifying and solving the problems of the future. All solutions may not all flow from traditional sources such as universities and research institutes. Partnerships among organizations should be encouraged. Researchers should be encouraged to partner with online communities and technology developers in collaborative research. Some recommended funding vehicles and approaches to support needed for research in health IT are presented.

Chapter 1. Introduction

AHRQ has been at the forefront of health IT research for more than a decade. Since 2004, AHRQ has spent more than $300 million to identify effective ways to use health IT to improve health care quality. A significant proportion of that investment has been spent on the development of the evidence base for how health IT improves health care quality. In addition, the Agency has funded the creation of evidence-based tools and methods to support health care researchers working at the cutting edge to advance knowledge about the appropriate uses of health IT, and to assist health care providers in putting that knowledge into practice.

Considerable investments by the U.S. Government since 2009 has increased the need for health IT research by advancing the adoption and meaningful use of health IT to improve the quality of health care in the United States.[2] The progress made toward widespread adoption and implementation of EHRs, coupled with the pace at which individuals are collecting data about themselves, has created the opportunity to effect major changes in how health care is delivered. In the short term, research is needed to better understand how these technologies perform in practice. Mandl and Kohane (2012)[3] have raised concerns about the current state of EHR technology and its fitness to manage the complexity of health information. Research is also needed to identify and address implementation and workflow challenges that may hamper the ability to achieve anticipated benefits of health IT.[4-9]

Other questions about the future of health care have been raised: How can self-generated health information be integrated with clinical data to create a holistic view of health and well-being? How can genomic and other metabolic data be integrated into clinical care to enable precision medicine? Over the next 10 years, greater advances can be expected as health IT interoperability is expanded and the potential for analytics to improve clinical outcomes is explored.[10] Numerous advances will affect the patient-provider relationship. Mobile health applications will empower patients to track and monitor information about their health and behavior. The development of games focused on improving health and health care may help to improve engagement in preventive care.[11] With the ability to monitor patients remotely, providers will be better able to identify triggers in patients with chronic diseases and work to reduce emergency department visits and hospital admissions.[12]

The purpose of the Health IT Horizon Scanning project was to identify the trends that will inform the future of health IT research and to develop research priorities based upon those trends. A panel of innovative thinkers was engaged to present their individual insights into trends impacting the use of health IT to improve health care quality from the perspective of their individual area of expertise. These innovative presentations are referred to collectively as the Visionary Panel Series.

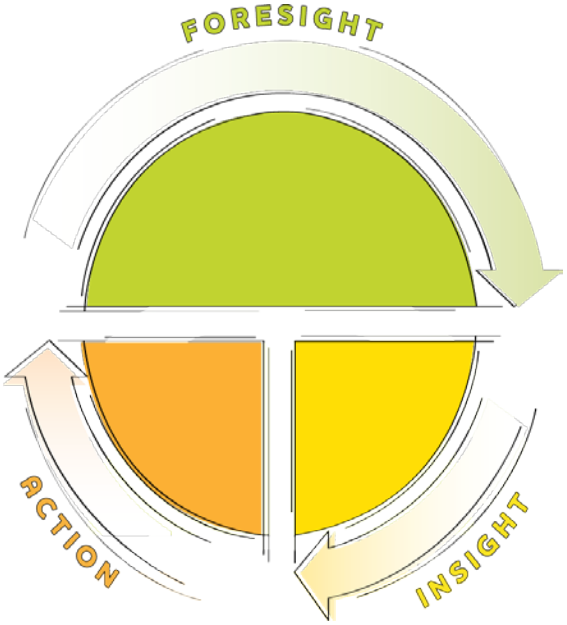
This report is a summary of the findings of the Health IT Horizon Scanning project that was conducted from 2012 to 2014. This report includes a brief discussion of the goals and objectives of the project and the methodology and approach used to establish the Visionary Panel. The report also discusses the major trends shaping the future, a vision of the future of health care, and the research implications for health IT.

Chapter 2. Methodology

Framework for Developing Research Priorities

Research priority-setting processes assist researchers and policymakers in effectively defining research agendas. The design of the Visionary Panel Series was informed by a framework for establishing health research priorities developed by Viergever et al. (2010).[1] Viergever et al. conducted a literature review and synthesis of multiple approaches to identify research priorities and found many different approaches to health research prioritization, but no agreement about what approach might be best. Moreover, because of the many different contexts for which priorities can be set, attempting to define one approach as best may not be appropriate. They proposed a checklist for health research priority setting that allows for informed choices on different approaches and outlines nine common themes of good practice. The checklist explains what needs to be clarified to establish the context for priority setting; it reviews available approaches to health research priority setting; it offers discussions on stakeholder participation and information gathering; it sets out options for use of criteria and different methods for deciding upon priorities; and it emphasizes the importance of well-planned implementation, evaluation, and transparency. A key element of the research-priority setting process is gathering the information needed. The model selected for this purpose was developed by the Institute for the Future (IFTF); it is titled the *Foresight to Insight to Action* model, and the process is shown in Figure 1.

Figure 1. Foresight to Insight to Action Model



The project team adapted this framework to the Horizon Scanning project by mapping the nine checklist items to the steps needed to achieve the project's goals and objectives.

Step 1: Setting the context. Agreement on the context for the project ensured that AHRQ and the project team all agreed on the goals of the project and the roles and responsibilities of each stakeholder.

Step 2: **Comprehensive approach to information collection.** The approach selected was the *Foresight to Insight to Action* model developed by IFTF. The application of the model in this context was to gather information on emerging trends and indicators of change in fields of study related to health care and health IT and to gain insight through facilitated discussions.

Step 3: Inclusiveness. The Visionary Panel process was designed to include many opinions and perspectives. It was important to ensure that a clear rationale existed for each participant included in the presentations and discussions, along with a clear set of expectations based on the decisions made in Step 1 regarding goals, objectives, roles, and responsibilities.

Step 4: **Information gathering.** The *Foresight to Insight to Action* model was the approach on which information gathering was based. The IFTF's foresight-to-action cycle was designed to stimulate futures thinking in an effective, actionable way. This cyclical process begins with developing **foresight** to sense and understand the directional changes. As this context becomes clearer, people can develop their own **insight** about the future and stimulate insight for others; a key sense-making step. Taking **action** is the next step. This learning prompts change, and the change creates new possibilities for the future, which cycles back to foresight. The three stages were applied to the Horizon Scanning project in the following manner:

*Foresight***:** The presentations by Visionary Panel members provided information on relevant trends and signals of change emerging in their own fields of expertise that may inform the future of health care delivery. The presentations identified trends that would inform the health IT research agenda in the next 5 to 10 years.

*Insight***:** IFTF staff with expertise in the areas of technology innovation and health facilitated discussions with the Visionary Panel members following each presentation.

Action: The discussions were synthesized and the information will be used to inform the AHRQ Health IT Portfolio's research agenda.

Step 5: **Planning for implementation of research priorities.** Research priorities intended to inform funding opportunities need to be linked with implementation strategies. The project team was tasked with providing AHRQ with the information necessary to make decisions about research priorities and implementation strategies.

Step 6: **Criteria for deciding research priorities**. The criteria on which research priority decisions were based were intended to ensure that all dimensions are considered.

Step 7: **Methods for deciding priorities**. Two different methods can be used to decide on priorities: consensus-based approaches and metrics-based approaches. At the conclusion of the project, AHRQ will determine the research priorities.

Step 8: **Evaluation**. The identification of health IT research priorities should be viewed in the broader context of the health care system that is changing rapidly. Research priorities must be revisited annually to ensure that priorities are up to date.

Step 9: **Transparency**. This step ensures that the decisions and recommendations reported are transparent to the reader, and the evidence is presented clearly and logically.

Table 1 presents a summary of how the Viergever et al. checklist was used as a framework for this project.

Table 1. Adaptation of the Viergever et al. Checklist to the Health IT Horizon Scanning Project

Step	Activities
Preparation Phase	
1 Set the Context	• Agree upon clear specific goals for the project. "What does success look like?" • Scope/boundaries for Visionary Panel Series and discussions • Goals and objectives for Visionary Panel, Visionary Panel Series, AHRQ • Roles and responsibilities of participants: Visionary Panel, audience, project team
2 Develop a Comprehensive Approach to Gathering the Information	• Visionary Panel Series • Presentations focused on trends, disruptions and change factors, signals of change, and future states • Facilitated discussions of research priorities • Methods for synthesizing the information
3 Be Inclusive	• Identify which stakeholders need to be involved and why • Decide what roles they should play in the process (for example, providing opinion, providing evidence, or being a part of the group that decides on priorities)
4 Gather the Information	• Conduct the Visionary Panel Series • Conduct presentations followed by facilitated discussions with key
5 Plan for Implementation	• Identify themes and trends
Setting Priorities Phase	
6 Criteria for Developing Research Priorities	• Will it advance our current state of the knowledge; tell us something new? • What is the likely impact on health care quality? • What is the impact on cost? • What is the impact in practice? Is there a match between issues and methods? (e.g., experimental studies do not take into account "in situ" or "in practice" factors—data may not inform practice; policy)
7 Deciding on Research Priorities	• Consensus among key AHRQ stakeholders
Post-Priority Setting Phase	
8 Transparency	• Final report and presentation will include "the who and the why"
9 Evaluation	• Feasible plan to update priorities based on rapid change in field of health IT—monitoring key change factors.

Chapter 3.Vision of a Future Health IT—Enabled Health Care Delivery System

Visionary Panel presenters included experts from academia, industry, and practice who are knowledgeable about trends impacting health and health care delivery and who could convey a vision of the future grounded in evidence. The selected list of topics and presenters is shown in Table 2.

All 12 Visionary Panel presentations (listed in Table 2) and facilitated discussions provided unique views of how the practice of health care and health care research will look in the future. Although each presenter discussed a different topic, all agreed that the current cost of health care is unsustainable and that advances in information technologies have the potential to transform the way that health care is delivered in the future.

Table 2. Visionary Panel Members, Topics, and Presentation Titles

Visionary Panel Presenter	Topic	Presentation Title
T.R. Reid Journalist and Author	Future of Health and Health Care/Trends in Health Care	What The U.S. Can Learn From Health Care Payment Models From Around The World
David Ellis, M.S.C. Futurist and Author	Future of Health Care/Trends in Technology	The Future of Health Information Technology: From Health Information Technology to Health Insight Technology
Jason Hwang, M.D., M.B.A. Cofounder and Chief Medical Officer, PolkaDoc	Future Trends in the Business of Health Care	The Innovator's Prescription: A Disruptive Solution for Health Care
Steve Agritelley Director of Health Research and Innovation, Intel Labs, Intel Corporation	Future Trends Related to the Aging Demographic	Shifting Demographics Driving Health Care Technology Transformation
Martin S. Kohn, M.D. Chief Medical Scientist for Care Delivery Systems, IBM Research	The Future Impact of Big Data Analytics on the Practice of Health Care	Analytics in the Transformation of Health Care
Christopher Johnson, Ph.D. Distinguished Professor and Founding Director, Scientific Computing and Imaging (SCI) Institute at the University of Utah	Use of Data Visualization Techniques in Health Care: Making Sense of Multiple Data Streams	Visualizing the Future of Biomedicine
Joseph Kvedar, M.D. Founder and Director of the Center for Connected Health at Partners Healthcare	The Future of Connected Health and Personalized Preventive Care	Connected Health: Transforming Care Through Technology

Table 2. Visionary Panel Members, Topics, and Presentation Titles (continued)

Visionary Panel Presenter	Topic	Presentation Title
Donald Jones, M.B.A. Vice President of Global Strategy & Market Development, Qualcomm	Future Trends Related to Mobile Technology	A Look Ahead: The Future of Connected Health
Benjamin Heywood, M.B.A. President and Cofounder of PatientsLikeMe	Future Trends Related to Patient—Generated Health Information	Patients Like Me Horizon Scan
R. Craig Lefebvre, Ph.D. Lead Change Designer, Center for Communication Science, RTI International	Future Trends Related to Social Media in Health Care	A Future For Social Health
Kevin Patrick, M.D., M.S. and Jerry Sheehan, M.A., Calit2, University of California, San Diego	Future Trends Related to Digital Health	Personal Data for the Public Good
Roni Zeiger, M.D., M.S. Cofounder and CEO of Smart Patients	Future Trends in Participatory Health Care and Research	Participatory Health Care Delivery and Research

Key Drivers Shaping the Future of Health Care

The Visionary Panel raised a number of key drivers that are expected to influence the future of health care. These drivers include the following:

1. **Consumerism.** Consumers' expectations and demand for ready access to their health information online—and the capability to manage prescriptions and appointments and to coordinate resources—will drive innovation. Further, as consumers assume greater responsibility for the cost of care, they will increasingly demand greater price transparency that will help to create a true marketplace for health care services. The rapidly growing use of smart, mobile technology among consumers has created a widely held expectation that the same convenience available to individuals for banking or managing travel will also be available to manage the health and health care needs for themselves and for loved ones.

2. **Aging.** The aging population in the United States is a major factor in the rising cost of health care. According to the National Council on Aging (NCOA), about 91 percent of older adults have at least one chronic condition, and 73 percent have at least two chronic conditions including diabetes, arthritis, hypertension, and lung disease. Chronic conditions place a significant financial burden on individuals and the health care system.[13] In addition to the financial impact of the aging population, better ways are needed for caregivers to coordinate resources and manage the health care needs of aging loved ones.

3. Technology innovation. Innovation in IT will continue to change the way that individuals and care providers manage health and health care. For example, mobile technologies are on track to be the fastest growing technology ever adopted in human history.[14] The rapid proliferation of more powerful, less expensive mobile technologies offers significant opportunities to advance care delivery—from providing access to health information and online health communities to engaging with health care providers. According to industry estimates, 500 million smartphone users worldwide will use a health care application by 2015, and by 2018, 50 percent of the more

than 3.4 billion smartphone and tablet users will have downloaded mobile health applications. Adoption of mobile devices has changed business processes in other sectors including media, retail, and banking and it is expected to change the way care is delivered. The widespread use of mobile devices is growing within health care, as evidenced by increases in provider adoption of mobile technologies to support the screening, diagnosis, and treatment of patients in primary care and consumers' use of mobile technologies for health and wellness or disease management.

4. **Advanced analytics and big data**. The use of big data and advanced analytics will improve health care decisionmaking. The rapidly growing volume of electronic health data generated by EHRs, sensor technology, personal tracking devices, online health communities, and biomedical and genomic research coupled with advances in computing will enable a more data-driven approach to health care delivery. Access to data that provides a more holistic view of individuals creates the opportunity for providers (and care teams) to personalize care and treatment based on patient preferences and needs. Access to advanced decision support systems capable of processing large volumes of data will improve decisionmaking at the point of care reducing error and improving patient safety.

5. **National health care payment and policy changes.** Recent Federal Government actions have created the opportunity for new health care business models to emerge by aligning incentives to reduce payment for quantity of care and reward care activities that promote health instead. The Medicare and Medicaid EHR Incentive Programs, established under Title IV, Division B of the Health Information Technology and Economic and Clinical Health (HITECH) Act, pay incentives to eligible hospitals and providers to adopt and use Certified EHR Technology (CEHRT). The adoption and use of EHR systems will improve the management and use of clinical data. In addition, the Patient Protection and Affordable Care Act (ACA) will drive change in how health care is paid for, creating the price transparency necessary to transform the market for health care services. Key components of the ACA—including individual and employer mandates, accountable care organizations (ACOs), and wellness programs—will improve access to health care for more individuals creating a larger health care market. The influx of new consumers into the health care market will increase demand for primary care and specialist services and create the opportunity for new, more cost-effective care delivery models to enter the market. Together, these Federal initiatives create opportunities for new business models to emerge.

The interplay among these drivers has created an environment that supports the innovative changes to the health care system expected to occur over the next 5 to 10 years.

A Health IT-Enabled Health Care Delivery System

Visionary Panel members were asked to present their vision of the major trends affecting health and health care delivery and the facilitated discussions were intended to draw out the implications for health IT research. Each presenter offered a glimpse into the future from their own unique perspective. This process resulted in a view of a future health care system based on these various perspectives, which are summarized below. Specific presenters are noted in parentheses. Other ideas that are not attributed to particular individuals were mentioned by participants or came up during the facilitated discussions.

Data Infrastructure and Analytics

1. The future health care delivery system is one that is highly integrated and data-driven (Ellis, Kohn, Johnson). Patients and providers have access to advanced decision support systems. Data sources include health information generated by individuals from medical and fitness devices, mobile applications, sensors, online health communities, and published literature (Agritelley, Jones, Patrick, Sheehan, Heywood, Lefebvre, Zeiger).
2. The health care system is optimized for continuous improvement. Process outcomes are captured and used in continuous improvement activities. (Ellis, Kohn, Kvedar, Zeiger).
3. Knowledge discovery is advanced by novel analytic methods and new sources of data (Agritelley, Kohn, Johnson). Knowledge sharing is open and transparent so that all stakeholders benefit.
4. Patient information is readily accessible to patients, caregivers, and providers on the device of their choice. The information is securely aggregated and remotely stored for immediate access via the Internet, and includes self-generated health information, sensor data, clinical data including diagnoses and prescriptions, laboratory results, and other sources of data, and is accessible in real-time (Ellis, Kohn, Jones).
5. Patients and providers have access to visualization options needed to quickly access the information and make accurate decisions (Johnson).
6. Patients, caregivers, providers, technology developers, data scientists, and visualization experts work collaboratively to design safe, efficient health IT that supports a data-driven health care system (Johnson).

Collectively, presenters described a future in which the rapid development of new sources of health data, combined with advances in natural language processing (**NLP)** and cognitive computing, will result in new sources of information and advanced decision support tools that providers can use to personalize diagnosis and treatment. Advances in population health analytics will enable a more tailored approach to the diagnosis and treatment of patients. Using analytic methods to tailor treatments may reduce the cost of care by minimizing spending on diagnostic testing and treatments that do not improve outcomes. Broad-based interventions that treat all patients with a specific diagnosis the same way are costly and have limited clinical effectiveness. One-size-fits-all approaches to prevention and chronic disease management will be replaced by economically efficient and clinically effective strategies that assess an individual patient's specific needs and create prevention and wellness programs that meet those needs. The goal is to focus the intensity of the program on the individual patient to minimize the use of ineffective treatments.

Providers will be able to take advantage of advanced analytic systems that will process data from many sources, including published biomedical literature, social media, self-tracking devices, remote monitoring devices, and clinical and genomic data.

Given the information-intensive nature of health care and the rapidity with which information is being generated, strategies and tools that help synthesize and present data in a comprehensible form, are essential.

Patient Experience of Care

1. Access to care is expanded through innovative business models that provide streamlined care for common conditions and technologies designed to reach all patients, including vulnerable populations (Reid, Hwang, Agritelley, Kvedar, Jones).

2. Health care is ubiquitous, convenient, personalized, and encompasses wellness and preventive care that is delivered in both traditional and nontraditional care settings. It emphasizes continuity of care and chronic care management (Agritelley, Hwang, Jones, Kvedar).
3. Care teams, supported by health IT, manage a patient's conditions in a coordinated way rather than disjointed episodes of care (Agritelley, Kohn, Kvedar).
4. Patients make decisions about health collaboratively with their interdisciplinary care team and family members. Decisions are informed by multiple sources of data and robust decision support systems (Ellis, Heywood, Lefebvre, Patrick, Sheehan, Zeiger).

Presenters expected that advances in health IT and innovative approaches to payment will drive the development and implementation of a more distributed model of care delivery that makes routine care more convenient for patients to access, thus reducing the use of care delivered in traditional settings such as physicians' offices and hospitals.[15] Changing the point of care based on patient's needs will create more options for patients seeking care than are currently available. Currently, the most expensive care is delivered at the hospital where the most advanced medical technology and specialized expertise are located. Many common conditions and minor injuries can be treated in lower-cost, more convenient settings such as local retail clinics or at home.

A fully interoperable, data-driven health care system will enable improved care coordination needed to support a distributed care model.[*] In the future, health IT will facilitate coordinated care by providing ready access to the information and tools necessary to coordinate the activities of care teams that include participants from multiple organizations, the patient, and family caregivers.

The increasing availability of personal digital devices (for example, smartphones, tablets, and wearable technologies for activity tracking) along with changes to reimbursement models will drive innovative new care models that may deliver more effective, cost-efficient health care in the future. Technology-enabled models of care focus on personal interactions, data exchange, and tailored communication, which create a more patient-centric experience through enhanced patient engagement, education, and the provision of personally relevant feedback to users. Care is integrated into people's day-to-day lives and employs technology to deliver quality services outside of traditional clinical settings.

Health IT will also enable providers and patients to maintain health and wellness, manage chronic disease, and improve patient adherence and engagement in their own care. Technology-enabled care programs that incorporate remote monitoring can facilitate transformation of care from a few measurements per year in the provider office to daily or near-real-time monitoring of chronic health conditions. Monitoring can occur in the patient's daily living environment rather than in the artificial and sometimes anxiety-inducing setting of the examination room or hospital. This adaptation places responsibility and control for aligning health behaviors with desired health outcomes squarely in the patient's hands. Face-to-face visits with providers are reserved for complex and/or acute care situations that require immediate attention of care professionals. The development of wellness programs will create another opportunity to develop innovative

[*] Care coordination may be defined as the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the coordination of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care.[16]

business models that are personalized to take into account an individual's preferences and needs. The use of consumer health IT to enable preventive care programs is viewed as a key enabler of long-term behavior change.

Health care consumers, empowered by unprecedented access to health information and the use of smart technologies to manage other aspects of their lives, will increasingly demand more convenient services in health care. Unprecedented access to high-quality information and online communities will be an important mechanism for patients and their families to become better informed and more active participants in their care. Since the advent of the Internet, patients have used online resources to share experiences, learn about diseases and treatments, and become advocates, all facilitated by the growth of disease-specific online communities that have engaged patients and their families in the health care process. Members of online health communities will play important roles in community health decisionmaking or as part of collaborative treatment teams addressing their diseases. Empowered by their access to information, patients will take a more active role in their care, enhancing the patient-provider relationship and allowing providers and patients to bring their own expertise and knowledge to the clinical relationship to produce the best outcomes.

Chapter 4. Implications for Research

The future vision of an integrated, data-driven health care system raises many research questions. The Visionary Panel members recommended a number of topics that need research. Some of these topics raised research questions aimed at understanding the role of health IT in the envisioned health care system. Other topics raised broader questions related to health services research, and finally some topics raised questions relevant for researchers outside the health services domain. These research questions are presented in three subsections as follows: (1) questions that fall within the purview of the Health IT Portfolio; (2) questions that fall outside of the purview of the Health IT Portfolio but are relevant to AHRQ's mission; and (3) questions that are important but fall outside of AHRQ's purview.

Research Topics and Questions Relevant to the Health IT Portfolio

A data-driven health care system requires an infrastructure that can rapidly aggregate and analyze large volumes of both structured and unstructured data and present actionable information to patients, caregivers, and providers. The widespread adoption and use of EHRs, sensor technology for continuous monitoring, and advances in imaging technology, genomics, social media, and other sources of data are contributing to the rapid growth of health care datasets.[17 †] This rapidly growing body of digital health information presents both challenges and opportunities for health care delivery. Some challenges include data quality, data standardization, interoperability, data privacy, workflow impact, and the usefulness and accessibility of the data. Advances in machine learning and NLP may be helpful tools for managing and processing large volumes of unstructured text but their potential may be limited by the quality of the data. Systematic errors introduced through data entry and data documentation practices affect data quality.[18] The number of data users is also increasing—many of those users will come from outside traditional health care settings. Opportunities include advanced decision support tools to support diagnostic and treatment decisions, advanced analytics and visualization tools to enhance communication, and tools that support efficient, safe distributed care delivery. Ensuring continuous access to accurate, human, and machine-understandable high-quality data will require experienced computer and data scientists to derive actionable information from vast quantities of data.

Advanced Decision Support Tools

To stay current with the rapidly expanding body of clinical knowledge, providers and other care team members, patients, and caregivers will increasingly rely on advanced decision support systems to inform patient care decisions. Advanced decision support tools will employ intelligent logic and enable updates to decisional algorithms to accommodate new information, such as scientific discoveries and clinical evidence. The systems will operate in the background, often invisibly to users, and will integrate seamlessly with standing health IT infrastructure, such as

† Other sources of data may include social, economic, environmental and other types of data from outside traditional health care settings.

EHRs. Robust and workflow-friendly decision support systems will transform raw data into actionable information, improving overall quality, efficiency, and safety.

Funding research that identifies how advanced decision support systems will perform consistently and transparently is critical. Some key questions to explore include—

- What information is needed at the point of care to support effective care delivery?
- How can diagnostic decision support tools be developed and used to improve the quality of diagnosis?
- How can clinical decision support tools be most effectively developed and used to assist patients with challenging clinical decisions?
- In a health care ecosystem that provides access to various data streams, what tools are needed to help individuals to manage that information and extract knowledge from it?
- How can health IT be used to develop decentralized analytic tools that provide decision support based on locally available data for patients and health care professionals?

Big Data Analytics

Advances in the aggregation of large volumes of data and powerful analytic tools are creating health IT research opportunities. Providing innovative, data-driven solutions that leverage big data will require a better understanding of the technical and methodological challenges to aggregating, analyzing, and presenting data to end users. The use of big data analytics in care delivery will create challenges for clinical workflow. Integrating new information flows into clinical workflows will optimally deliver the right amount of data to the right individual at the right point in the workflow to facilitate effective evidence-based decisionmaking. Some key questions to explore include the following:

- What are the best methods for aggregating patient/clinical data from multiple heterogeneous data sources?
- How will record matching (to a unique individual patient) be assured and verified?
- For very large datasets, how will aggregation take place—will it be logical (leaving data in its source system) or physical (copying data from their source system)?
- How might the use of big data analytics change the health care workforce and care delivery?
- How might big data analytics be effectively used to support providers to deliver better health care as opposed to driving more services?
- How will integration of analytics into clinical practice change the patient-provider dynamic?
- What are the best workflow and form factor approaches to incorporate big data analytics into health care?
- How can big data analytics be used to support patients to better access and effectively use health care?

Using Health IT to Display and Communicate Health Information

Presenting clinical and health information in a meaningful way is critical for patients, caregivers, and providers. Advances in visualization science and health IT, both of which are quickly evolving and cross multiple disciplines, suggest a number of areas for future research.

Scientific visualization techniques, in which spatial characteristics of an object, dataset, or signal are analyzed to uncover meaningful information, may yield new and useful applications

for organizing and presenting data collected from sensors and biometric devices to help with diagnosis, treatment, risk assessment, or pattern recognition. Important challenges for basic and applied research include assuring the following: that the variety and volume of data produced for a given patient are well supported and managed using health IT; that robust methods for searching, indexing, and analyzing the data are developed to yield useful information; and that information captured once can be shared and used many times.

Information visualization techniques, in which nonspatial characteristics of an object, dataset, or signal are analyzed and presented graphically, may also help address the growing challenge of uncovering hidden associations in data, especially in very large datasets or in those containing disparate kinds of data.

Data that combine both spatial and nonspatial dimensions and attributes present additional challenges. Because visual information displays are filtered through the human brain, research to understand how to enhance and support effective visual understanding, and when to bypass it (using machines, for example) for improved results, is paramount. For example, research into the use of generalized dashboards that help to alert a patient, caregiver, or provider about a medically significant event is becoming more important as the volume of information about a patient expands and patient visit lengths and the attention span of the typical provider shrink. Alerts on dashboards may include notification(s) that a medication is no longer helping, that a treatment plan should be revisited because desired symptom improvements are not occurring, or that follow-up rehabilitation visits are not taking place. Research that brings cognitive science, data analytics, clinical workflow and decisionmaking experts, and visualization scientists together to tackle these problems could yield innovative solutions that improve workflow, understanding of uncertainty, diagnostic and treatment performance, and perhaps, cost containment.

In addition, research is needed to evaluate the effectiveness of information visualization in practice—not only to systematically determine the useful mappings of nonspatial data that permit researchers, providers, and patients to identify and extract meaningful information from the data, but also to determine whether one approach to visualization is equal to or better than another.

Some key questions to explore include—

- What are the best ways to display information for patients, caregivers, and providers in the clinical care setting to improve efficiency, minimize bias, and reduce error?
- How can new methods of organizing and displaying health care data be used to quickly and easily communicate information (especially at the patient level)?
- How can data visualization be used to bridge literacy gaps (for example, to aid patients in understanding a care plan)?
- How might high-quality data visualization change the way care is delivered for wellness, prevention, diagnosis, and disease management?

Use of Health IT to Support Distributed Care Models

The Visionary Panel presented a vision of the future in which the individual health care consumer is at the center of a health care ecosystem that encompasses a wide range of health care resources that cross organizational and geographic boundaries. These resources may include personal fitness trainers, nutritionists, health coaches, peer educators, retail clinics, social media outlets, and wellness and preventive care applications. This health care ecosystem may also include care delivered by staff at differing levels of medical licensure: nurses, physician assistants, nurse practitioners, primary care physicians, specialists, and personnel at acute care

facilities when needed. The medical staff may use a range of technologies to deliver care: remote monitoring, virtual visits, email, and text messaging.

The design and development of appropriate IT to support distributed care models requires a thorough understanding of the services and information needs of each participant. The Visionary Panel discussed several approaches to understanding these needs: for example, patient segmentation analysis that accounts for the social, cultural, and economic demographics of a given patient population to better understand their risk factors and need for services. The information needs for each participant in coordinated care models differ, and understanding those information needs is critical to the success of these models. What information is needed, by whom, and in what form? Answers to these questions may be found in both the operational data collected about business practices in hospitals and data collected on the clinical side of the organization. Once the information needs of the stakeholders are known, they can be matched to the resources that may provide the answers. Because of rapid advances in medical knowledge, the growing complexity of health care delivery, and the varied sources of data available, health IT will continue to play a key role in facilitating access to the necessary information.

Some key questions for researchers are as follows:

- Based on the needs of the patient, what is the appropriate composition of the care team (including nonmedical care team members)?
- What role does each care team member play and what are the information needs for each role?
- What factors influence the information needs of care team members (e.g., diagnosis, sociodemographics, treatment, point of care)?
- What are the health IT needs of the team (decision support, information access, analytics, visualization, integration of nonmedical staff)?
- How can health IT be used to effectively integrate nonmedical care providers into the traditional health care team?
- How can health IT be used effectively to help patients and caregivers manage health outside of their interactions with their health care team?
- What role will mobile devices such as smartphones play in helping manage communications effectively?
- How will technology design factors impact patients who switch between models of care or between care providers (assuming a period of time where current practices coexist with decentralized care practices resulting in challenges coordinating information and activities as patients move between different care settings)?
- How can health IT better facilitate patient-provider-caregiver communication in a distributed, decentralized care delivery model?
- How can health IT be used to effectively integrate patients and caregivers into the care team?

Planning the technology to support a distributed health care model requires studying the structure of the care delivery components and the organization's goals. For example, a Coordinated Care Organization (CCO) may be made up of all of the major health care providers in a major metropolitan area, Medicaid, Medicare, private payers, and social service providers. If the immediate objective for coordinating among the organizations is to reduce emergency department visits, that care could be provided elsewhere in the system such as primary care, dental care, and behavioral and mental health care. Developing technology to support this objective requires understanding the roles of all participants and their information needs.

Understanding the skill mix necessary to provide care is also important. Very little is known about how to coordinate the optimal mix of services among such varied groups that may include workers who perform home-based custodial tasks, home health workers, nurses, nurse practitioners, physician assistants, physicians, medical specialists, dentists, social workers, psychologists, and psychiatrists. A corollary to patient segmentation analysis is a skillset segmentation analysis aimed at understanding the skill mix necessary to support coordinated care based on the individual needs of the patient and other factors, such as whether care is being provided in urban versus a rural environment.

The Use of Health IT to Improve Efficiency

Value-based care delivery models reward providers who eliminate unnecessary or ineffective activities and to work more efficiently. Shifting from a fee-for-service model that rewards volume to a value-based care model that rewards cost-effective, quality care will require providers to structure their delivery networks to favor lower-resource care while maintaining high quality. This change will strongly favor the use of ambulatory and home care settings by patients whenever possible and will rely on and accelerate the use of technology-enabled care delivery using connected health or telemedicine solutions and communication with patients through patient portals, phone, and email. Health IT may also enable a redistribution of responsibilities among clinical staff such that staff at lower levels of licensure may perform tasks that were previously performed by physicians, for example. This redistribution of work ensures that higher cost resources are only used where appropriate.

Some key research questions include—

- How can routine or low-risk medical tasks be defined and how can health IT be used to automate these tasks to allow care team members to more effectively manage complex tasks and activities?
- What new processes or workflows will be needed to best use health IT to facilitate care coordination and improve quality of care?
- How can advanced health IT systems improve health care quality in a measureable way in a more patient-centered health care model?

As the volume of medical information grows and as providers are inundated with data from multiple sources, automated methods must be developed and refined to handle both clinical and patient-generated data—including methods to triage the data, create alerts based on the data, and identify when the value of collecting and accessing the data outweighs the effort and resources required to manage it. This raises important questions about how to manage and present the needed information to the right person in the most effective way possible. Some important research questions are as follows:

- How might mobile devices, small form factors, and process redesign reduce suboptimal workflows and foster more ubiquitous clinical decision support that is not disruptive to the provider and patient?
- What health information needs are best served by high-quality visualization (for health information management)?
- How can designers and developers of health IT learn more effectively from patients as expert users of health IT?

Evaluation studies of technology-enabled care delivery and interventions should be conducted to understand the extent to which they provide cost-effective solutions that improve operational efficiencies and the quality of care delivered across care settings. The data collected

across care settings can be integrated, analyzed, and used to provide targeted feedback to patients and providers. Such an approach enables shifting from a reactive, episodic health care model to a more proactive, sustained practice of wellness that connects providers and stakeholders, placing patients at the center of a highly individualized process of delivering care. Data sources may include actively or passively collected patient-generated health information, clinical measures, observations of daily living, or other data generated outside traditional health care settings.[19-22]

Health IT Safety Monitoring and Testing

Widespread reliance on the use of health IT and analytics in clinical practice will alter the way care is delivered. Suboptimal health IT systems may negatively impact providers' job satisfaction in turn affecting care delivery. Automating minor or routine medical tasks can lead to unintended safety issues and may also impact the patient-provider dynamic. Safety issues may arise from heavy reliance on analytics and decision support for diagnosis and treatment decisions. In addition, new methods of using data in care delivery, to support quality improvement initiatives and to develop new clinical guidelines for screening, diagnosis, and treatment of disease may also increase safety risks by creating a situation where providers are overwhelmed with information.

Linking datasets continues to raise privacy concerns that are heightened by the addition of genomic and other metabolic data. Synthetic datasets may be used to conduct analyses that test theoretical models and frameworks without compromising the confidentiality of the data (for example, using large synthetic datasets to test new analytic tools).[‡]

Some important research questions are as follows:

- What role does health IT play in provider performance?
- If health IT impacts the providers' job satisfaction, does it impact quality of care? For example, does work/stress impact safety and quality?
- What is the value of large synthetic datasets for conducting simulation studies?

Research Topics and Questions Relevant for AHRQ

The Visionary Panel presenters raised a number of questions that are important for researchers interested in better understanding how new sources of health information may be used to improve care delivery. Although these questions are not specific to health IT, they are important questions to include in this report. One new source of health information is generated by patients as they interact in online health communities. Data about how patients access and share health information in social media and in online patient and health communities are a valuable source for research. Online patient communities function as both consumer platforms that offer services to individuals and their caregivers and as research platforms providing aggregated and contextual data for extraction by researchers. It will be important to understand how patient-generated information from these online communities can be used in conjunction with provider-generated data to create research networks to recruit patients into research studies, collect and validate data, match patient data across different sources, and coordinate research across multiple platforms and organizations. The converse is also a challenge. Currently, no mechanisms are in place that will integrate information produced by EHRs, laboratory systems,

[‡]Synthetic data are the result of a process of data anonymization.

and other health technologies into online communities for patients' use in the community context. Identifying tools and policies that facilitate the use of information generated by patients in online health communities or social media for research purposes and in clinical care is important future work.

The lack of standardization is another challenge in using patient-generated data from online communities for research and clinical purposes. Semantic interoperability, in which phrases and language that patients use are defined and understood through a controlled vocabulary, was also raised as a future area of focus. Questions that might be explored include—

- How are medical terms understood by the patient?
- How are patient terms understood by the medical community?
- How can the mappings be used to enhance communication among care team members (including the patient)?
- What research is needed to develop the concept of a "folksonomy" that can be used to communicate clinical and health information to nonclinical audiences?

Visionary Panel presenters also raised the concept of patients as "experts" in their own experience and noted that patients and family members are highly motivated to understand everything that they can about their situation, including their condition in their personal context. Access to online resources and health communities makes it easier for individuals to develop and share their expertise. Online discussions among these patient "experts" provide a rich source of data for research which raises the following questions:

- How can patients' expertise be developed and incorporated into the care team and care process?
- What mechanisms may be needed to assist providers in leveraging patient expertise?
- How can patients be encouraged, coached, facilitated to become experts and share their expertise?
- What approaches and methods are most effective in helping patients/caregivers to develop their expertise? To better support all patients, how can guides and caregivers develop expertise as well?

The discussion of the value of data from online patient communities made a distinction between "information resources" and "person resources." Information resources can be stored, are searchable, can be researched, and can be easily shared with computers. However, information resources usually do not offer the level of interaction, context, experience, and judgment that person resources can provide. Person resources include groups of individuals, such as patients talking to one another either in person or through online communities. Understanding how the information gathered from person resources can be captured and used for research purposes raises a number of questions:

- How can one evaluate what constitutes a good "person resource"?
- How are the strengths and the limitations of person resources assessed, such as recognizing levels of bias or objectivity?
- How can social or interpersonal factors be leveraged or managed to avoid cultural rejection or discounting a person's expertise?
- As social technologies advance, how can group sharing of expertise be facilitated?
- How effectively is reliable information promoted and unreliable information discounted in direct patient-to-patient sharing?
- What are the best ways to promote such sharing and collaboration?

Because providers play an integral role in the health of patients, it will be important to understand how providers can learn to recognize relevant expertise of patients, including the use of crowdsourcing among recognized or informal experts. For common problems, crowdsourcing helps to garner many perspectives on the problem; for uncommon or rare problems, it may be the most effective way to surface the few perspectives from individuals with expertise. Finding ways to usefully semistructure or code natural narrative from patients, patient-provider interactions, or patient-community interactions could help to connect rich narrative information with a broad group of interested health consumers.

Some additional research questions include the following:

- What privacy, security, ethical, and legal issues will be raised by linking datasets (including genomic and biomonitoring data)?
- How might home-based monitoring technologies be linked to EHRs/health IT systems to improve health care quality?
- What types of career funding and training will be needed for future generations of computational biologists, algorithm developers, and data scientists to conduct clinical analytics on a large scale?
- How will busy health care providers stay current with the new tools and technologies that may be useful to their patients?
- How will health literacy and health IT literacy be considered in the technology-enabled health care model of the future?

Finally, Visionary Panel presenters discussed data generated by wearable devices as another important source of data for research. The challenge is to identify how these types of data may be aggregated for research, other "public good" purposes, or commercial uses in an open-data platform. The business model of organizations that make the devices and collect these data may not have planned for the data to be used for other purposes. This poses a challenge for researchers wanting to access the data because the holders of the data do not have mechanisms in place for data sharing. One solution would be to create an open-data platform whereby these organizations could share the data with health care researchers. The challenge is how to identify ways to sustain the cost of aggregating, curating, and analyzing data in an open-data platform. Developing self-sustaining mechanisms to monetize and use the data while maintaining appropriate privacy and security protections are important challenges to explore. Further work to develop and standardize data protection and sharing agreements is important for data generators and consumers to maintain trust that the systems that store, manage, and aggregate their data will be safe.

Research Topics and Questions Outside of AHRQ's Mission

A few questions were raised that are important to the future of health care but are outside AHRQ's purview. These questions fall into three categories: health care workforce and training, use of genomic and metabolic data in health care, and big data tools and methods broadly defined. The questions include the following:

- What new roles for health care professionals will be needed based on availability of data and analytics? How will these roles be created and integrated into the current health care system?
- What approach will be needed to develop the workforce needed to fill the new roles in health and health care? What new standards and licensure requirements may be needed?

- How can genomics data be integrated and used in everyday health care delivery?
- What analytic methods are needed to extract the value from big data?

Chapter 5. Potential Considerations for Research Funding

The Visionary Panel presenters raised many topics where research is needed. Some of these topics are aimed at health IT researchers and others are aimed at health services and other researchers working to improve health and health care in the United States. Health IT research involves a complex interplay between people and technology in the context of health care delivery. The Visionary Panel suggested that the five major drivers of change will impact all three areas. Patients, caregivers, and providers will demand more convenience, technology is rapidly evolving, and the point of care is changing. Research into how health IT will facilitate change in health care delivery will require a multidisciplinary approach that includes social science and biomedical researchers, technology users and developers, computer scientists, computational biologists, device makers, and third-party aggregators. Funding for health IT research should take into account new approaches to identifying and solving the problems of the future. All solutions will not flow from traditional sources such as universities and research institutes. Partnerships among organizations should be encouraged. Researchers should be encouraged to partner with online communities and technology developers in collaborative research. Some recommended funding vehicles and approaches to support needed research in health IT are presented.

Table 3 includes suggested funding vehicles to support needed research in health IT. A comprehensive scan of currently funded projects for each topic may need to be conducted to avoid duplication of effort among Federal and private sector funders. This research environment is rapidly evolving. Notably, the National Science Foundation (NSF) and the National Institutes of Health (NIH) have launched large research programs of topics ranging from the Smart and Connected Health (SCH) Program, which aims to accelerate the development and use of innovative approaches that would support transformation of health care from reactive and hospital-centered, to preventive, proactive, evidence-based, person-centered and focused on well-being rather than disease to the Big Data to Knowledge (BD2K) Program aimed at enabling the use of big data for biomedical research.

Table 4 includes suggested funding vehicles to support research areas that are not directly related to health IT but are important to health services researchers more broadly.

Table 3. Suggested Research Funding Mechanisms for Health IT Research

Category	Research Topic	Potential Funding Mechanism[a]
Advanced Decision Support Tools	Research that identifies how advanced decision support systems will perform consistently and transparently is critical.	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs Small business technology transfer (STTR) grants (R41/42) may be used to stimulate innovative research between small businesses and research institutions
Big Data Analytics	Research aimed at better understanding of the technical and methodological challenges to aggregating, analyzing, and presenting data to end users. How can big data analytics be integrated into the clinical workflow? How can new information flows be designed to work within clinical workflows to optimally deliver the right data to the right individual at the right point in the workflow to facilitate effective evidence-based decisionmaking.	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs
Health IT Data Visualization	Research aimed at understanding how to present clinical and health information in a meaningful way is critical for patients, caregivers, and providers. Advances in visualization science and health IT are quickly evolving and cross multiple disciplines. • What are the best ways to display information for patients, caregivers, and providers in the clinical care setting to improve efficiency, minimize bias, and reduce error? • How can new methods of organizing and displaying health care data be used to quickly and easily communicate information (especially at the patient level)? • How can data visualization be used to bridge literacy gaps (for example, aid patients in understanding a care plan)? • How might high-quality data visualization change the way care is delivered for wellness, prevention, diagnosis, and disease management?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs Small business technology transfer (STTR) grants (R41/42) may be used to stimulate innovative research between small businesses and research institutions

Table 3. Suggested Research Funding Mechanisms for Health IT Research (continued)

Category	Research Topic	Potential Funding Mechanism[a]
Health IT in Support of Distributed Care Delivery	The design and development of appropriate IT to support distributed care models requires a thorough understanding of the services and information needs of each participant. Questions about the needs of the care team: • Based on the needs of the patient, what is the appropriate composition of the care team (including nonmedical care team members)? • What role does each care team member play and what are the information needs for each role? What factors influence the information needs of care team members? • What are the health IT needs of the team (decision support, information access, analytics, visualization, integration of nonmedical staff)? • How can health IT be used to effectively integrate nonmedical care providers into the traditional health care team? Questions about the needs of patients and caregivers: • How can health IT (including mobile devices) be used effectively to help patients and caregivers manage health outside of their interactions with their health care team? • How will technology design factors impact patients who switch between care providers? • How can health IT better facilitate patient- caregiver-provider communication in a distributed, decentralized care delivery model? • How can health IT be used to effectively integrate patients and caregivers into the care team?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs Small business technology transfer (STTR) grants (R41/42) may be used to stimulate innovative research between small businesses and research institutions

Table 3. Suggested Research Funding Mechanisms for Health IT Research (continued)

Category	Research Topic	Potential Funding Mechanism[a]
Health IT to Improve Efficiency	Research that demonstrates that health IT improves efficient delivery of quality care is needed. Some key research questions include— • How can low- and high-value tasks be defined and how can health IT be used to automate lower-value tasks (that is, reduce the time spent on lower-value tasks) and support higher value tasks to create more effective care teams? • What new processes or workflows will be needed to best use health IT to facilitate care coordination and improve quality of care? • How might mobile devices, small form factors, and process redesign reduce suboptimal workflows and foster more ubiquitous clinical decision support that is not disruptive to the provider and patient? • What health information needs are best served by high-quality visualization (for health information management)? • How can designers and developers of health IT learn more effectively from patients as expert users of health IT?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs Small business technology transfer (STTR) grants (R41/42) may be used to stimulate innovative research between small businesses and research institutions
Health IT Safety, Remote Monitoring	New methods of using data to change the way health care is delivered, to support quality improvement initiatives, and as the basis for developing new clinical guidelines for screening, diagnosis, and treatment of disease may also increase safety risks. Understanding the way health IT impacts safety is critical and more sophisticated analyses are needed as health IT is used in new and different ways. • How might reliance on IT change the way providers practice and what role does health IT play in provider performance? If health IT impacts the providers' job satisfaction, does it impact quality of care? For example, does work/stress impact safety and quality?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs

Table 3. Suggested Research Funding Mechanisms for Health IT Research (continued)

Category	Research Topic	Potential Funding Mechanism[a]
Use of Synthetic Data for Testing Theoretical Models and Frameworks	Linking datasets continues to raise privacy concerns that are heightened by the addition of genomic and other metabolic data. Synthetic datasets may be used to conduct analyses that test theoretical models and frameworks without compromising the confidentiality of the data (for example, using large synthetic datasets to test new analytic tools).[b] What is the value of large synthetic datasets for conducting simulation studies?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs
Keeping Ahead of Trends in Health IT Research	Environmental Scans of Funding Opportunities for Research Impacting Health IT Research and Development Annual Visionary Panel Meeting 1-day Meeting (example topics may include) • Trends in health IT for patients, caregivers, and providers • Trends in health IT research methods • Trends in new sources of health data	Contracts may be used to support discrete, clearly scoped technical assistance and research tasks. R13/U13 Support for Conferences and Scientific Meetings

[a] A key to the standard NIH funding mechanism descriptions can be found at: http://grants.nih.gov/grants/funding/funding_program.htm

[b] Synthetic data are the result of a process of data anonymization.

Table 4. Suggested Research Funding Mechanisms for Research Questions for Health Services Researchers

Category	Research Topic	Potential Funding Mechanism
Online Health Communities and Social Media; Patient-Generated Health Information	• Integrating patient-generated information from online communities with provider-generated data to create research networks to recruit patients into research studies; collect and validate data; match patient data across different sources; and, coordinate research across multiple platforms and organizations. Patients as "person resources" and "experts" in their own experience • How can patients' expertise be developed and incorporated into the care team and care process? • What mechanisms may be needed to assist providers in leveraging patient expertise? • How can patients be encouraged, coached, facilitated to become experts and share their expertise? • What approaches and methods are most effective in helping patients/caregivers to develop their expertise? To better support all patients, how can guides and caregivers develop expertise as well?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs Small business technology transfer (STTR) grants (R41/42) may be used to stimulate innovative research between small businesses and research institutions
Data Standards for Patient-generated Data	Developing a standard for patient-generated data and a controlled vocabulary to: • define phrases and language that patients use • learn about how medical terms are understood by the patients • to learn how are patient terms are understood by the medical community • to learn how these mappings can be used to enhance communication among care team members including patients and caregivers • to develop the concept of a "folksonomy" which can be used to communicate clinical and health information to nonclinical audiences	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs Small business technology transfer (STTR) grants (R41/42) may be used to stimulate innovative research between small businesses and research institutions

Table 4. Suggested Research Funding Mechanisms for Research Questions for Health Services Researchers (continued)

Category	Research Topic	Potential Funding Mechanism
Open Data Platforms for Data Generated by Wearable Devices	• How might patient-generated data be aggregated for research, other "public good" purposes, or commercial uses? • What mechanisms can be used to support the aggregation, curation, and analysis of large patient-generated datasets while maintaining appropriate privacy and security protections? • How can standardized data protection and data sharing agreements be developed that will streamline the process of accessing data from organizations and ensuring consumers that the systems that store, manage, and aggregate their data will be safe?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs Small business technology transfer (STTR) grants (R41/42) may be used to stimulate innovative research between small businesses and research institutions

Table 5 includes suggested funding vehicles to support research areas that are not directly related to health IT or health services research, but are important questions to explore. Many of these topics are currently being funded through Federal and private foundations. For example:

- The NIH-funded Big Data to Knowledge (BD2K) initiative enables biomedical scientists to capitalize more fully on the big data generated by these research communities. The long-term goal of the BD2K initiative is to support the advances in data science, other quantitative sciences, policy, and training that are needed for the effective use of big data in biomedical research. Funding opportunities are specifically focused on data access and sharing, analysis methods and software, enhanced training, and career development in data sciences.
- The NSF-funded opportunities that support the fundamental science and underlying infrastructure to enable the use of big data for research across disciplines under its Cyberinfrastructure for the 21st Century framework and Expeditions in Computing programs. The NSF is also funding statistical approaches to address big data.

Table 5. Suggested Research Funding Mechanisms for Research Questions that Fall Outside of AHRQ's Mission

Category	Research Topic	Potential Funding Mechanism
Workforce and Training	• What new roles for health care professionals will be needed based on availability of data and analytics? • How will these roles be created and integrated into the current health care system? • What approach will be needed to develop the workforce to fill the new roles in health and health care? • What new standards and licensure requirements may be needed?	Contracts or RO1 research grants may be used to support discrete, clearly scoped research designs Small and exploratory grants (R03, R21) may be used for testing feasibility and exploring early stage designs
Finding Value in Big Data	• What analytic methods are needed to extract value from big data?	NIH, NSF, Private Foundations
Integrating Genomic and other metabolic data into health care delivery	• How can genomics data be integrated and used in everyday health care delivery? • What analytic methods are needed to extract the value from big data?	NIH, NSF, Private Foundations

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