



Consumer Vision for Ensuring that Health Information Technology Enables and Promotes Patient-Centered Health Care

As the nation begins to reform our health care system, it is clear that Health Information Technology (HIT) is a critical and foundational element for change. References to HIT were woven throughout the recently enacted health reform law as a foundational component of reforming the health care delivery and payment systems. There is widespread recognition that reorienting the system to meet the needs of consumers is a key ingredient in any recipe for successful reform. If the benefits of HIT are to be fully realized, it must be designed and implemented in ways that improve health outcomes and directly benefit consumers, patients, and their families.

HIT is fundamental to delivery and payment system reform. The prevailing approaches – such as the Medical Home Model, Accountable Care Organizations, or bundled payments for episodes of care – all require linkages in real time to share critical information for improving care delivery and providing accountability for improved outcomes. These linkages are also vital to achieving the benefits consumers want, such as better coordination of care, the ability to set and achieve health and wellness goals, and the kind of secure and accessible communication channels that support partnerships between patients and providers. In addition, full and effective implementation of HIT is necessary to align payment for health care with the quality of care patients need and deserve. Below, we have articulated a broad vision for the role of HIT in creating a truly patient-centered health care system.

Robust patient and family engagement can occur with today's tools and information, if we put the right set of policies in place and market forces in motion. But doing so requires a **common vision and guiding framework**, so that all stakeholders – and especially consumer organizations – can work to catalyze these changes.

This guiding vision is designed to enable the identification of gaps in current policy, anticipation of new issues, prioritization of opportunities, and proactive shaping of policy to meet the needs of consumers and patients into the future. This vision is also a means of engaging the broader stakeholder community in support of the shared agenda of patient-centered care, enabled by HIT. Such a partnership between a sophisticated coalition of consumer and patient organizations and other stakeholders who share our vision will catalyze the key policy changes and market forces necessary to leverage electronic health information and tools to support patients and their families in better understanding, managing and using health information, in order to live fuller, healthier, and more productive lives.

To support improvements in health outcomes and status—including increasing patient activation, reducing health disparities and improving access to care—we must employ a “whole person” orientation to our view of health and health care, and work toward enabling patients and their families to use electronic information and tools to:

- **Set and achieve personal health and wellness goals**, including improved ability to manage chronic health conditions over time.
- **Make more informed decisions** that reflect their needs, values, and preferences, in partnership with their care providers.

- **Be connected** to health care providers, community resources and others with similar health interests.
- **Participate actively** in the continuous improvement of the quality, efficiency and effectiveness of care.

In almost every other industry outside health care, electronic tools and applications have evolved to support the management and effective use of information by consumers. For example, online banking allows consumers to manage accounts, conduct transactions, and maintain up-to-date knowledge about their finances via electronic alerts – all with the convenience of never having to go to a bank during normal business hours. Similarly, online travel tools allow consumers direct access to flight scheduling and other reservations, provide automated updates, and maintain information about an individual’s travel history. All of these benefits would be useful to consumers in managing their health and health care, and would significantly increase their access to and engagement with the health care system.

There are a variety of tools available today that begin to offer consumers direct benefits. Some electronic tools can be used to monitor and communicate key information back to providers, thus enabling better care coordination. Others can be used more independently by patients to track key intermediate health outcomes, such as HbA1c levels for diabetic patients, trends in weight gain, cholesterol levels, or blood pressure. Beyond these patient self-management activities, shared decision-making tools offer interactive information that is useful in helping patients and their families – in partnership with their providers – decide between various treatment options, based on their needs, preferences and values. Finally, internet-based social networking platforms, such as PatientsLikeMe™, provide various benefits to consumers, including access to individualized information, social support, and the ability to participate in research.

In spite of the existence of some very innovative consumer tools, they are being used by a very small but increasing percent of the U.S. consumer population. In a 2008 survey commissioned by the Markle Foundation, only 2.7% of those surveyed actually used a personal health record (PHR), in spite of the fact that 79% of those surveyed felt that tools such as PHRs could provide significant benefits.¹ According to a 2010 survey commissioned by the California HealthCare Foundation, the percent of adults who have used a personal health record has since more than doubled to 7%, with a key determinant in use being whether an individual’s doctor uses an Electronic Health Record (EHR).²

Despite low usage rates, early experiences with these electronic, patient-oriented tools indicates that consumers and patients can effectively be engaged and empowered through the use of technology, if the technology meets their immediate needs, with the chronically ill, lower-income, and adults without a college education standing to benefit the most.³ Automatic uploading of data from provider records into their personal electronic health tool is a very basic necessity for widespread use. Given that consumers have diverse needs, the best way to meet these needs may be an eco-system of tools working together from which consumers could select the specific features they find most useful in managing their health, their health information and their health care.

¹ “Americans Overwhelmingly Believe that Electronic Personal Health Records Could Improve Their Health,” The Markle Foundation, June 2008. Available at www.connectingforhealth.org. Accessed 10/2/09.

² “Consumers and Health Information Technology: A National Survey,” California HealthCare Foundation, April 2010. Available at <http://www.chcf.org/publications/2010/04/consumers-and-health-information-technology-a-national-survey>. Accessed 05/04/10.

³ Ibid.

Widespread consumer engagement and empowerment would be a direct result of technology being used in ways that really matter to consumers, such as:

- ~ Anytime, anywhere access to health information, such as diagnoses, medication lists, lab test results, and immunization records.
- ~ Immediate and convenient connections with the clinical care team.
- ~ Online scheduling of appointments.
- ~ Access to information, such as after-visit summaries, care plans and supporting information, which helps them prepare for their encounters with clinicians and later recall key information.
- ~ Online prescription refills and access to electronic prescription information, such as dosing, frequency, side effects, benefits of adherence, drug-drug interaction and cost comparisons.
- ~ Access to detailed procedure information regarding what to expect, how to help ensure safety, and potential long and short term impact and outcomes. Customized, evidence-based decision support that considers the particular needs and preferences of the patient.

Capitalizing on the promise of widespread use of patient-oriented electronic tools will require identifying and overcoming a number of barriers. These include both **policy challenges**, like difficulty accessing and moving electronic health data, financial incentives that aren't aligned to support a partnership between providers and patients, the need for information policies that earn the public's trust, and changing roles and expectations in the provider-patient relationship, and the need to stimulate **marketplace innovations** in consumer health products, which have been outpaced by most other industries.

In today's environment, things are beginning to shift. The American Reinvestment and Recovery Act is opening new doors for policy changes around financial incentives and privacy policy, which will enable marketplace advancements toward our vision. The Patient Protection and Affordable Care Act calls on HIT to be used to support new care delivery models and to be incorporated into a national strategic plan to improve health care quality. It also provides additional support for HIT implementation efforts and workforce training and development in HIT. But effective advancement in these areas requires that consumer and consumer advocate input be built into policy development – both on the Federal and state/local level – rather than sought for “buy-in” after critical decisions have already been made.

Those key areas include:

1. Use of HIT by providers and patients and their families to **coordinate care**, including providing linkages with community resources and supports that are outside of the healthcare system.
2. More widespread use of tools that **promote patient education, engagement and activation for individual self-management**.
3. Advancing the role of HIT in **engaging patients in improving the quality, efficiency and effectiveness of care** through feedback on their experience of care, evidence-based shared decision making and research.

Each of these areas includes fundamental questions about trust and privacy that must be tackled as policy progresses.

To make progress in these key areas, policy changes are needed, and these changes have a role in supporting and stimulating market innovation.

Policy changes include:

- Access to understandable, useable, and useful information, including real-time, up-to-date personal health information, in whatever format the patient prefers.
- Portability/liquidity of data.
- Designing new incentives that reward the time and skills necessary to provide patient-centered care, including the active engagement of patients and their families in patient-centered care.
- Quality measurement and improvement, including measures of patient-centered care and health outcomes, which will spur redesign of care processes.
- Standardizing and requiring the collection of data on race, ethnicity, primary language and gender in order to measure and improve disparities in care among underserved populations.
- Protecting privacy and security, and maintaining trusting relationships.

If designed well, policy changes can stimulate market factors in a way that drives the evolution of technologies that are useful and affordable to consumers and patients and that meet their information needs. With effective policies, our expectation is that the market will be able to respond with innovative products that are:

- User-friendly for consumers.
- Effective in making consumers' lives simpler and helping them integrate health care into the full context of their lives.
- Capable of connecting consumers to their providers, their communities and each other.
- Privacy protective and secure.
- Affordable for consumers.

This vision is intended as a framework for understanding how both policy change and market innovation can evolve to support and promote the three key issue areas mentioned above. The National Partnership and the Consumer Partnership for eHealth, through effective advocacy and strategic alliances, will work to bring this vision into sharper focus.

Vision for HIT Enabled Patient-Centered Care

