



**Health IT Policy Framework for Integrating
Self-Management and Shared Management
of Health and Health Care**

***Unleashing the Power of Each
Individual to Manage Their Health and
Partner in Their Health Care, Enabled
by Information and Technology***

White Paper

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Executive Summary

While the concept of “patient-centered health care” has been emerging over the past decade, there is vast distance between that concept and a truly “person-centric” vision that embraces the value of the individual inside and outside the health care system for improving both health and health care. The current health care environment emphasizes episodic activities centralized in health care settings and does little to provide resources for people and their families where they live, work, and play. Within health care settings, the person is often a recipient of health care services rather than an active partner with the health care provider and care team. This dynamic limits the opportunities for people to manage their own health and to share in care management when interacting with their health care providers. Changing the paradigm to a person-centered vision is vital to improve health and health care outcomes. Existing and emerging technologies provide a path to make information and resources for health and health care management ubiquitous, integrated, and suitable to achieve the goals of promoting individual well-being and effective care.

The Office of the National Coordinator for Health Information Technology (ONC) initiated the development of this policy framework to articulate a vision, to identify how health IT can support this paradigm shift by the year 2020, and to facilitate effective health management by individuals, their caregivers, and their health care teams. Through this framework ONC seeks to enhance the visibility of this topic, promote nationwide dialog, and catalyze change among stakeholders involved in the health of the U.S. population.

Vision

The vision for the policy framework empowers each individual as the manager of their health and as a partner in their health care with health IT tools and resources to support them. It assumes that people’s health and quality of life will improve if they have the assistance of information and technology for self-care and shared decision-making with their providers. This vision for the future is one where:

The power of each individual is unleashed to be active in managing their health and partnering in their health care, enabled by information and technology.

Core Values

The vision is underpinned by several core values centered on the person. Although patient-centered care is a central tenet of modern American health care, this notion is expanded here to encompass “person-centered” efforts to reach individuals wherever they are and whatever their situation at the time, not just as patients in traditional health care settings.

- Individual self-determination and the public good are both optimized.
- People can decide whether and how much to participate in managing their health and health care.
- People can access wellness and health care services enabled by technology that reflects their individual needs, values, and choices.

- Health care is a partnership between the patient, their caregivers, the care team, and supporting services.
- Information is shared, as appropriate, between the individual and all their care partners to enable informed, participatory decision-making as desired by the individual.
- Everyone who holds information about an individual exercises responsible information stewardship.
- Easily used and useful, trusted tools are available to support the person’s decision-making.

Goals

The vision for this policy framework will only occur if there is cultural change regarding the individual’s role in how health and health care is managed, delivered, and received at any point on a continuum of wellness and disease states, supported by health IT. Three overarching goals result from the vision:

- **Self-Management and Prevention:** Empower individuals to be healthier and to manage any health conditions. Motivate policymakers, employers, and other stakeholders to establish guidelines and environments that promote and support healthy behavior and self-management of conditions.
- **Interactions:** Enable smooth, easy interactions and seamless transitions as the individual moves between wellness and self-management activities, and participating in the health care system. Soften or erase the boundaries between what occurs inside and outside of the health care system by promoting increased information flow and empowering people to perform on their own some of the activities that now occur only in formal health care settings. Allow “light touches” with the health care system when needed.
- **Shared Management:** Support more partnering of the person with his or her care team within the health care system through shared decision-making. Support and integrate caregivers appropriately into the care team. Encourage providers to value patients and their data, viewing them more holistically and longitudinally.

Building Blocks: High Impact Approaches to Achieve Vision

The building blocks are key policy ideas that address the changes that are required to support people as they act within and move between the spheres of wellness and health care. While not comprehensive, the building blocks are congruent with the values and organized by the goals. These building blocks are categorized as: 1) self-management and prevention; 2) interactions; 3) shared management; and 4) cross-cutting. Some building blocks that are assigned to one category also support other categories.

Self-Management and Prevention

- Efforts to motivate individual behavior change should go beyond traditional approaches (e.g., education about nutrition and exercise) to include self-learning and critical-thinking skills.
- Consumer-facing lifelong prevention and care guidelines should be developed and incorporated in useful tools.
- Public and private sector policy efforts should elevate the focus on prevention and on self-management outside the health care system.

- Self-management and prevention activities of the individual should be supported.
- Research should be conducted on self-management and caregiving activities to guide efforts to support and strengthen these activities.

Interactions

- Individuals should be enabled to make light touches with health care system as needed, rather than interacting only during formal encounters for episodic care.
- Consumer eHealth tools should be widely available for testing, self-assessment, and care decisions outside of a medical setting.

Shared Management

- Roles and responsibilities for individuals (and their caregivers) for their interactions with the health care system should reflect their ability and needs, and mutual expectations should be established with health care providers.
- Person-centered data should be made available for both self-management and clinical care.
- The role of the caregiver as a partner in shared decision-making should be valued and enabled with relevant tools.
- Policies, programs, and tools for providers should be developed that build appreciation for and competence in health IT-enabled shared-management of health and health care.

Cross-Cutting

- Tools and information should come to people where and how they already live, work, and play. “Health comes to you.”
- Tools for individuals and caregivers should be easy to use and enable sharing of data as desired by the person.
- Trusted, curated health content should be made available to people.
- Increased social support regarding health and health care should be provided for individuals acting alone and interacting in online and physical communities.
- Policies, programs, and tools for individuals should be developed that build appreciation for and competence in health IT-enabled self- and shared management of health and health care.

Person-centered health and health care represents a leap in how individuals and providers can and likely will relate to each other and how information will be shared, enabled by health information technology. Because it requires changes for consumers, patients, caregivers, individual providers, health care organizations, and the health care system itself, this evolution will require a wide range of efforts by all stakeholders over an extended period of time. The vision offers the goals of increased prevention and self-management, smooth interactions and seamless information flow as the individual moves between wellness activities and the health care system, and more partnering within the health care system. This framework has outlined three categories of building blocks and some that are cross-cutting, twelve building blocks in all, to serve as the foundation for policies that will move toward achieving the vision. As this policy framework highlights, these changes offer significant promise for providers, consumers, caregivers, technology innovators, and society at large.

I. Introduction

A. Purpose of Framework

An environment that integrates health information, technology resources, and care will be pivotal to ensuring that individuals in the United States can manage their own health and health care, both in health care settings and in their personal lives. The development of such an environment by the end of the decade requires a framework to guide development of supportive policy and programs. This paper establishes a vision for how health IT can support self-management and shared management of health and health care and articulates a policy framework with building blocks that can support this vision.

While the concept of “patient-centered health care” has been emerging over the past decade, there is vast distance between that concept and a truly “person-centric” vision that embraces the value of the individual inside and outside the health care system for improving both health and health care. The current health care environment emphasizes episodic activities centralized in health care settings and does little to provide resources for people and their families where they live, work, and play. Yet it is in these settings where actions are taken or not taken by individuals that significantly determine the person’s health status and outcomes (Backonja, Kim, & Casper, 2012; Bodenheimer, Wagner & Grumbach, 2002; IOM, 2001). Within health care settings, the person is often a recipient of health care services rather than an active partner with the health care provider and care team. This dynamic limits the opportunities for people to manage their own health and to share in care management when interacting with their health care providers (Frosch et al., 2012). Changing the paradigm to a person-centered vision is vital to support improved health and health care outcomes. Existing and emerging technologies provide a path to make information and resources for health and health care management ubiquitous, integrated, and suitable to achieve the goals of promoting individual well-being and effective care.

The Office of the National Coordinator for Health Information Technology (ONC) initiated the development of this policy framework to articulate a vision, to identify how health IT can support this paradigm shift by the year 2020, and to facilitate effective health management by individuals, their caregivers, and their health care teams. ONC’s intent is to enhance the visibility of this topic, promote nationwide dialog, and catalyze change among stakeholders interested in the health of the U.S. population.

B. Background and Context

1. Tenets

The policy framework is based on several key tenets. First, a central tenet is that the focus is on the person, the person is at the center. When a person is involved with the health care system and becomes a patient, the focus is on the individual’s needs and interactions with the health care team, rather than on the needs and actions of providers and the larger health care system. People can decide how much or little to participate in self-care and in partnering with their care teams. An aim is to have a health care system

that engages patients by meeting their needs. Providing the information and tools that would help people to be proactive health and health care managers can facilitate their effective participation.

In this framework, the term “person” also refers to a person’s lay caregiver, if applicable. A caregiver is a family member, friend, or paid individual who manages or helps manage a person’s health condition(s), including navigating the health care system, negotiating with providers, and possibly performing the critical tasks of personal and household care. Caregivers may play a critical role in supporting and coordinating a person’s health care. When people cannot fully manage their own health and health care decisions, caregivers who step into that role must be included appropriately.

The policy framework makes several references to the person’s care team. Traditional notions of the care team have often included only professional health care workers and medical institutions, but this document defines the care team as including anyone the person wants to be involved. The care team may include family members, friends, and caregivers, along with traditional medical providers, alternative medicine providers, physical trainers, nutritionists, social workers, and others.

Health care reform may improve access to health care services. People could also benefit from improved access to general and personalized health information and health IT tools and services. Existing law generally gives people the legal right to see and to obtain a copy of their health information from their doctors, hospitals, pharmacies, nursing homes, and health insurance plans. As health care providers switch from paper to electronic health records, the ONC is working to ensure that consumers and patients have electronic access to information that is increasingly delivered via digital channels. In order to avoid a growing gap between people with adequate resources and those on the other side of the “digital divide,” people require access to hardware and software, as well as fast and reliable connectivity.

Access to electronic health information should be easy, timely, and secure but also should be in a form that can be incorporated into consumer health IT tools. How the information is presented also is worthy of attention. Health IT can be used to tailor and personalize the messages conveyed, even to the desired language and appropriate literacy level. The user interface with which the messages and information are displayed also can be formatted in such a way that will promote engagement with the information. User-centered research and design procedures can help ensure that consumers will be able to use health IT tools and applications effectively.

This policy framework assumes that people require trustworthy information to allow them to make informed decisions about their health care. Also, health care providers may be more likely to endorse and use health IT resources that are effective in helping individuals develop health-promoting knowledge, skills, and behaviors. Finally, health IT tools and services should work reliably so people will be confident about using them during times of need.

2. ONC Consumer eHealth Program

The ONC Consumer eHealth Program supports efforts to empower individuals to improve their health and health care through health IT. The collective aims of the eHealth program are best summarized by the objectives of access, action, and attitudes. The following are some examples of recent accomplishments:

- To increase access, ONC works with the Centers for Medicare and Medicaid Services (CMS) to implement incentives for the meaningful use of electronic health records (EHRs), including the ability of patients to electronically view, download, and transmit to a third party their health information. ONC has been encouraging adoption of “Blue Button” capabilities so that patients and caregivers can download health information with a single click.
- ONC encourages action by co-chairing the National eHealth Collaborative’s (NeHC) Consumer Consortium that consists of more than 150 stakeholders from government and industry who are working to drive innovation and establish best practices for consumer eHealth products. ONC also periodically issues innovation challenges to spur innovation related to consumer health information.
- ONC seeks to change attitudes by sharing information and using the wisdom of crowds. For example, ONC has sponsored a series of contests encouraging consumers to create videos telling their own stories about how Health IT improved their health and increased involvement in their own care.

3. Other Important Considerations

Empowering people to be active in self-management and shared management of their health care is a “wicked” problem. Wicked problems are those policy problems that have long-term, complex, and sometimes conflicting causes (Conklin, 2005). As a result, little agreement exists on the best way to tackle them. Because many stakeholders are involved, no single organization has the capacity to solve such problems acting alone. Confronting wicked problems requires multiple, diverse, synergistic approaches. Solutions may also require the disruption of existing systems, as well as sweeping changes in the behavior of individuals and groups.

Efforts to achieve the required cultural transformation would likely entail tradeoffs that cannot be fully anticipated. Increased personal empowerment and partnering would be expected to reflect greater sharing of power within the health care system. Ideally, people would benefit from new tools and enhanced care that better fit their needs. This change, however, would also mean increased responsibility for each person to be actively engaged and to make difficult decisions. Also, more of the costs of health care might be shifted to the consumer.

In order to foster shared responsibility, the nature of health care encounters and how care is paid for would be expected to change. The current health care system and its payment incentives are not well-aligned with the goal of putting the person at the center. The Affordable Care Act (ACA) will bring about helpful improvements in care coordination and wider application of the medical home model. Indeed, the success of accountable care organizations will depend in part on fuller partnership with their patients. However, additional payment reform and structural change would enable patients and providers to share more equitably in the benefits.

Another potential barrier is that many patients and their care teams are not familiar with shared management. Moreover, consumers and providers bring different views, expectations, and skills to the table. Promotion of shared management may require efforts to overcome the asymmetry of information between patients and providers. Patients could share more information with their providers via health IT tools (patient-generated health data), while providers could entrust their patients with more information and decision-making about their health conditions.

Integrating health IT may be hampered if people or providers distrust information delivered via health IT tools and services. People may have doubts about the validity and relevance of online health information, or they may not be aware of quality online health information sources. Providers may have concerns about information that their patients are viewing online, including opinions and advice gleaned from social media, and concerns about whether discussing these with patients would be time consuming and nonproductive.

People also may have concerns about sharing personal information via health IT because of potential threats to privacy and security. These concerns persist in the context of health IT, amid increasing awareness of the sensitivity of personal health information and the risk that it could be misused.

This policy framework was conceived in this context of rapid technological and cultural change. Examples from history suggest that people can be trusted to manage their own health through the use of new technology, just as they have been able to manage other aspects of their lives that were previously managed by professionals: finances (e.g., online banking, electronic tax preparation and filing), travel (e.g., driving cars, using online travel services), and education (e.g., online coursework and degrees). In these cases, technological advances have changed cultural expectations regarding what people can learn, know, and do.

The logical conclusion is that health IT can and should be used to support ongoing change, even trigger it. Health IT can address the information asymmetry between individuals and providers by helping people develop improved life skills and a better understanding of their health management competencies, while also offering to providers more complete information about patients. It can also help connect communities, and build virtual communities that support the individual's effort to achieve self-management. As with other advances in technology, health IT has the potential to disrupt existing systems and alter behavior patterns, moving the country toward the vision of health-promoting cultural change.

C. Methodology

To create a model and an initial policy framework for describing the environment that would support the achievement of the aforementioned goals, a literature review was conducted, an advisory group of thought leaders was convened, and an interactive workshop of key stakeholders was conducted. This effort to develop a policy framework supports ONC's goal of empowering individuals with health IT to improve their health and strengthen the health care system, as established in the Federal Health IT Strategic Plan: 2011-2015.

The literature review was conducted in the fall of 2012 to report on trends and future projections about the integration of health IT into self-management and shared management of health and health care. The literature review also formed the basis for understanding the current state of technology development, and the opportunities and challenges involved in moving toward the use of health IT to enable health care consumers to better manage their health care, make health-related decisions, and practice healthy behaviors. The review included recent scientific and gray literature that captured the latest implications of the technology environment and developments related to personal health management.

The advisory group consisted of thought leaders and professionals active in the field of patient engagement, patient advocacy, participatory medicine, and consumer health IT to assist in providing innovative thinking and inspiration to this effort. The advisory group members (see Appendix A) brought diverse expertise to the project, offering cross-cutting perspectives, and innovative ideas and strategies. Advisory group members played key roles in formulating a vision and defining the critical actions for the policy framework.

The interactive workshop was held in Rockville, Maryland on November 13-14, 2012, attended by 29 people with richly diverse backgrounds, including medicine, public health, policy, technology, business, and academia. The three main objectives were to: a) craft a vision for and articulate the principles for "putting the person at the center" of the management of their health and health care; b) begin to define the components for a model and their relationships to support the vision; and c) offer insights on strategic-level policy and technology actions to achieve the vision.

A unique feature of this set of activities was the level of collaboration and open dialog between the federal government, the Westat team, and the various experts and stakeholders. This approach serves as a model for the type of open discourse that ONC would like to continue to pursue around the vision of putting the person at the center of his or her health and health care.

II. Foundational Components

A. Vision

Expansion of consumer technology goods and services has grown exponentially, enabling people to take action wherever they are and whatever their situation in ways that could not have been foreseen even a few years ago. This same technology can be applied to health, helping people break away from the medical offices and institutions where they receive health care. With health IT in their hands and under their control, people can be proactive consumers and agents of their lives, health, and health care.

The vision for the policy framework seeks to empower each individual as the manager of their health and partner in their care. It assumes that people's health and quality of life will improve if they have the assistance of information and technology for self-care and shared decision-making with their care team. This vision for the future is one where:

The power of each individual is unleashed to be active in managing their health and partnering in their health care, enabled by information and technology.

This vision is meant to inspire key stakeholders and the general public. The goal of the policy framework is to identify drivers that support health IT-enabled self-care and shared health management and encourage innovation, policy, and programs that support this vision. As a result, the framework is intended to help promote informed decision-making by individuals and foster productive partnerships between individuals and their care teams.

Intended audiences include the government sector; health care and technology industries; and trade, professional, and consumer/patient advocacy associations. These entities can use the vision and the policy framework to develop action plans and initiatives to address the identified needs. These groups can also join this effort by promoting the ideas contained in the framework among their constituents and the population as a whole.

This vision and the related building blocks for achieving it are an initial step in articulating common convictions and principles. Once the vision has been embraced, it can serve as a foundation for next steps for fully integrating health IT in support of self-care and shared management initiatives.

B. Core Values

The vision is underpinned by several core values centered on the person. Although patient-centered care is becoming a central tenet of modern American health care, this notion is expanded here to encompass “person-centered” efforts to reach individuals whomever and wherever they are, and whatever their situation at the time, not just as patients in traditional health care settings. People generally are not in contact with the health care system when they are managing their day-to-day health and health care needs. Indeed, the more self-activated people are, the more likely it is that they will be proactive in practicing wellness, prevention, and disease management behaviors (Mosen et al., 2007).

These are the core values that support the vision:

- **Individual self-determination and the public good are both optimized.**

Health care can be person-centered only if the individual determines the course of action. However, medical ethicists have long established that the right to self-determination has limits; it should be balanced with the cost and benefit to the society. Therefore, it would be ideal to optimize both individual self-determination and the public good in any given situation.

- **People can decide whether and how much to participate in managing their health and health care.**

Although individual self-determination is balanced with the public good, an individual’s right to determine the degree of participation in managing his or her health and health care should be recognized. It is undesirable to force people to manage their own health and health care against their will. Some individuals will have better outcomes when they choose to allow others to direct their care.

- **People can access wellness and health care services enabled by technology that reflects their individual needs, values, and choices.**

To achieve person-centered health and health care and to support individual self-determination, individuals should be able to identify and access personally relevant health and health care services. Technologies should be developed and made available to provide and support such access.

- **Health care is a partnership between the patient, their caregivers, the care team, and supporting services.**

Person-centered health care is a team effort with the patient in the center of the team, surrounded by lay caregivers, a range of health care providers, and supporting services. Members of the team should explicitly recognize that they are in a partnership with the patient and other team members, working together collaboratively to achieve the best health outcome for the patient.

- **Information is shared, as appropriate, between the individual and all their care partners to enable informed, participatory decision-making as desired by the individual.**

To achieve true partnership between the individual and the care team, information should be shared appropriately among all of the care partners to support informed decision-making. Informed, participatory decision-making can only be achieved when each care partner has the information they need for their decision-making process, and is aware of the factors considered by the individual and other care partners. The individual should also be provided information on the potential impact of sharing or not sharing information, so they can make informed decisions about when to share information and when to keep it private.

- **Everyone who holds information about an individual exercises responsible information stewardship.**

Proper and responsible information stewardship is a critical component of trust between individuals and care partners. Care partners should exercise responsible information stewardship when accepting and using person-centered data to properly safeguard the information and protect the individual's privacy and safety, in order to be entrusted with complete information from the individual. Similarly, the individual should exercise responsible information stewardship by sharing relevant information with care partners to support informed decision-making, enhance care partners' decision-making, and engender their trust.

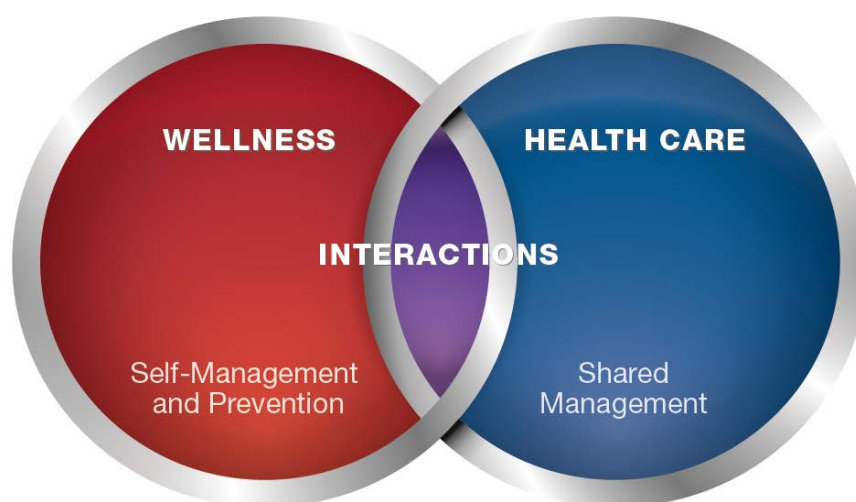
- **Easily used and useful, trusted tools are available to support the person's decision-making.**

Health and health care decisions are complex, requiring the consideration of many dimensions such as the individual's needs, values, and choices as well as the medical evidence. Many factors that influence the individual's decision-making are often outside the individual's control or even the individual's direct knowledge, such as available community resources, insurance coverage, provider performance history, or comparative effectiveness of therapeutic options. Therefore, effective tools can help individuals exercise self-determination in their decision-making. These tools should be both useful and easily used, in order to encourage individual adoption and enhance health care decision-making.

C. Goals

Across a life span, each person is likely to experience a continuum of health and disease states, including some that present opportunities for self-care and others that present opportunities for shared management with a health care provider, caregiver, or care team. The vision for this policy framework will only occur if there is cultural change regarding the individual's role in how health and health care is managed, delivered, and received at any point on a continuum of wellness and disease states, supported by health IT.

Figure 1. Continuum of Spheres of Wellness and Health Care



Three overarching goals result from the vision:

- **Self-Management and Prevention:** Empower individuals to be healthier and to manage any health conditions. Motivate policymakers, employers, and other stakeholders to establish guidelines and environments that promote and support healthy behavior and self-management of conditions.
- **Interactions:** Enable smooth, easy interactions and seamless transitions as the individual moves between wellness and self-management activities and participating in the health care system, often balancing both. Soften or erase the boundaries between what occurs inside and outside of the health care system by promoting increased information flow and empowering people to perform on their own some of the activities that now occur only in formal health care settings. Allow “light touches” with the health care system when needed.
- **Shared Management:** Support more partnering of the person with his or her care team within the health care system through shared decision-making. Support and integrate caregivers appropriately into the care team. Encourage providers to value patients and their data, viewing them more holistically and longitudinally.

D. Areas of Development Needed to Achieve the Vision

The policy framework is based upon several areas that could contribute to realizing each goal. These reflect the national dialog that has been emerging in recent years and that has continued with the activities of the advisory group and workshop supporting this effort.

Self-Management and Prevention. People could benefit from and become empowered by opportunities and tools to increase their level of self-management in their health care in ways that are consistent with their preferences. The growing use of mobile and sensing devices and applications has changed the expectations of the average American consumer regarding the information that they can have available at their fingertips. The emerging “quantified self” movement views health IT as a central tool for basing health decisions on personal metrics (Singer, 2011). Enhanced efforts in this area could help to promote the benefits of prevention, provide support for healthy choices and behavior, and foster development of self-management skills. Further research could provide the evidence base to determine how health IT can support and strengthen self-management and how to develop effective policies and programs.

Interactions. Individuals could benefit from better communication with the health care system and their care team so that information could flow in both directions more easily and efficiently. Technology could be used to reduce the friction points (barriers) that prevent or discourage a person from seeking, finding, or getting needed services. People would be able to perform some health management tasks independently or with minor support, including support from self-assessment tools and decision aids.

Shared Management. Further changes in the health care system may foster partnering between the person and his or her care team. Patients and could benefit from access to trustworthy health IT tools and services that support partnering and shared decision-making. Providers might also be more able and willing to support partnering and shared decision-making if there were a shift toward these areas in medical training and professional society support. Health information generated by individuals could be used to enhance management of their health care and to inform their care team, and health information generated by the health care system could be used to enhance a person’s self-management. Personal information and attributes (e.g., preferences, values, and social environment) could be integrated more effectively into the care setting so that they are more easily recorded, clearly and accurately captured, and used at appropriate points of care.

Cross Cutting Areas. Overall, a shift is required in public perception about the role of the individual in managing health and health care. People would benefit from knowing their options and how the use of health IT for self-management could benefit wellness, prevention, and disease treatment for themselves and their families. They might also be more interested in securing and sharing their personal health information if its value to their care and public health was more obvious and compelling. Conveying health advice and information in a clear and meaningful manner that is tailored to their needs would further help individuals make informed health decisions (e.g., medical costs, treatment choices).

Health IT could be implemented more broadly and used to support health and health care management that is pervasive and ubiquitous in the context of people's lives rather than centralized and episodic within health care system encounters. In this context, health IT tools could provide people the ability to find health information and services, manage their health, and share information in the ways they need and want. Health IT tools would better fulfill these high expectations if they were designed with usability as a priority, particularly with vulnerable and underserved populations that may have greater challenges in adopting and using health IT. Health IT tools and resources that are interoperable and work together would optimize the quality and utility of health data used for self- and shared management of health and health care.

III. Building the Future: High-Impact Approaches

In order to realize the vision, several changes must take place in the culture and in behavior at the individual, professional, and institutional levels to address the identified areas of development. These changes may be disruptive because they represent a new way of thinking and operating for each person as well as for the health care, government, and technology sectors. However, by changing how self-management and shared management of health and health care can be integrated seamlessly into our lives, supported by health IT, a profound difference can be made in health status and outcomes.

A. Building Block Categories

The building blocks reflect key policy ideas that address the changes that are required to support people as they act within and move between the spheres of wellness and health care. Although not comprehensive, the building blocks are congruent with the values and organized by the goals. This set of approaches is not meant to be comprehensive but rather to illustrate a way forward to achieve the vision. These building blocks were selected because they are game-changing, are broad-reaching in scope, support behavior change, and make use of health IT and information-sharing.

In support of the goals of the vision, these building blocks are categorized as: 1) self-management and prevention; 2) interactions that occur while navigating between the spheres; 3) shared management while participating in the health care system; and 4) cross-cutting. Some building blocks that are assigned to one category support other categories.

B. Building Blocks

1. Self-Management and Prevention

Building Block 1.a:

Efforts to motivate individual behavior change should go beyond traditional approaches (e.g., education about nutrition and exercise) to include self-learning and critical-thinking skills.

Engage people in their health and health care in a way that resonates with them and has a broad impact on their quality of life. For an individual, health is one part of one's life and not generally the focus, except in times of illness. Health behavior is difficult to change for many reasons, most of which are not related to a lack of knowledge (Norcross, Krebs, & Prochaska, 2011). Achieving a change in one's behavior is more likely if the change is personally meaningful and consistent with one's values, beliefs, and preferences.

People could be provided training opportunities and coaching on self-observation, self-analysis, and self-experimentation, so that they can gain insights about the types of actions that positively or negatively impact their health. Even the best available health facts known today are fluid and subject to change. Health and medical sciences is still and "art" and do not indisputably have the right answer for every individual in every circumstance. Individuals could be encouraged to discover what is best for themselves with support from the health care system.

Policies that promote self-management, health education, and disease prevention would benefit from including motivational agents tailored to the individual. For example, making personal health coaches available to those with chronic conditions could help encourage and maintain an individual's engagement in self-care. Another factor that might be considered for motivating engagement with self-care is to ensure accessible, user-centric outreach for self-management. Concepts such as leveraging mobile technology (e.g., texting, alerts) for personal health reminders and personal health tracking may also support maintenance of motivation for self-management, particularly for a more technology-oriented population. Accessible personal risk profiles based on generalized health risk assessment (HRAs), or individualized risk profiles based on genetic information, could also motivate individual behavior change.

Although many health IT products and services are available, they are often not being adopted and implemented as hoped (Agrawal et al., 2011), suggesting that they are not addressing the wishes and motivations of individual users. As health IT tools are created for self-management and prevention, tools that address the user's personal motivations for health management (such as managing and interpreting genetics and genomics information) and fit into the user's daily activities may be more likely to be adopted into the user's life.

<p>Building Block 1.b:</p> <p>Consumer-facing lifelong prevention and care guidelines should be developed and incorporated in useful tools.</p>	<p>Tailor prevention and care guidelines so that they jointly address lifelong health management and consumers' needs and resources. Health management and prevention guidelines are largely aimed at health care professionals and applied to individuals with specific health conditions. A comprehensive guideline collection that addresses key stages of health, illness, and health management could help individuals to integrate self-care behaviors more easily into their everyday lives and gain more control in managing their own health.</p> <p>Several existing standards and practice guidelines for prevention and care provide varying levels of information that is potentially contradictory. The feasibility and benefits of establishing a consumer-facing repository of trusted and validated prevention and self-care practices and guidelines could be considered, including genetic information for informed decision-making related to preventive self-care based on personalized risks (e.g., prophylactic procedures). A resource for individuals that provides lifelong and updated self-care guidelines would enable individuals to selectively identify those prevention and health services for self-management. The sponsorship of such a resource would have to be carefully considered, especially if federally supported, to develop appropriate consensus and governance policies.</p> <p>Developing consumer-facing prevention and care guidelines requires consideration of many factors and individual preferences, and this adds significant complexity as compared with clinician-facing guidelines and other decision-support tools. Personalized decision support tools, a form of health IT-enabled personalized medicine tool, could integrate personal health information, applicable guidelines from multiple sources, and personal preferences to provide individualized information and advice for each specific context.</p>
<p>Building Block 1.c:</p> <p>Public and private sector policy efforts should elevate the focus on prevention and on self-management outside the health care system.</p>	<p>Focus is placed on the overall health of the person rather than a person's experience as a patient interacting with the health care system. Traditionally, health care has been reactive, focusing on the identification and treatment of disease after it has developed rather than on prevention. Keeping the focus on the person allows public and private sector policy to seek ways to help people thrive and to mitigate health risks, thus reducing the demand for clinical care. This approach could extend a person's years of healthy life and could expand people's choices because health concerns would be identified and managed earlier.</p> <p>Health care policy that is holistic, focusing on the individual as a person, rather than as an individual is sick, can support this building block. Policies should be designed to support an integrative approach to health care, incorporating the community, social welfare, and health</p>

care system. Outreach programs can ensure that individuals are aware of all health and social services available outside the health care system that can support health maintenance. Policies should be designed to support a community or regionally-based integrated approach to delivery of health and social services (e.g., Meals on Wheels). Wellness programs sponsored by insurers, worksites, and community-based organizations should be designed to empower and encourage access to resources outside the health care system.

Health IT tools could be used both to support patient-provider interaction outside of a traditional encounter, and to support wellness and self-management outside the health care system. Some suggest that ubiquitous, or pervasive, computing is a way for prevention, self-management, and personalized health care to become seamlessly integrated into people's lives, although it is not now widely available. These and other tools could be designed with the needs of end users in mind if they are to be adopted and used like other successful IT products and services.

Building Block 1.d:

Self-management and prevention activities of the individual should be supported.

Providing rewards could help encourage positive actions and make the benefits of such actions clear and appealing to individuals. People often face barriers and costs when they seek to practice healthy lifestyles and manage their health. Incentives for these behaviors for the individual are weak or non-existent, while unhealthy choices are often attractive and provide instant gratification. Self-management requires learning new information about health and about personally relevant ways to optimize it. This strategy may be particularly important for people who have little experience with or low confidence in their ability to follow a healthy lifestyle or make decisions about health management for which they have little or no experience.

Policy options that support this building block could encompass lower co-payments, lower insurance premiums, or tax credits for individuals that could motivate self-management and healthy behavior. Financial support could encourage and enable individuals to take advantage of tools and services for self-management. Programs and health promotion activities or classes in self-management could be offered in the workplace or the community. Realignment of reimbursement would help to motivate and support health care providers to promote healthy lifestyles among individuals in their care

Personally controlled health IT tools could be developed that use health data to determine goal attainment and provide rewards that are valuable to individuals who succeed. Population level health IT tools could also be used to track self-management efforts so that actuarial models can be developed to determine impact on and benefit to

population health and the health care system. These models could be used to allocate financial rewards for self-management efforts to individuals and care teams. However, these models will also need to account for individual differences such as genetic predispositions to provide optimal and equitable expectations and attribution of benefits.

Building Block 1.e:

Research should be conducted on self-management and caregiving to guide efforts to support and strengthen these activities.

Establish a baseline of understanding about the scope, nature, variations, and gaps in self-management and caregiving activities. While past and ongoing research on patients' involvement with the health care system and about personal health behaviors is extensive, relatively little is known about self-management and caregiving activities. Research could improve understanding of: what individuals and caregivers are doing to manage health and wellbeing; how self-management activities are balanced with other priorities in life; what challenges they face in executing self-management and caregiving activities; who is involved in these activities; variations across populations; the financial costs of these activities; and the current and potential contributions of health IT tools to these efforts. The research should also identify opportunities for strengthening and expanding these activities, such offering and implementing improved health IT resources, training, or support programs.

A solid research base is essential for refining all the other building blocks described in this paper and developing policies and programs to implement them. Ongoing research will be critical for refining policies and programs over time. This research could also reveal policy options for incentivizing or compensating these efforts – particularly for the underserved – as part of efforts to realign rewards across the health and care spectrum.

In addition to the basic research on self-management and caregiving activities, resources also need to be invested in applied research, specifically how health IT can help support and strengthen these activities. This research will also help guide technology innovators to develop tools and other resources for unmet need, such as self-monitoring, mobile health, and social networking. In addition, tools to increase competency in self-management and caregiving would be invaluable, as would tools to help organize and share with others, as appropriate, the diverse information related to self-care and caregiving.

2. Interactions

Building Block 2.a:

Individuals should be enabled to make light touches with health care system as needed, rather than interacting only during formal encounters for episodic care.

Establish a culture where individuals interact regularly with the health care system outside of formal visits associated with episodic care. This could support people in having brief interactions (i.e., “light touches”) with the care team. A person who wants to access health or medical advice usually must make an appointment with a health care provider and find the time to go to it. For some questions or concerns, a short contact or message exchange may be adequate to obtain the information needed. For example, a person may want to confirm the instructions for taking a medication or check on a test result. Shorter, remote, or asynchronous interactions can be an effective use of people’s time, and can promote efficient use of the health care system and staff resources. People may be more likely to seek help if the process becomes less burdensome and inconvenient.

Current systems for short interactions with providers typically rely on nurse advice lines. Patient gateways are gaining traction, whereby an individual can submit a secure message for “light touch points,” but these are in limited use. Medication therapy management (MTM) services, which allow for brief contact between the individual and a pharmacist or other credentialed professional who can assist in medication reconciliation and other prescription questions, are becoming more common among health plans and CMS through Part D programs, but are not widespread. Several policy efforts could support this building block, including: assessing evidence about the cost effectiveness of these types of short interactions; pilot testing demonstrations for such services (as in the case of secure messaging); considering changes in the definition of eligible providers for reimbursement; and assessing or increasing the level of reimbursement for these types of services for brief contact.

Pervasive and secure communication systems and tools could to be developed to support seamless, light-weight communications between individuals and the health care system. These communication systems would be more useful if they could fully integrate with both provider-facing and consumer-facing health IT systems such electronic health records (EHRs) and personal health records (PHRs). They would also intelligently support distributed health care teams, the flow of information among team members, documentation of responses, tracking of follow-up needs, and smart filtering for individual patients or groups of patients.

Building Block 2.b:**Consumer eHealth tools should be widely available for testing, self-assessment, and care decisions outside of a medical setting.**

Provide consumer accessible tools that link people to information that can support their health decision-making without having to engage the health care system. For example, people may want to privately seek testing services for certain health conditions (e.g., HIV) or for routine risk factors they are regularly monitoring (e.g., blood pressure, cholesterol). Self-assessment tools could also enable people to identify concerns, risk factors, or symptoms for which they could then seek further help as needed. Having convenient access to these tools could remove significant barriers to self-care and help-seeking. People could determine their health care options prospectively and more efficiently. Requirements to obtain permission from or to include oversight by healthcare professionals would be imposed only when necessary.

Current stringent requirements for over-the-counter (OTC) home test kits in the United States have been shown to introduce delays and discourage inventors and manufacturers from offering their devices for OTC sale (Von Eschenbach & Hall, 2012; Zablou, 1996). Research that identifies those devices and tools that are cost effective for individual use could be promoted. As mentioned above, efforts to review, approve, and certify consumer-facing health IT products and services have not yet been established. Comparative effectiveness research could contribute to understanding of the value of these types of tools. In addition, while some OTC home tests are available, consideration of enabling individuals' access to hospital-based or freestanding laboratories for certain tests (e.g., strep tests, genetic testing, HIV tests) without a provider prescription would support this building block and empower individuals for self-care and management.

The health IT industry should be encouraged to establish a common platform (e.g., user interface and communication protocols) for use in consumer-facing testing and self-assessment tools. This would minimize the cognitive burden for consumers and reduce resultant stress and potential errors. A common platform would also ease comparative effectiveness research efforts and regulatory burden.

3. Shared Management

Building Block 3.a:

Roles and responsibilities for individuals (and their caregivers) for their interactions with the health care system should reflect their desires, abilities, and needs, and mutual expectations should be established with health care providers.

People and their caregivers may require a better understanding of expectations and their roles in creating positive interactions with health care providers. They would then be prepared to provide accurate information, such as current medications and symptoms, to the care team to help determine care options. They would also be aware of what they can ask for and expect from their providers, making them more confident about advocating on behalf of themselves or the person for whom they are caring.

Guidelines can be developed that outline suggested roles and responsibilities for the person and their providers within the health care system. The guidelines should highlight the benefits of following them to support education and represent a starting point for a dialog between the person and the provider about each party's role. Similar types of guidelines may be helpful for people engaging in self-management or receiving other health-related services in the community.

Common security and data standards should be established for defining, assigning, managing, and documenting roles and responsibilities for individuals and their caregivers within health IT systems. Applicable algorithms and workflows within health IT systems may be rewritten to leverage roles and responsibilities assignments rather than hardwired to specific individuals (e.g., patient, mother, primary care physician).

Building Block 3.b:

Person-centered data should be available for both self-management and clinical care.

Use patient-centered data to help people and their care teams work together better. Person-centered data includes data created or gathered in a clinical setting, by the provider or a clinical tool, and created or gathered outside a clinical encounter by the person or a personal tool. Person-centered data include information not traditionally considered by providers, such as values, preferences, and social and economic context factors—all of which can have an important impact on health status and outcomes. Data from both sources are valuable in both settings. Person-centered data includes “patient-generated health data,” referring specifically to data generated by the person outside the clinical setting and then shared with the care team.

Integrating patient-generated health data into health care activities enables care teams to gain a better understanding of the person's health status. It facilitates monitoring of health conditions between visits. For patients with serious chronic diseases, these data can be used by providers to identify adverse developments requiring action. The integration of patient-generated health data with clinical data can also help clinicians tailor preventive care more closely to the

individual's health status and risks. The availability of genetic information for use by providers and by the individual will also empower individuals' self-care and management efforts.

For people and their caregivers who are self-managing conditions in a non-acute stage, perhaps lifelong conditions with infrequent clinical encounters, having the patient's clinical data together with their person-centered data creates a more robust and comprehensive knowledge base from which to work. Clinically-generated data and data generated by innovative personal tools can also strengthen personal wellness and prevention activities. Existing wellness programs generally rely on self-administered health risk assessments that reflect personal health data and behaviors to identify areas that can be targeted for health improvement. Adding data from the patient's clinical record can refine the program to more closely fit the individual's overall health profile. Ideally, most of these data elements can be derived directly from EHRs and laboratories or perhaps from a comprehensive PHR. Additionally, data from personal tools such as tracking devices enrich personal health maintenance efforts.

This building block requires new or improved policies, practices, and technologies to enable the optimum bidirectional sharing of both types of data. Policies that set expectations about the use of the data by providers, individuals, and caregivers may be essential to reduce provider concerns about information overload and liability. Standards for health data content, structure and source identification could be identified and integrated into health IT systems and personal health tools, including explicit labels and tracking strategies for data originating outside a clinical setting that is to be integrated into the health care record.

Building Block 3.c:

The role of the caregiver as a partner in shared decision-making should be valued and enabled with relevant tools.

Caregivers play an important role in supporting and ensuring that people get the care they need. Much of the care that people receive is in the home rather than health care settings, so caregivers are the day-to-day support system that people turn to most to meet their physical health and emotional needs. Therefore, elevating the concerns of caregivers in their support role is crucial. Caregivers who are acting for another person would benefit from help with planning and coordinating health care especially during transitions in care settings to ensure safety and prevent medical errors (Levine, 2008). Caregivers are an invaluable resource for providers in translating medical care recommendations and in providing information about the patient's health status.

More individuals will require caregivers as the population ages. A conservative estimate of the current annual cost of unpaid family caregiving is \$492 billion (Keckley, Coughlin, & Korenda, 2012). The

costs of shifting this burden to the health care system, in the absence of these informal unpaid caregivers, would be significant. It is critical to support the informal care system. Informal caregivers would benefit from information, resources, and services that would enable them to become effective members of the care team. Insurance coverage for caregiving technologies (e.g., electronic organizers, movement monitoring systems, caregiving coordinating systems) could provide incentives for informal caregivers.

Applicable decision-support algorithms and workflows within health IT systems could be rewritten to leverage roles and responsibilities assignments for caregivers. Particular attention should be focused on key care decisions, patient placements, and health management outside of institutional settings to avoid assuming that the patient is self-managing, and to ensure that the caregiver is integrated as a partner in decision-making.

Building Block 3.d:

Policies, programs, and tools for providers should be developed that build appreciation for and competence in health IT-enabled shared-management of health and health care.

Patient-centered care, patient-centered medical homes, and other health care reforms have established the principle of patient involvement in their care. Establishing a true patient centric partnership model will require further, and often significant, changes in attitudes and practices by individual providers and provider organizations. Although some innovators have begun to implement shared decision-making and other patient-provider partnership activities, a broader cultural shift is necessary across the health care system. In a partnership model, patients and their caregivers are assumed to be part of the care team. Their self-generated information, self- and shared-management efforts, knowledge, motivations, values, and decisions would all be appreciated as vital contributions to the partnership and care planning.

Diverse policy initiatives will be needed over an extended period of time to achieve this cultural change. Examples include requirements for patient and caregiver input into care plans; creating efficient processes to incorporate patient-generated data into care decisions, following agreed upon mutual expectations; routinely soliciting patient-reported outcomes of care; and including patient satisfaction with their role in the care team as part of quality measures.

Programs for provider training and credentialing should include the use of health IT for shared decision-making. Medical school curricula could be strengthened to incorporate training on the use of health IT and the role of patient-generated data. Standards and policies for indicating which data are patient- or caregiver-generated are important features for providers to ascertain. Requiring patients to provide a minimum set of self-generated health information might be considered.

4. Cross-Cutting Building Blocks

Building Block 4.a:

Tools and information should come to people where and how they already live, work and play. “Health comes to you.”

People would benefit from just-in-time assistance and tools for health similar to those available in other spheres of their lives, such as online banking and streaming media for entertainment. They want the same convenience and personalized service when practicing self-care and managing their health care. A requirement of this building block is providing the means for integrating data generated about the person by the health care system into his or her health management activities in everyday life. Integrating health management into daily life may help people to overcome many of the barriers that currently exist with episodic care (e.g., scheduling appointments in a timely way).

Continued efforts to develop secure messaging and data transfer (e.g., Blue Button) could support this building block. These efforts enable individuals to download and access their health information in a safe, secure, easy-to-use, and reliable manner. Blue Button initiatives are currently underway at the Department of Veterans Affairs and CMS; several private insurers are deploying Blue Button or similar initiatives. These types of tools and information are in their infancy, requiring research to identify best practices for their use by individuals and providers, as well as optimal user-centered design features. As mobile health technologies and applications continue to grow and mature, research could determine their efficacy and cost effectiveness in improving health outcomes and reducing cost. In addition, policies around designation of quality consumer-facing products and services could support individuals in their decisions to adopt and use them.

Mobile devices are clearly evolving as the most common conduit to reach people where they live, work, and play. History and trends with the mobile phone application markets clearly demonstrate the strong impact of a common user interface and programmatic framework in encouraging software and product development. To promote the increased availability of tools and information, a common programmatic, user interface, communication, and financial framework could lower the threshold of entry and encourage independent development.

Building Block 4.b:

Tools for individuals and caregivers should be easy to use and enable sharing of data as desired by the person.

Health IT would be better able to deliver on its promise if people can understand and use it. Low health literacy is common and leads to inappropriate use of health services, more hospitalizations, and poor health status (National Academies Press, 2004). Even well-educated people have difficulty with complex health and medical information when they are ill. People also have varying degrees of technology skills, so the health IT applications that are developed would be more useful if they are user-friendly. These tools would also be more valued if people could use them to inform caregivers or the care team about their health and health care. Individuals could benefit from tools that

helped them to share their health-related data as they wish with caregivers and providers more easily, and providers might have greater confidence in data gathered via such tools.

Tools that can be used by individuals to develop personalized risk profiles based on both general health risk assessments and individual available genetic data will support this building block. However this information, especially information about genetic risks, must be easy to understand and interpretable. Thus, the low health literacy issues described above are critical factors for consideration as individuals gain access to their health information. Increased understanding by the individual of their own health care data will empower individuals to define their preferences for the type of information to be shared with their providers and caregivers.

Continued efforts to offer guidance on best practices for providing appropriate health information could support this building block. Tools and services could be developed to make self-management and family caregiving easier, less time consuming, and less stressful. In addition to “decision-support,” people could benefit from “action-support.” Such action-support tools and services would encompass the full range of people’s self-management and family caregiving activities, not only those that are prescribed by health care professionals. As more tools are developed, trusted bodies (whether government, non-profit or for-profit) could evaluate and recommend useful tools. Evaluation would include, but not be limited to, medical effectiveness, financial costs, time burden, and ease-of-use as equally important criteria.

Building Block 4.c:

Trusted, curated health content should be made available to people.

Individuals could benefit from obtaining high-quality, relevant health content. Health content should be provided in such a way that individuals are not overwhelmed or misled and can have confidence in and take action upon the information that is relevant to their needs and preferences. Curated content helps people avoid the typical information glut because it is based on a structured process for screening, selecting, and organizing pertinent material. The validity of health content should be transparent, ideally with documentation of sources and any areas of debate among experts, so people can judge the value of the information.

Many tools and online resources offer individuals health care content for self-diagnoses, treatment, and self-care. In addition, several federal efforts focus on providing guidelines and research on optimal approaches to ensure that content is aligned with health literacy. Despite the abundance of such health information resources, variation exists regarding their validity and health literacy as well as providing evidence-based research to information seeking individuals.

Continued efforts to offer guidance on best practices for providing appropriate health information could support this building block, especially in providing information about genetic risks so that such information is easily understood and individuals can use the information to assess their likelihood of developing different health conditions. Other efforts that require review and certification of the validity of health content may be beyond the purview of federal efforts. Consumer groups (e.g., Consumer Reports, AARP) and professional organizations (e.g., the American Medical Association) could offer qualified ratings or endorsements of credible health information.

Many public and private efforts to create trustworthy collections of health content have met with limited success. However, there have been significant advances in social media and collaborative environments in recent years. Additional research could establish how approaches for establishing electronic content collections of virtual community resources could be leveraged to establish trusted, curated collection of health information.

Building Block 4.d:

Increased social support regarding health and health care should be provided for individuals acting alone and interacting in online and physical communities.

Managing one's health and navigating the health care system often requires social support: informational, instrumental, and emotional. Such support helps people feel normal and accepted, find solutions to real-world concerns, and overcome fears and anxiety about their health status. People can seek social support from their care team, but they are more likely to seek it from trusted friends, family members, and communities. Technology has provided even more options for social support through social media, email communication, and mobile devices.

The boundary between work and home has become less distinct, due in part to the increase in communication technology increased productivity demands, given the fiscal environment. Employers could be encouraged to develop policies that provide employees the flexibility and autonomy to support their self-management and caregiving responsibilities. The random nature and frequency of the demands of self-management and caregiving require innovative approaches for the individual to management their time and health. In addition, employers could build healthy environments for their workers, to include smoke-free campuses, provide on-site nutritious food options, and offer healthy take-home meals (for a fee) that might benefit over-worked working families.

Individuals with limited social support systems can be, and often are, identified in order to arrange for social services when needed. In addition, online communities offer additional support for individuals. As with building block 1.b, a centralized resource of guidelines for

self-care can also incorporate resources for social support. Care coordination models (e.g., medical homes) can also provide incentives to individuals to leverage online personalized resources and communities.

Efforts to create a trusted, curated health information (building block 4.c), bringing health to the individual (building block 2.c), and especially addressing what truly motivates people (building block 1.a) should explicitly recognize the increasing importance of online communities in providing social support. Therefore, social networks and online communities should be considered and integrated appropriately into efforts to promote self- and shared management of health and health care.

Building Block 4.e:

Policies, programs, and tools for individuals should be developed that build appreciation for and competence in health IT-enabled self- and shared management of health and health care.

Raising awareness, increasing knowledge, and building skills in self- and shared management could enable individuals to take advantage of increased engagement in their health and health care. People would benefit from knowing how health IT can be used to manage their health care, including options for partnering with the care team, acting on their own behalf, or serving as caregivers.

Building competence requires more than information, so programs and policies that help individuals develop skills, experience, and confidence in self- and shared-management of health and care should be developed; for example, guided practice opportunities such as coaching (Moore, 2012). Promoting changes in attitudes, beliefs, and social norms may be critical to help motivate positive health behavior in general and usage of health IT to support it (Hibbard & Greene, 2013). Research may also be needed to determine the knowledge, attitudes, and behaviors of people in different circumstances, which can inform the most effective ways of encouraging and supporting the use of health IT for self- and shared management among various audiences. As medical research continues to evolve, education could also be expanded for individuals and providers to include the potential of health IT in supporting personalized health care through the integration of genetic information.

To better support individuals in their decision-making, the expected benefits, implicit assumptions, possible risks, and potential costs of health IT tools could be clearly conveyed to them. Tools for shared management could be used to help set expectations about roles and responsibilities for how the individual and his or her care team interacts by increasing transparency. Personalized health care could be supported by health IT tools that include information about the relative predictive nature of genetic tests and the availability and efficacy of treatment options, thereby offering decision support.

IV. Conclusions

Person-centered health and health care represents a leap in how individuals and providers can and likely will relate to each other and how information is shared, enabled by health information technology. In this vision, people will have an expanded role in how they take care of their own health and interact with the health care system. People will be reached and provided support wherever they are geographically in their communities as well as where they are physically on the health continuum. They will be able to leverage the advances in technology to help them care for themselves and their families and partner effectively with their health care providers.

The HITECH Act and the Affordable Care Act have strengthened the impetus and support for integrating health information technology into the delivery of care and use by individuals. The ACA has also increased the need to engage individuals as partners in their health and care. The framework for health IT-enabled self- and shared management proposed in this framework can further progress toward the goals of health care reform by improving health status and care outcomes.

However, the groundwork for this effort demonstrates that moving beyond patient-centered care to “person-centered” health and health care will require re-evaluation of existing policies and programs. New approaches to support and facilitate person-centered health and health care must be bold to achieve change. The framework and building blocks presented in this paper require cultural change on the part of individuals, their caregivers, providers, and health care organizations. Some of the groundbreaking ideas include ways to foster self-management through skills and resources such as consumer-facing care guidelines, self-assessment tools, and coaching. Other innovative ideas seek to break down barriers between individuals and their providers by proposing new strategies and tools for interacting that are time and cost efficient while giving more control to the individual. The approaches for shared management seek to encourage information symmetry and information liquidity to create productive partnerships between individuals and providers. The ideas are based on tenets of mutual respect, greater integration of person and provider generated data, and increased emphasis on shared decision-making and care planning.

Collaboration among key federal agencies, the health care sector, and other stakeholders is required to achieve this vision by 2020. Consumer and patient advocates as well as health care providers are critical stakeholders in this effort. Synergistic strategies will be required to bridge the multiple, complex organizational boundaries and interrelationships to achieve the vision.

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Appendix A: Acknowledgements

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Glossary

Term	Definition (In Context of this Framework)
Access	Ability to access information, including personal health data stored in clinical records, and care services.
Caregiver	A person (e.g., a family member, friend, or paid individual) who manages or helps manage a person's health condition(s), including navigating the health care system, negotiating with providers, and possibly performing the critical tasks of personal and household care. The caregiver might also serve as a health care proxy and be responsible for making the person's medical decisions. Caregivers may play a critical role in supporting and coordinating a person's health care.
Care Team	People involved in the care of a patient, including a range of health care providers and the patient's caregiver(s).
Consumer	A person who purchases health care goods and services for self or as a caregiver.
Health Literacy	The ability to understand health information and to use that information to make good decisions about health and medical care. (DHHS, MedlinePlus)
Health Care Proxy	A person (an agent) appointed to make a patient's medical decisions if the patient is unable to do so. The person selected is someone the patient trusts to speak for him/her if he/she becomes unable to do so. This role becomes effective when an attending physician determines in writing that a patient is unable to make or communicate health care decisions.
Patient	A person receiving or registered to receive medical treatment.
Patient-centered health care	Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care. (IOM, 2001)
Patient-generated health data	A subset of person-centered data: Health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) <i>submitted to the provider</i> to help address a health concern (Shapiro et al., 2012 ONC modifications in italics).
Person	An individual regardless of relationship to the health care system.

Person-centered care (also “person-focused care”)	Care that is accessible, comprehensive (dealing with all problems except those too uncommon to maintain competence), continuous over time, and coordinating when patients have to receive care elsewhere. The essence of the person focus implies a time focus rather than a visit focus. It extends beyond communication because much of it relies on knowledge of the patient (and of the patient population) that accrues over time and is not specific to disease-oriented episodes. (Starfield, 2011)
Person-centered data	Person-centered data encompasses all data relating to the individual relevant for the individual’s health and health care. It includes data created or gathered in a clinical setting, by the provider or a clinical tool, and created or gathered outside a clinical encounter by the person or a personal tool. It includes information not traditionally considered “clinical data,” such as values, preferences, and environmental and social context data.
Provider	A health care professional (e.g., physicians, nurses, home health aides) or a group of health care professionals, a clinic, or a hospital providing services to patients.
Self-Management	The act of individuals handling their health either on their own or with assistance from family or other lay caregivers. It includes coordinating wellness and prevention activities, and also addressing health concerns outside the health care system.
Shared Management	The act of individuals participating in the treatment of a health problem with health care providers for whom they are patients. They may have assistance from family or other caregivers who are part of the care team in partnership with the patient.