

# The Consumer Platform for Health IT

**ADVANCING PATIENT AND FAMILY  
ENGAGEMENT THROUGH TECHNOLOGY**

May 2011



Consumer  
Partnership  
for **eHealth**

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### Executive Summary

**M**embers of the Consumer Partnership for eHealth (CPeH) have been working for more than five years to advance patient-centered, consumer-focused health IT (information technology). We believe our nation is at a pivotal moment for transforming our health care system with the support of better information. This platform outlines a vision for how health IT can help patients, and how consumer groups can work alongside other stakeholders to improve health outcomes.

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**Consumers are the most significant untapped resource in health care.**

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Consumers are the most significant untapped resource in health care. We are eager to be partners in advancing and using technology — which empowers us in so many areas of our lives — to participate more actively in matters of health. As we move toward new care delivery and payment models, the collection and sharing of information with all stakeholders, and especially consumers, will be paramount. Health IT is a critical enabler of the kind of information sharing that is crucial for continuously improving the health of individuals and populations, as well as the nation. Achieving better care, healthier communities, and more affordability will require the utilization of all our collective resources, and consumers have critical assets to bring to policy making tables and to individual decision-making processes.

By involving consumers actively in the policy-making process, they are able to contribute critical information and potential solutions that other stakeholders might never consider. As a result, consumers participating at the policy level become invested in new approaches and will help ensure their success. Full engagement of consumers in leadership and decision-making roles at the policy and governance levels is essential, not just for gaining their trust and buy-in, but also for maximizing the likelihood of meeting patient and consumer needs.

When we think about a truly patient-centered health care system, we expect that:

- Clinical information and information contributed by the individual is used to provide holistic care. [More]
- Communication of information results in seamless attention to health needs, regardless of an individual's physical location. [More]

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\* The National Partnership for Women & Families and the Consumer Partnership for eHealth thank Lygeia Ricciardi, EdM, of Clinovations, for drafting this document with guidance from our members and other health IT experts. Significant input was provided by Eva Powell, MSW, CPHQ, of the National Partnership, and Lisa Fenichel, MPH, Consultant.

- The right information is provided to the right person at the right time to ensure safety and quality. [More]
- Information is available and shared in real time to increase accessibility, efficiency and affordability of care. [More]
- Information is presented and used in ways that are meaningful to the individual. [More]
- Information is exchanged privately and securely, without erecting unnecessary barriers to its use. [More]
- Information is used to ensure that all people are treated fairly and equitably by our health care system. [More]

**Consumers are ready and willing to work collaboratively as:**

- **Agents of change**
- **Informed decision-makers**
- **Sources of verification and contextual information**
- **Decision-makers about how best to integrate better health into the context of their lives**

Prioritizing these goals and including strong consumer involvement in redesigning care delivery approaches will help create an environment that is better prepared for engaging with empowered consumers about their individual care. Consumers are ready and willing to work collaboratively as:

- Agents of change,
- Informed decision-makers,
- Sources of verification and contextual information, and
- Decision-makers about how best to integrate better health into the context of their lives.

Fulfillment of these roles will require access to information and the tools to make it meaningful and useful. These are vital benefits to ensure consumers receive adequate return for their investment in incentives for the meaningful use of health IT, and they are essential for the successful transformation and sustainability of our health care system.

## Introduction

Our health shapes nearly every aspect of our lives. Yet our health care system is dysfunctional and in many ways operates far from the influence of consumers and patients — the people who should be at its very center.

There is no single solution to the problems in our health care system. Like many others, we believe that the meaningful use of health IT can transform health and health care, much as technology has transformed other industries. In addition, we believe that the ability of health IT to improve outcomes in the quality, efficiency and experience of health care services is dependent upon the degree to which consumers are engaged in efforts to implement and use these new technologies. Health IT can be a tool that empowers consumers to: work in partnership with the professionals who care for us; make better choices about individual providers and treatment options; and live healthier, more fulfilling lives. But these benefits of health IT will not be achieved automatically.

Building on CPeH's previous work,<sup>2</sup> this platform describes how consumers, patients and their caregivers envision the impact of health IT on their lives, as well as the ways we seek to work with other stakeholders to ensure that implementation of health IT results in the improved outcomes we all want.

<sup>2</sup> The Consumer Partnership for eHealth (CPeH) is a coalition of more than 50 consumer and patient groups led by the National Partnership for Women & Families, a non-partisan, non-profit consumer advocacy organization that has been working for 40 years to promote access to quality health care, fairness in the workplace, and policies that help women and men meet the dual demands of work and family.

We believe that consumer, patient and caregiver engagement is the game-changing element of a comprehensive, effective strategy for reforming our overburdened, overpriced health care system, through more effective use of information.

CPeH and its members have been working actively on health IT issues since 2005 and have brought consumer voices into policy development and implementation to advocate for patient-centered care enabled by health IT. CPeH is dedicated to changing the way health care is organized, financed and delivered by using information more effectively.

Our perspective and priorities for health IT are both a call for change and a touchstone to which we and other stakeholders can refer as we develop policies that enable and promote the shared goals of better care, healthier communities and greater affordability.

## Where We Are Now: Health Care Today

### AN UNSUSTAINABLE PATH

There have been great advancements in health care, especially over the last several decades. Great developments and improvements in medical and surgical procedures, diagnostic tests, pharmaceutical drugs and medical devices,<sup>3,4</sup> combined with public health services like vaccinations and better sanitation, have helped double life expectancy in the U.S. since 1900.<sup>5</sup>

However, this progress in what we do to provide care has not been accompanied by similar progress in how we do it, especially with regard to the management and use of information. There is a high price to be paid for this lack of advancement, both in quality and cost of care. While Americans are living longer, they are often sicker, with multiple complex health conditions.<sup>6</sup> As a result, the U.S. notoriously spends more on health care than any other country,<sup>7</sup> yet our health system ranks 37th worldwide (tied with Serbia's).<sup>8</sup> Studies show that patients here only get the right care — at the right time and for the right reason — about half the time.<sup>9</sup> There are pronounced disparities in access to and quality of care,<sup>10</sup> and more than 98,000 people die every year as a result of medical error.<sup>11</sup>

In addition to the poor outcomes these statistics represent, they also fuel the skyrocketing and unsustainable cost growth in our health care system. The total burden of illness, including opportunity cost, is staggering, and many question the sustainability of the path we are on. This crisis, which will only worsen as the baby boomer generation ages, calls into question the very competitiveness of our nation and the well-being and potential of future generations.

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<sup>3</sup> National Center for Health Statistics. Health, United States, 2009: With Special Feature on Medical Technology. Hyattsville, MD. 2009. Library of Congress Catalog Number 76-641496. Retrieved Feb. 1, 2011, from <http://www.cbsnews.com/htdocs/pdf/hs09.pdf?tag=contentMain;contentBody>

<sup>4</sup> The Centers for Disease Control and Prevention, Health, United States, 2001: Morbidity and Mortality Weekly Report. Retrieved Feb. 1, 2011, from <http://cdc.gov/mmwr/preview/mmwrhtml/00056796.htm>

<sup>5</sup> Central Intelligence Agency World Factbook Field Listing: Life Expectancy at Birth, Country Comparison to World Retrieved Feb. 1, 2011, from <https://www.cia.gov/library/publications/the-world-factbook/fields/2102.html>

<sup>6</sup> National Partnership for Women & Families, Campaign for Better Care, 2009, "The Case for Better Care," Retrieved Feb. 1, 2011, from [http://www.nationalpartnership.org/site/DocServer/Fact\\_Sheet\\_1--The\\_Problem.pdf?docID=6202](http://www.nationalpartnership.org/site/DocServer/Fact_Sheet_1--The_Problem.pdf?docID=6202)

<sup>7</sup> Organization for Economic Co-operation and Development, Directorate for Labor, Employment, and Social Affairs, OECD Health Data 2010. Retrieved Feb. 1, 2011, from [http://www.oecd.org/document/16/0,3343,en\\_2649\\_34631\\_2085200\\_1\\_1\\_1\\_1,00.html](http://www.oecd.org/document/16/0,3343,en_2649_34631_2085200_1_1_1_1,00.html)

<sup>8</sup> Murray, Christopher, and Frenk, Julio (2010, January 6). Ranking 37th — Measuring the Performance of the U.S. Health Care System. NEJM Retrieved Feb. 1, 2011, from <http://healthpolicyandreform.nejm.org/?p=2610>

<sup>9</sup> [http://www.nationalpartnership.org/site/PageServer?pagename=issues\\_health](http://www.nationalpartnership.org/site/PageServer?pagename=issues_health)

<sup>10</sup> For example, African Americans have higher rates of mortality from heart disease, cancer, and HIV/AIDS, and cerebrovascular disease than any other racial or ethnic group in the U.S.. See IOM, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" (Brian Smedley et al. eds., 2003)

<sup>11</sup> IOM Report

Health IT alone will not solve these problems. Yet its implementation and effective use can help establish better access to and use of information — key milestones along the path to reform. The unprecedented resources made available by the United States government in the HITECH legislation of 2009<sup>12</sup> and in the health reform law<sup>13</sup> of

2010 represent a historic opportunity to transform care so that it is noticeably improved in the eyes of consumers — the taxpayers who finance these initiatives. There is already evidence that incentives established by HITECH have increased adoption of both basic and fully functional health IT systems.<sup>14</sup> We cannot afford to squander this opportunity. Changing the way we collect, access and use information — and including consumers among those collecting, accessing and using information — is one of the most powerful levers for changing our health care system in ways that will benefit all stakeholders.

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**Changing the way we collect, access and use information... is one of the most powerful levers for changing our health care system.**

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## CONSUMERS: THE UNTAPPED RESOURCE

Technology is empowering people in many aspects of their lives. It is changing attitudes and expectations relative to information. Given the right tools, it has the potential to make us more adept at using information in ways that will benefit both individuals and society. There is every reason to believe that using technology to give people access to health information, and the tools to make it useful, will transform both personal health and the health care system.

Consumers routinely search for health information online,<sup>15</sup> and many information and communications technologies developed for other purposes could be used in a health context. In fact, some already are. For instance, the use of mobile devices, equipped with basic SMS text or more sophisticated smart phone applications<sup>16</sup> to find, record and share information and to monitor, manage and improve health<sup>17</sup> — along with the rapid growth in social communities such as Facebook, Twitter, Flickr and LinkedIn<sup>18</sup> — indicate that individuals can integrate health more fully into their everyday lives. Presently, the fastest growth in use of these technologies is among older Americans,<sup>19</sup> who generally have the most interaction with the health care system.

Consumers can be partners in achieving a transformed health care system if they have access to the information they need to be engaged. New delivery and payment system models, such as Accountable Care Organizations and Patient-Centered Medical Homes, will not only require greater

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<sup>12</sup> The American Recovery and Reinvestment Act of 2009.

<sup>13</sup> The Patient Protection and Affordable Care Act of 2010 and the Health Care and Education Reconciliation Act of 2010, collectively known as the Affordable Care Act or ACA.

<sup>14</sup> Hsiao, Chun-Ju; Hing, Esther; Socey, Thomas; and Cai, Bill. (2010, December 8). Electronic Medical Record/Electronic Health Record Systems of Office-based Physicians: United States, 2009 and Preliminary 2010 State Estimates. *NCHS Health e-Stat*. Retrieved Feb. 1, 2011, from [http://www.cdc.gov/nchs/data/hestat/emr\\_ehr\\_09/emr\\_ehr\\_09.htm](http://www.cdc.gov/nchs/data/hestat/emr_ehr_09/emr_ehr_09.htm)

<sup>15</sup> Eighty percent of Internet users have looked online for health information. Many of them say the Internet has had a significant impact on the way they care for themselves or for others. The Pew Internet and American Life Project. Data from website as of September, 2010 — <http://www.pewinternet.org/topics/Health.aspx>

<sup>16</sup> There are about 6,000 health apps available on the major smart phone platforms, 70% of which are intended for use by consumers (as opposed to health care professionals). This includes apps for iPhone, Google's Android, Blackberry, Palm, and Nokia. Stats compiled by mobihealthnews, March 11, 2010 <http://mobihealthnews.com/6908/3-million-downloads-for-android-health-apps/>

<sup>17</sup> While mhealth specifically is not yet mainstream, 90% of Americans have a mobile phone. People under age 55 send more texts than they make phone calls. Teens text 1700+ times a month. See "quick mobile facts" at <http://www.infieldhealth.com/>.

<sup>18</sup> Facebook has more than 500 million active users, 50% of whom log in on a given day <http://www.facebook.com/press/info.php?statistics>

<sup>19</sup> Social networking among Internet users ages 50 and older nearly doubled from 22% to 42% between April 2009 and May 2010 <http://pewresearch.org/pubs/1711/older-adults-social-networking-facebook-twitter>

consumer engagement in their health, but will also require consumer trust and acceptance as these new approaches aim to improve care and decrease costs. Absent information to the contrary, any effort to reduce costs is likely to be perceived as an effort to skimp on care. Therefore, it is wise for the architects of new models to include consumers in the information flow in ways that are meaningful to them. Health IT plays a foundational role in facilitating the collection and sharing of information essential for engaging consumers in new models of care.

## Where We Want Health Care to Be: The Vision

We envision a health care system that genuinely focuses on the health and well-being of the individual, while using knowledge gleaned from individuals to continuously improve care for specific populations and for the nation as a whole. Consumers and patients have clear expectations for the health care system of the future, and we intend to work collaboratively with other stakeholders to build a new system with the following characteristics:

### **Clinical information and information contributed by the individual is used to provide holistic care.**

- There is a strong emphasis on prevention and wellness, in addition to treating illness and injury.<sup>20</sup>
- The individual's whole body is considered, as opposed to an injury or diagnosis considered in isolation.
- The whole person is viewed in the context of his or her family and community, school, job and home, and mental and physical condition.
- The preferences, values and priorities of the individual, which may be cultural, religious or based on other ideals — not just his or her perceived physical needs — are respected and reflected in treatment plans and choices.
- Each individual will be asked about his or her experience of care, and clinicians will routinely use that feedback to improve.

### **Communication of information results in seamless attention to health needs, regardless of an individual's physical location.**

- Care is integrated into people's lives. Instead of "going to the doctor" for everything, we connect to the system on a regular basis whenever and wherever we need to.
- Consumers have complete, continuous access to health information including:
  - Personal clinical data about themselves and (with permission) their loved ones;
  - Prevention modalities and wellness strategies;
  - Evidence-based data on risks/benefits of treatment options; and
  - Cost and quality data and comparisons.
- Health data, which is securely collected by individuals and care team members outside of the care facility using mobile phones, remote medical devices or sensors, is accessible by all members of the care team.
- All members of the care team (including the individual and his or her family or caregivers) share a comprehensive, longitudinal picture of the individual's health, both previous health status and conditions, and future health goals.

<sup>20</sup> As Senator Tom Harkin (Chair of the Senate Committee on Health, Education, and Labor) said in *Shifting America from sick care to genuine wellness*, his June 25, 2010, op ed for The Newsroom blog, "Currently in the United States, 95 percent of every health care dollar is spent on treating illnesses and conditions after they occur. But we spend peanuts on prevention." [http://news.yahoo.com/s/ynews/ynews\\_ts408](http://news.yahoo.com/s/ynews/ynews_ts408)

- A longitudinal, shared care plan — developed through a shared decision-making process — is accessible and used by all members of the care team, including the patient and his or her caregivers.
- The coordinated care team expands beyond members of the traditional health care system to include others, such as a nutritionist, personal trainer and school nurse, according to the needs and preferences of an individual.

**The right information is provided to the right person at the right time to ensure safety and quality.**

- Empirical evidence of what works is accessible at the point of care.
- Complete and unbiased information, as well as tools for using it to make shared decisions, are available to both the individual and the clinician.
- Patient-centered quality measurement continuously informs system improvement.
- Ongoing monitoring by clinical systems helps avoid and correct medical errors, identify individuals at risk and prevent acute health crises.
- Information about each individual's experience of care is aggregated and communicated back to the care team for purposes of improvement.
- Consumers, patients and their caregivers are encouraged and easily able to report safety concerns, including inaccuracies in their health information, and mechanisms are in place to address them efficiently and effectively.

**Information is available and shared in real time to increase accessibility, efficiency and affordability of care.**

- New technologies are used to bring high quality health care and various tools to support it into people's communities and homes, when appropriate and per their preference.
- Appropriate and secure linkages are made to facilitate coordination among care providers and other health care stakeholders, including consumers.
- Consumers can easily access, interact with, transmit and receive their health information in the form most convenient for them.
- Decisions are informed by near-real-time aggregation and sharing of data among consumers, providers and researchers.
- Policymakers have the aggregate data they need to make sound policy decisions.
- Technology is used to eliminate duplication and waste.
- Data is used to compare efficacy of available treatments for various populations.
- Cost information is made available for comparison and efficient use of resources.
- Logical, consumer-friendly electronic enrollment systems help individuals seamlessly enroll in, retain and manage health insurance coverage.

**Information is presented and used in ways that are meaningful to the individual.**

- Culturally appropriate educational material is available in the language and level of detail desired by the individual, and at a level of literacy understandable by the individual, including those facing communications, learning and comprehension challenges.
- Information is clearly presented, incorporating visual elements and clean design, making the information accessible and usable to all individuals.

### **Information is exchanged privately and securely, without unnecessary barriers to its use.**

- Comprehensive, consistent privacy and security policies based on Fair Information Practices provide clear guidance about who may access and use health information, under what circumstances and for what purposes.<sup>21</sup>
- Audit logs showing who received, requested and viewed health information are available for purposes of enforcement and consumer information.
- Strong enforcement mechanisms are in place.
- Broad-based anti-discrimination policies protect individuals.
- Whistleblowers reporting privacy and security concerns are protected from retaliation.
- Sanctions and remedies for breaches of the above policies are clear, easy to implement and fair.

### **Information is used to ensure that all people are treated fairly and equitably by our health care system.**

- Consumers participate in health care policymaking or “governance” activities on a national, state and local level and routinely have leadership or decision-making roles.
- Aggregate data and electronic tools are used to identify and eliminate disparities in care among population groups, as well as to engage those most at risk for experiencing health disparities.<sup>22</sup>
- Electronic tools and information are equally accessible to all, including people with disabilities.
- Financial incentives for all stakeholders — health care providers, business organizations, consumers and other interested parties — are aligned to minimize conflicts of interest.

## **The Power of Health IT**

We are not interested in using technology merely to tweak a dysfunctional system; we want to transform it. For consumers, gaining access to the information necessary for our engagement, and the tools to make it useful, are key benefits of health IT. We do not want to be our own doctors, however, so all members of our care teams must also make greater use of information through the meaningful use of health IT. We believe the characteristics described above will benefit consumers and clinicians in similar ways.<sup>23</sup>

We expect that the use of health IT will improve communication and coordination of our care, lower the number of dangerous drug interactions and other medical errors, and minimize repeat tests and procedures, which result in inefficient use of our time and financial resources. We expect that populations, not just individuals, will benefit through: 1) reduction and elimination of disparities in care, 2) improved quality reporting that enables payment for outcomes, not services — many of which are unnecessary and ineffective, 3) strengthened and connected public health, and 4) more rapid and targeted research that results in the development of new, more effective treatments.<sup>24</sup>

**We expect that populations, not just individuals, will benefit.**

<sup>21</sup> Center for Democracy and Technology

<sup>22</sup> Gibbons, Michael Christopher. (Winter 2011). Use of Health Information Technology among Racial and Ethnic Underserved Communities. *Perspectives in Health Information Management*. Retrieved Feb. 1, 2011, from [http://perspectives.ahima.org/index.php?option=com\\_content&view=article&id=206:use-of-health-information-technology-among-racial-and-ethnic-underserved-communities&catid=63:telehealth](http://perspectives.ahima.org/index.php?option=com_content&view=article&id=206:use-of-health-information-technology-among-racial-and-ethnic-underserved-communities&catid=63:telehealth)

<sup>23</sup> The Markle Foundation (2011, January 31). *Markle Survey on Health in a Networked Life 2010*. Retrieved Jan. 31, 2011, from <http://www.markle.org/publications/1461-public-and-doctors-overwhelmingly-agree-health-it-priorities-improve-patient-care>

<sup>24</sup> Today there is a typical lag time of 15 years between the discovery of a medical improvement and its availability to patients. Health IT could help to shorten that time. See [www.fastercures.org](http://www.fastercures.org)

Despite its enormous potential, we understand that current use of robust health IT tools is low due to some very real barriers. Financial reimbursement for health care is not currently aligned with the outcomes we want to achieve through the use of health IT. Many providers need help with the initial costs of technology, as well as the redesign of clinical workflow. Cultural barriers must be overcome and privacy concerns must be addressed in ways that foster trust by all stakeholders. We know the path forward will require significant change, and that the entirety of this vision will be achieved over the course of many years. But maintaining the status quo is not an option, and consumers will no longer accept it.

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**Considering the tremendous growth in the number of people who care for a sick or elderly loved one, greater access to information and electronic tools would meet the direct and daily needs of a burgeoning population that desperately needs information and tools to be more effective caregivers.**

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## The Consumer Role

As representatives of consumers, patients and their caregivers, through this Platform we are communicating that we expect an information-rich health care system and we wish to work with other stakeholders to overcome barriers and bring it to fruition. We intend to refashion the broken health care system — as partners.

While not every individual has the interest, need or capacity to engage deeply in their health and health care, we believe a significant subset of individuals representing a range of socio-economic backgrounds and health statuses will.<sup>25</sup> Considering the tremendous growth in the number of people who care for a sick or elderly loved one, greater access to information and electronic tools would meet the direct and daily needs of a burgeoning population that desperately needs information and tools to be more effective caregivers. As more people gain access to information and understand how it can be useful to them, social norms and expectations will shift, and engagement will grow.

Most Americans express some level of dissatisfaction with the health care system — dissatisfaction that opens their minds to change. For example, according to a poll by the California HealthCare Foundation:<sup>26</sup>

- 63% of caregivers wish they knew more about a loved one's care
- 60% of Americans wish their doctor had more time to talk with them
- 55% of Americans wish their doctors talked and shared more information with each other
- 51% of Americans wish their doctor knew them and their health better
- 50% of Americans find keeping track of all their health information difficult

Health IT is a critical tool for making needed improvements to our health care system, through solutions such as consumers' ability to download personal health information, telemedicine and bi-

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<sup>25</sup> For more information on the level of health engagement among different population groups, see the Edelman January 2009 Health Engagement Barometer, which reported that about 20% of Americans are currently involved, informed and engaged health care consumers. [http://www.edelman.com/expertise/industries/health/documents/Edel\\_HealthBarometer\\_R13c.pdf](http://www.edelman.com/expertise/industries/health/documents/Edel_HealthBarometer_R13c.pdf)

<sup>26</sup> California HealthCare Foundation poll, see p.5 <http://www.chcf.org/~media/Files/PDF/C/ConsumersHealthInfoTechnologyNationalSurvey.pdf>

directional electronic communication between patients and their care teams. As active participants in a variety of roles, consumers can and will use health IT to help ensure the success of these collective efforts.

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**55% of Americans wish their doctors talked and shared more information with each other.**

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### **ACTING AS AGENTS OF CHANGE**

If we want a health system that serves us better, we must participate in redesigning it, become activated and contribute to its success. This includes policy and implementation engagement by consumers and consumer advocacy organizations — for example, developing and supporting recommendations related to health IT — and engaging in health policy making and governance more broadly, whether at the federal, state or local level. With regard to our own personal care, it also means educating ourselves, conversing with our care providers about our priorities and goals, speaking up when we have questions or concerns, taking action to meet our health goals, and providing feedback about our care experiences.

### **MAKING INFORMED DECISIONS**

Patients and their families make numerous decisions related to health care — many before they ever even interact with a provider. Selecting an insurance policy and seeking a referral or appointment with a provider are two such decisions, and today these decisions are often made without the benefit of quantifiable, comparable information. Once established with a provider, there are numerous decisions to be made about preventive care or treatment. The volume of traditional medical- and health-related studies has grown exponentially, while an explosion of information has been added to the mix via new media such as wikis, blogs and online communities. Doctors and other clinicians simply cannot be experts in every aspect of every medical condition, nor do they always understand what patients value and prefer in choosing among treatment options.<sup>27</sup>

Individual patients are the best experts on what matters to them personally, and these needs, preferences and values play a tremendous role in both the appropriateness of an intervention and its efficacy. With similar conditions, one patient may choose a high-risk intervention, while another may prefer to take no action. Greater patient engagement and activation, through shared decision-making and self-management support, is necessary to ensure that a patient's choice of treatment is made with full understanding of the clinical options and is consistent with his or her personal preferences. Patients, their families and caregivers, and all of their providers must approach decision-making together every step of the way.

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**50% of Americans find keeping track of all their health information difficult.**

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Better information is also a critical enabler of patients making decisions that are right for them with regard to insurance coverage and provider selection. Basing these kinds of decisions on quality measures that matter to patients will contribute to achieving better patient-centered outcomes.

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<sup>27</sup> Even 10 years ago the National Library of Medicine's search service linked to more than nine million articles from three thousand nine hundred current medical journals. Beasley, S. W. (2000), 'The Value of Medical Publications: "To Read Them Would ... Burden the Memory to No Useful Purpose". Australian and New Zealand Journal of Surgery, 70: 870–874. doi: 10.1046/j.1440-1622.2000.01987.x. Abstract available at <http://onlinelibrary.wiley.com/doi/10.1046/j.1440-1622.2000.01987.x/abstract?systemMessage=Online+Library+is+experiencing+intermittent+brief+disruptions+when+loading+some+pages++this+is+currently+under+investigation>

## VERIFYING FACTS AND PROVIDING CONTEXT

Facts about an individual's health typically reside in many places — with their primary care provider, with their specialists, at their pharmacy, with their insurance provider and in their own minds. Just as other members of the care team have information to contribute, consumers also possess unique information necessary for creating a comprehensive picture of their overall health. Even as health IT becomes more widely adopted and personal health information begins to move easily and securely among members of the care team, the quality and accuracy of this information will need to be verified and updated. Consumer input is vital to this process. Consumers can also help to put the facts into context by explaining how they relate to the bigger picture of their daily lives. Consumers need to be active partners in their care, ensuring that information is accurate, diagnoses are consistent with the latest evidence and care is appropriate for them.

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**Consumers need and want to be active partners in their care, ensuring that information is accurate, diagnoses are consistent with the latest evidence and care is appropriate for them.**

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## INTEGRATING BETTER HEALTH INTO THE FULL CONTEXT OF OUR LIVES

The reality for most people is that we spend far more time at home living our lives than we do interacting with the health care system. As a result, the degree to which we can incorporate health and health care into our daily lives will have a tremendous impact on our ability to make and meet health goals.

Whether an individual's health goals are primarily related to wellness and prevention or management of chronic illness, health IT can help individuals track, measure, understand and manage specific health needs. This is particularly important for individuals with multiple chronic conditions and their caregivers, who need to engage in ongoing disease management. Individuals who are empowered by information and emerging technologies, like remote monitoring devices and personal health records (PHRs), can more successfully maximize their health and the outcomes of clinical interventions they receive.

Consumers are enthusiastic about the benefits health IT will afford them, and we are eager to work actively to implement health IT in ways that result in better care, healthier communities and greater affordability.

*AARP*

*Advocacy for Patients with Chronic Illness, Inc.*

*American Association of People with Disabilities*

*American Association on Health and Disability*

*American Heart Association*

*American Hospice Foundation*

*Caring From a Distance*

*Center for Democracy and Technology*

*Center for Medical Consumers*

*Childbirth Connection*

*Consumers Union*

*Family Caregiver Alliance*

*Healthwise*

*Mothers Against Medical Error*

*National Alliance for Caregiving*

*National Coalition for Cancer Survivorship*

*National Consumers League*

*National Family Caregivers Association*

*National Health Law Program*

*National Partnership for Women & Families*

*National Women's Health Network*

*OWL - The Voice of Midlife and Older Women*

*SEIU*

*The Leadership Conference on Civil and Human Rights*

*The Empowered Patient Coalition*

*The Children's Partnership*

*Well Spouse Association*