Snapshot of People’s Engagement in Their Health Care
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Abstract

Health care is one of many strategies we enlist in our effort to live our lives free of suffering.

A review of 31 national surveys performed by the Center for Advancing Health found that we do not actively and consistently perform many of the actions directly linked to benefiting from the health care available to us.

The review of surveys conducted from 2001-2009 found that for the majority of engagement behaviors for which survey data were available:

- One-third of American adults perform them consistently at this time.
- About one-third of people perform them inconsistently or tentatively.
- A final third do not perform them at all.

More of us appear to perform simpler tasks (e.g., make a list of medications) than more complex actions (e.g., make informed treatment decisions). We seem to defer information- and advice-seeking until we have a specific need for it. And the depth of our participation in any engagement behavior set tends to be shallow. For example, many more of us seek out information about a provider or health plan than actually use the information to make a choice. Poor health; insufficient knowledge, skills and confidence; and lack of external support and insurance all hinder our ability to participate fully.

While we bear responsibility to engage actively and knowledgeably in our health care, we cannot do so effectively unless health professionals and care settings welcome and encourage our participation.

The promise of health reform initiatives and legislation to improve care will only be achieved with increased engagement of individuals. Health care professional organizations, consumer advocates, health plans, hospitals and government agencies have critical roles to play in reducing barriers to our participation, producing better tools to support our engagement and ensuring that health care is accountable to and with us.
Recent passage of health care reform promises increased access to health care for many and improvement in the quality of care for all. But these changes alone will not result in improved health for individuals or the nation. Our active, knowledgeable participation — whether we are sick or well — is necessary if we are to benefit from the care available to us or to loved ones on whose behalf we are acting.

I experienced this personally when I was diagnosed with cancer after my first screening colonoscopy when I turned 50. I was amazed at how much I was expected to know and do in order to find good care and to ensure the safety and effectiveness of my treatment: get a second opinion, choose the surgeon, deliver records to the hospital, arrange payment, undergo pre-operation tests, then come home from the hospital two days after major abdominal surgery and manage the symptoms, pain, drugs, diet, rehabilitation and communication with various clinicians for weeks. At each step, this journey could have gone wrong. The success of my care wasn’t dependent on just what the doctors and nurses did: my own efforts were critical.

I was particularly struck by the contrast between this experience and my two previous cancer diagnoses 20 and 30 years earlier. Of course the diagnostic and treatment technologies had vastly improved. But what also had changed dramatically were the expectations — often unstated — of what I had to do to care for myself.

I am not alone in being surprised at my new responsibilities. Since getting well, I have interviewed hundreds of people about how they found and used treatment following a serious diagnosis, and hundreds more about how they manage routine health care interactions. For some, this remains a straightforward process. For many others, though, the confluence of increased complexities in health insurance, health care delivery and self-care regimens presents a considerable challenge. Many people report being overwhelmed and confused by these new responsibilities even when they are not ill.

They — and I — find our new role sobering: it is clear that participating knowledgeably in one’s care is not optional. In order to obtain the full benefit of services, drugs and technologies available today, our active participation is required.

What will it take to ensure that each of us, sick or well, is able to take on — with the help of family and other caregivers — the growing number of tasks that now fall to us? What do we have to know how to do to fulfill them? And how can primary care and specialty practices, health plans, workplaces, the government and communities implement policies and practices and fund additional research that will enable us to perform these responsibilities successfully?

This report constitutes one step toward answering these questions by grounding “engagement”
A Snapshot of People’s Engagement in Their Health Care

in discrete, measurable behaviors for which information, support and guidance can be offered. Its primary aim is to understand what Americans are currently doing to find safe, decent health care and make good use of it.

Increasing our engagement in health care will require more effective actions by us, better tools for us and care that is more accountable to and with us. Understanding our current level of engagement behavior provides a foundation for building strategies that will address our needs and provide support to us and our caregivers.

Using responses to selected questions from 31 surveys supported by the federal government and private foundations and organizations, the Center for Advancing Health (CFAH) offers this Snapshot as an estimate of the extent to which Americans currently step up to the demands of 21st Century health care.

This Snapshot of Americans’ engagement in their health care also lays the groundwork for a series of ten white papers that will present a synthesis of the literature about what it takes for individuals to engage in their care. Each paper will focus on one of the ten sets of engagement behaviors described in this Snapshot and will describe what is at stake as well as the tasks, the challenges and the current efforts to support those behaviors. These CFAH What It Takes white papers will be released during 2010-2012.

Jessie Gruman
President and Founder
Center for Advancing Health
Introduction

Why Focus on Individuals’ Engagement in their Health Care?

Twenty-first century health care demands new levels of participation by individuals if they are to benefit from the care available to them.¹

This report indicates that for most of the behaviors for which such participation is required, two-thirds of American adults are unable or unwilling to consistently fulfill them.

Some of the new duties that individuals must now perform to benefit from care result from innovations, such as those in surgery, that enable people to leave the hospital quicker but sicker.¹-³ Others result from the drive to improve efficiency by achieving equivalent or superior clinical outcomes while reducing the role of professionals.⁴-⁶ New duties arise from a fragmented health system that has been slow to develop the capacity to support care coordination.⁶-⁷ Still others have developed as the practice of medicine shifts away from a paternal, authoritative style toward one based on the premise that patients do better when they participate in their own care.⁸,⁹

In this changing environment, individuals find themselves managing drug, wound-healing, dietary and rehabilitation recommendations on their own.¹⁰-¹² Those with chronic conditions that benefit from new drugs and devices are expected to manage complex drug and lifestyle recommendations, such as those associated with diabetes, asthma and HIV/AIDS.¹³-¹⁶ The widening variety in care providers, tests and treatments means that people must not only make more and often consequential choices about care but also coordinate information and services among providers for themselves and their loved ones.¹⁷-²⁰

These requirements for greater participation in health care are particularly burdensome for those who are older or already ill, or who lack knowledge, skills and resources to understand and fulfill these demands. Figure 1 shows some of the population groups that may find greater participation difficult.

¹ Family, friends and paraprofessionals play a critical role in meeting the demands of health care on individuals. In the interest of space, this report uses the term “individuals” to connote the responsibilities that accrue to a single person, recognizing that they are frequently shared by a range of informal and semi-formal caregivers.
Figure 1. Number of Americans with a Characteristic that Can Contribute to Difficulties in Managing their Health

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of US Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low educational attainment (adults age 25 and older with a high school diploma or less as highest level), 2008</td>
<td>88 million²¹</td>
</tr>
<tr>
<td>Chronic condition(s) (all ages), 2000</td>
<td>107 million²²</td>
</tr>
<tr>
<td>Low numeracy (limited ability to understand and use numbers; adults age 16 and older), 2003</td>
<td>93 million²³</td>
</tr>
<tr>
<td>Marginal health literacy (basic or below basic; adults age 16 and older), 2003</td>
<td>75 million²⁴</td>
</tr>
<tr>
<td>Chronic mental disorder (adults age 18 and older), 2008</td>
<td>58 million²⁵</td>
</tr>
<tr>
<td>Uninsured (all ages), 2008</td>
<td>46 million²⁶</td>
</tr>
<tr>
<td>Disability (adults age 18 and older), 2007</td>
<td>69 million²⁷</td>
</tr>
<tr>
<td>Living in poverty (all ages), 2008</td>
<td>40 million²⁶</td>
</tr>
<tr>
<td>Advanced age (80 and older), 2008</td>
<td>11 million²⁸</td>
</tr>
</tbody>
</table>

Those who are unable or unwilling to participate actively and knowledgeably in their care are more likely to receive suboptimal care, pay avoidable out-of-pocket costs, and experience poor outcomes and diminished quality of life. From a societal perspective, non-participation squanders public and private resources, contributes to unnecessary suffering and erodes the health of the population.²⁹-³²

What Is Engagement in Health Care?

In this report, “engagement” in health care is defined as actions that individuals must take to obtain the greatest benefit from the health care services available to them.

This definition focuses on behaviors of individuals relative to their health care that are critical and proximal to health outcomes. It does not describe the actions of professionals or policies of institutions that enable or inhibit individuals’ engagement.

CFAH developed this behavioral definition of engagement and created the Engagement Behavior Framework (EBF) based on extensive interviews, reviews of academic and advocacy literatures, and clinical reports.³³,³⁴ The 42 behaviors included in this definition can be found in Appendix A and are organized into the following ten categories:

- Find Safe, Decent Health Care
- Communicate with Health Care Professionals
- Organize Health Care
- Pay for Health Care
- Make Good Treatment Decisions
- Participate in Treatment
- Promote Health
- Get Preventive Health Care
- Plan for the End of Life
- Seek Health Knowledge

Purpose
This *Snapshot* of engagement is a review of existing, publicly available population surveys that contain items pertaining to the behaviors identified in the EBF (see Appendix A and B). CFAH’s aim was to describe:

- The size of the engagement challenge – what percentage of the US population practices various engagement behaviors?
- The scope of the challenge – what are some of the characteristics that distinguish those who are less likely to participate in their care?

The results are highly relevant to health services research, policy and practice because the findings are grounded in what Americans are actually *doing* (and not doing) to benefit from their health care. This is a shift from previous research focused in individuals’ knowledge, attitudes and intentions.

The report begins with a brief overview of what is known about people’s attitudes about engaging in their health care. Then, using the elements of the EBF, it reports on the public’s current level of activity on behaviors from publicly available population surveys, most of which were sponsored by the federal government and foundations. Findings are discussed, and goals and recommendations for policy and practice are proposed.

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Interviewees frequently used “decent” to describe a multi-dimensional understanding of desirable health care: care that meets their technical and interpersonal expectations for competence and in which they have confidence. “Decent” is used here to distinguish it from the professionally-defined “high quality” care, a concept that has to date been shown to have little meaning to the public.
This report on the prevalence of engagement behavior is built on a substantial body of research on people’s attitudes about taking those actions.

The predominant approach to assessing people’s engagement was pioneered by Judith Hibbard, a professor in health policy at the University of Oregon, who developed the Patient Activation Measure (PAM). The PAM is a validated instrument that assesses whether individuals understand the need to take an active role and the degree to which they feel able to take on this role.\(^{35}\)

Hibbard’s research found that three in five people are passive or hesitant about participating in their health and health care. Specifically, 22 percent of adults scored in a range that indicated they lacked the ability to manage their health and health care, and 37 percent were inhibited, facing significant knowledge and confidence barriers to caring for themselves. Only two in five adults felt able to participate in their care, but they were unsure if they could maintain their confidence under stress.\(^{36}\) A separate survey of Medicare beneficiaries produced similar groupings.\(^{37}\) (Appendix C presents selected data from these and other studies.)

These and other studies suggest that a sizable group of people have some interest in taking care of themselves and figuring out what to do to get the best possible health care, but that they remain uncertain that they are fully capable of doing so.\(^{36-44}\)

Research about people’s attitudes toward engagement is important. The evidence collected to date not only bears directly on the broad range of tasks that constitute active participation in health care, but also provides insights about the likelihood of individuals taking action over time.

**Gaps Between General and Specific Attitudes**

Although many people express confidence when asked abstractly about their overall ability to care for themselves, a somewhat different picture emerges when the survey question asks about specific preferences, views and behaviors. In Hibbard’s study, 41 percent of respondents expressed a readiness to play an active role in decisions about their care.\(^{36}\) In 2007, a large majority of patients age 40 and older ranked doing what the doctor thinks is best as the top priority in making certain medical decisions about breast cancer (86 percent of patients); hip replacement (84 percent); knee replacement (78 percent); and menopause (60 percent), according to research conducted at Massachusetts General Hospital.\(^{45}\)

These examples suggest that people’s reports of their readiness to engage may be skewed by the inclination to select a response that they perceive as more socially acceptable than other responses. Thus, people’s actual confidence in their ability to actively manage their health care—and their actual behavior—may differ from what they report when asked in general terms.

The CFAH examination of self-reported actions across ten defined sets of engagement behaviors offers more detail.
Methods

To understand the challenges of engagement, CFAH aggregated data from existing population surveys using behaviors included in the Engagement Behavior Framework (EBF) to explore the extent to which Americans currently perform behaviors directly linked to benefiting from health care.

The specific Snapshot objectives were to:

1. Describe current participation levels for the EBF behaviors.
2. Identify populations that are less likely than other groups to perform engagement behaviors.
3. Summarize overall participation levels for the ten sets of EBF behaviors.
4. Examine participation levels across the full range of engagement behaviors to comment on patterns in participation and measurement.
5. Identify major gaps in national population surveys in terms of producing data about the full range of engagement behaviors and about participation levels in population subgroups.
6. Offer recommendations for future health services research, policy and practice.

This exploratory analysis used qualitative methods to analyze the content and response rates of 31 existing surveys asking people how they find and use health care and how they care for themselves.

Survey Selection

CFAH identified surveys by consulting with an independent expert panel of health services researchers (see Acknowledgments for EBF team participants). The experts identified high-quality surveys that capture representative segments of the US population. CFAH also searched Web sites of credible survey sponsors, primarily the federal government and private foundations.

From this collection, CFAH selected surveys that were conducted in 2001—2009 and that met all or most of the following criteria:

- Use validated measures or survey instruments to collect data about how people behave.
- Query only US adults.
- Are conducted annually or periodically.
- Obtain a nationally representative sample.
- Are recognized in the academic and health policy communities as being credible sources of data.

CFAH obtained survey results (and documentation, if available) from survey Web sites. If multiple surveys were available, CFAH used the most recent one whenever related data was available. Some
data came from older survey modules that had special items relating to EBF behaviors but that had not yet been repeated.

To capture as wide a breadth of engagement behaviors as possible, CFAH supplemented data from federally and foundation-sponsored surveys with ones that met only some of the survey selection criteria. In particular, a few surveys were conducted before 2003, had a regional scope, had a commercial sponsor or queried only Internet users. (Appendix B describes the major surveys that CFAH used in this analysis.) In a few cases, published health services research augments the findings.

**Data Coding, Selection and Analysis**

After identifying survey items that relate to EBF behaviors, CFAH reviewers applied content analysis methods to code items using the EBF as the analytic framework. Reviewers disregarded survey items about attitudes, beliefs, confidence, health status, sources of specialty care, insurance coverage and behaviors such as risk-seeking and health care utilization. Survey items with access to care or costs as the primary focus were also passed over. Some data points could fit in multiple EBF categories, and the review team worked together to select the best fit. For the longer surveys, the team used Filemaker Pro to house survey data and documentation.

With the intent of developing a wide-ranging picture of self-reported performance levels for engagement behaviors, reviewers extracted response rates from coded survey items. Most of the data points came directly from survey results; however, in a few cases, noted accordingly, reviewers did their own calculations using the response totals to obtain percentages. The review team then narrowed this initial set by selecting among specific data points. If two or more data points presented similar data, the team opted for the one that had the best fit with the corresponding EBF behavior and was from a high-quality, credible and recent survey. Some data points could fit in multiple EBF categories and the review team worked together to select the best fit.

The review team grouped data from multiple surveys to examine performance within each set of EBF behaviors. Because of variances in survey methodologies, reviewers conducted a qualitative gap analysis to characterize the existing capacity of national surveys to capture actual performance of engagement behaviors. The team also examined participation levels across the full range of engagement behaviors to develop cross-cutting findings and recommendations for research, policy and practice.
Findings

1 Find Safe, Decent Health Care

What must people do to benefit?

- Find provider(s) who meet personal criteria (e.g., performance, cost, geographic access, personal style), will take new patients and accept personal insurance
- Use all available comparative performance information (including cost data) to identify prospective providers
- Establish a relationship with a health care professional or group
- Use all available comparative performance information (including cost data) to identify prospective health care facilities
- Seek and use the appropriate health care setting when professional attention is required

What’s at stake?

The risks of not actively seeking information to help guide the search for good health care, not having a regular doctor and not seeking care from the appropriate professionals are high. Among them: ineffective treatment, medical errors, unnecessary expense and suboptimal outcomes.46-48

What actions do people now take?

Highlights

Few people are doing their homework to find the best health care provider or health plan, yet most people say they have at least one personal doctor.49 Of those who seek information about quality, the effort appears to be casual and occasional. Acting on the information they attain is rare.

- Nearly two-thirds of people are not aware that physicians, hospitals and health plans do not all provide high-quality care, but just 5-10 percent of those surveyed consider such information in making a decision.50-52
- Rather than use objective sources, the vast majority of people base their decisions on their own and other people’s experiences with providers and health plans.54,50
- Some health plans make comparative quality and cost information available to their members. Among privately insured Internet users who had such information from their plan, half (48 percent) tried to use it when choosing a doctor. A smaller group—20 percent—said they looked for information about doctors’ costs and quality of care from non-plan sources.52
- People with a high school education or less tend to not use quality of care information when choosing a doctor. People with a college education are more likely to use it.40,50
A Snapshot of People’s Engagement in Their Health Care

Four in five Americans age 18 and older (80 percent) said they have at least one person whom they consider to be their personal or “regular” doctor(s). This means that 20 percent—millions of Americans—lack a regular source of health care.49

Younger age and lack of insurance were the strongest predictors of not having a usual source of care. For example, 36 percent of young adults age 18—29 lacked a usual source of care, compared with 8 percent of adults age 60 and older. Among people with no usual source of care, 66 percent said the main reason is that they rarely are sick. Cost concerns, although next most common reason, were cited by only 10 percent.53

A large majority of Americans are unaware that quality of care greatly varies among doctors, hospitals and health plans. This lack of knowledge exists despite health plan, employer and community efforts to disseminate comparative quality information about providers. In 2008, one in three people (30 percent) knew of big variations in the quality of care from primary care practitioners.40

Few people have acted on their knowledge about variances in health care quality.

- About 9 percent have seen and used information that compares the quality of various hospitals and doctors.50
- Up to 5 percent of Internet users in California said they considered changing their provider or plan based on comparative quality ratings. However, only 1-2 percent actually switched their provider or plan.51

A 2008 online survey indicated that 24 percent of privately insured Internet users age 21-64 used comparative quality information from their health plan before seeking care from a doctor or hospital.52

Along with quality, the cost of care is an important consideration when choosing a health care provider. Some health plans have made comparative quality and cost information readily available to their members. Among privately insured Internet users who had such information from their plan, about half (48 percent) tried to use it when choosing a doctor. A smaller group—20 percent—said they looked for information about doctors’ costs and quality of care from non-plan sources.52 (See also Pay for Health Care section regarding how people act with regard to financial choices about health care services.)

Many people make choices based on their own experience with providers, as well as reviews and recommendations from family, friends and other consumers. For example, in 2008, 59 percent of respondents preferred to choose a familiar hospital while a smaller group, 35 percent, indicated they would rather go to a hospital that has relatively high quality ratings.50

National survey data indicate that seeking health care is no easy matter, regardless of insurance coverage. A large majority of Americans (73 percent) have encountered problems getting the care they need. Two in five people (41 percent) had trouble getting their doctor’s advice during office hours. Another common problem, reported by 30 percent of adults, was getting a same- or next-day appointment with their doctor.54
Communicate with Health Care Professionals

What must people do to benefit?

- Prepare in advance of appointments a list of questions and issues for discussion with the health care professional
- Bring a list of all current medications (including supplements and alternative products) and be prepared to discuss their benefits and side effects
- Report accurately on the history and current status of physical and mental symptoms
- Ask questions when any explanations or next steps are not clear and express any concerns about recommendations or care experiences

What’s at stake?

The need for clear communication between clinicians and patients is increasingly important as individuals and caregivers take on more responsibility for complex care at home that previously was delivered or supervised by professionals. Intricate drug regimens, intravenous administration of chemotherapy and antibiotics, wound care, rehabilitation, feeding and home dialysis are only a few of the many high-risk tasks that are now handled at home. Mastering such tasks requires a clear understanding of what must be done, and how and when to do it.

What actions do people now take?

Highlights

Most people experience some difficulty in communicating with their care providers, even though 30 to 40 percent report taking some steps to have a twoway dialogue with their doctor, particularly in discussing treatment options.

- Half of Medicare patients appear to be poorly prepared for discussions with their doctors: 50 percent said they usually do not bring a list of questions to cover during their appointments.
- Two in five people make it a habit to always bring a list of medications when they see their doctors. About 25 percent of people never do so, increasing their risk for harmful drug interactions.
- About 60 percent of all adults have not told a health professional about a drug allergy unless the provider specifically asked for this health information.
- Twenty percent of Medicare beneficiaries report that they passively follow their health professionals’ lead.

In 2004, 46 percent of Medicare beneficiaries said they always discuss testing or follow-up care options with their doctor, but 20 percent said they passively depend on their doctor, with whom they rarely talk about options. Half of Medicare patients appeared to be poorly prepared for these discussions with their doctors: 50 percent said they usually did not bring a list of questions to cover during their appointments.
When people do not fully communicate with their provider, it increases the potential for harm. In 2008, about 60 percent of all adults had not told a health professional about a drug allergy when the provider did not ask for this information. 

It appears that during their medical appointments, people have problems effectively communicating with their providers.

Thirty percent of Americans age 44 and older with one or more chronic conditions indicated they sometimes or often leave a doctor’s office or hospital feeling confused about what they should do. While receiving cancer care, 15 percent of Americans said they or a family member at least once did not get their important questions answered during a doctor’s visit.

* The survey did not ask patients why the test results were not available.
3 Organize Health Care

What must people do to benefit?

- Make appointments; inquire about no-show policies; arrive on time
- Assess whether the facility can accommodate unique needs (e.g., physical navigation, hearing or visual impairment, translation services) and arrange for assistance
- Bring documentation of health insurance coverage
- Bring another person to assist if the patient is frail, confused, unable to move around or unable to remember the conversation with the provider
- Bring a summary of medical history, current health status and recent test results to visits as appropriate
- Ensure that relevant medical information is conveyed between providers and institutions
- Maintain personal health record

What’s at stake?

Poor care coordination among physicians and hospitals has been well documented: in the past two years, 24 percent of chronically ill adults have gone to a medical appointment only to find their provider did not have needed test results. Among survey respondents who had been hospitalized, 91 percent did not receive a written care plan when the hospital discharged them, and 72 percent left the hospital without arranging for a follow-up visit with any doctor.60

Individuals and their caregivers must step in to fill these and other gaps if they are to avoid unsafe, insufficient or duplicative care. They risk endangering themselves or their loved ones when home care instructions are inadequate.7,12,47

What actions do people now take?

Highlights

In the highly fragmented health care system, most providers operate in their own domains. Most are neither responsible for nor have incentives to coordinate a patient’s treatment with other providers. By default, it falls to each patient and that patient’s caregiver(s) to ensure that all health care providers get relevant test results and information about health risks, diagnoses and treatments, including prescriptions from multiple clinicians. For example, caregivers for the chronically ill spend considerable time managing the services for the care recipient, including coordinating care between two or more providers.61

Few national surveys explore how actively Americans try to organize their health care. These highlights suggest the majority of people do not actively work to make sure their providers have essential medical information about them.

- Just 8 percent have two or more personal health care providers.49 However, 20 percent of adults age 50 and older with chronic conditions report their health has suffered because of insufficient communication among providers.62
- Nearly two-thirds of Americans do not maintain their own medical record (paper or electronic).50
A Snapshot of People’s Engagement in Their Health Care

Highlights

• Most hospitals discharge patients with complex medical needs without giving them a written care plan or helping schedule follow-up medical appointments.60

The existence of systemic problems in care coordination is well known. In 2008, 24 percent of chronically ill US adults said that they had gone to a medical appointment in the previous two years only to find that their provider did not have needed test results.69 Among survey respondents who had been hospitalized, nearly all—91 percent—did not get a written care plan when the hospital discharged them, and 72 percent left the hospital without arranging for a follow-up visit with any doctor.60 Some of these problems relate to patients’ (in)actions, but many more concern insurance payment systems, organization of medical care and provider-to-provider interactions.

Figure 2 shows that one-quarter of Medicare beneficiaries (26 percent) never bring a prescription list to their doctor, and about one-third (30 percent) follow that practice sporadically.58 It appears this practice is also hit-or-miss among the general adult population. A majority of adults, 59 percent, have taken a list of prescription and over-the-counter medications to a doctor’s appointment on at least one occasion. However, that means that two in five apparently rely on memory or do not disclose their medications.50

**Figure 2. Frequency that Medicare Beneficiaries Report for How Often They Take a List of Prescribed Medicines to a Doctor’s Appointment, 2004**

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>26%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>13%</td>
</tr>
<tr>
<td>Usually</td>
<td>17%</td>
</tr>
<tr>
<td>Always</td>
<td>44%</td>
</tr>
</tbody>
</table>

Figures may not add up to 100 percent due to rounding. Source: Medicare Current Beneficiary Survey, Patient Activation Supplement, 200458

Surveys suggest that friends, family, caregivers and patient advocates help manage and organize care. As people age, many increasingly rely on adult children to help with getting to appointments (for any purpose) and taking care of errands. One in three (32 percent) adults age 65-74 and 46 percent of people age 75-84 have received this assistance. For seniors age 85 and older, two in three (64 percent) had this help.63

In a 2001 online survey of caregivers for chronically ill persons, caregivers reported devoting considerable time to managing health care for their care recipients. Besides managing medications, 60 percent of caregivers say they must coordinate medical services with two or more providers.61

Use of personal health records (paper or electronic) remains low: just 36 percent of adults (including people who have a family member’s assistance) have created their own medical record.60 Various studies have found that people who are less likely to have a personal health record are those with a complicated medical situation or with aging-related problems with memory or organizational skills.64

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## 4 Pay for Health Care

### What must people do to benefit?

- Compare coverage options, match to personal values, needs and preferences and select coverage
- Gather and submit relevant eligibility documentation if applying for or seeking to maintain public insurance (e.g., Medicaid, Medicare, SCHIP); compare coverage options if applicable; match to personal values, needs and preferences; and select coverage
- Before seeking treatment: ascertain benefit coverage restrictions or incentives such as mental health benefits limitations, pre-certification requirements, access restrictions to specialists or adjunct health providers, and variables in co-pays for specific types of care or providers
- Maintain or adjust coverage in the event of changes in employment, eligibility or family status (i.e., job change, marriage, divorce, birth of child)
- Maintain all receipts for drugs, devices and services; submit any documentation of services and/or payments upon request or as needed for thirdparty payers (e.g., private insurance, medical/flexible health savings accounts or public payers) and submit payment; negotiate schedule and amount if necessary

### What’s at stake?

Individuals are likely to pay more for less if they seek care without using available information to inform their choices about the cost and quality of providers, treatments and plans (where relevant), fail to maintain records of services and payments, and do not adjust coverage when circumstances change. “Less” may take the form of poorer quality care, fewer services covered by insurance, unnecessary out-of-pocket expenses or higher cost for similar quality services.\(^{55-67}\)

### What actions do people now take?

#### Highlights

- One in 10 compare the quality of health plans to inform their choice of coverage, even though 44 percent recognize there are big differences in health plan quality.\(^{50}\) A larger group—about one in three—may consider cost or other factors before making a decision or obtaining a medical service.
- While 44 percent of American adults are aware that the quality of health plans varies considerably, only 9 percent of respondents in 2008 had seen and used information comparing the quality of health insurance plans.\(^{50}\)
- Among Internet users who had a choice of health plans, one in three compared their options before making a decision.\(^{44}\)
- Among Medicare beneficiaries with a disability, 28 percent have looked for information about Medicare, Medicaid and supplemental insurance, such as to learn about coverage.\(^{68}\)
- In 2007, 30 percent of Americans reported spending time on paperwork or disputes concerning medical bills and health insurance.\(^{49}\)
- Most hospitals discharge patients with complex medical needs without giving them a written care plan or helping schedule follow-up medical appointments.\(^{60}\)
Relatively few people act to reduce the costs of their care.

- Among privately insured adults (age 21-64 who received medical care in the 12 months prior to a 2008 survey or after enrolling in their current health plan), 44 percent said they had talked to their doctors about treatment options and costs.\(^{49}\)
- One-third of online adults made sure their health insurance plan would cover a service before they obtained that care.\(^{44}\)
- One in three people who are uninsured have asked how much a treatment would cost.\(^{69}\) The same proportion said they would consider cost or other factors before making a decision or obtaining a medical service.
- Uninsured people with chronic conditions say they reduce costs by forgoing medical care and prescriptions and relying on hospital emergency departments.\(^{39,70}\)
- In a survey of people covered by health plans based on high deductibles, 39 percent of those who were aware of applicable deductible expenses reported that instead of going to an emergency department, they elected to delay care, contacted a health professional by telephone or the Internet, did not seek care or pursued another alternative. Thirty percent indicated they delayed or avoided medical tests because of cost concerns.\(^{71}\)

**Quality is Not a Major Factor in People’s Choice of a Health Plan**

Among American adults, 44 percent are aware that the quality of health plans varies considerably, but few appear to consider this in choosing a health plan. Nine (9) percent of respondents in 2008 had seen and used information comparing the quality of health insurance plans.\(^{50}\)

Polling Internet users, a 2009 online survey produced very different results. Among online adults who had a choice of more than one insurance company, one in three compared health plans as part of their purchasing decision.\(^{44}\) (See Find Safe, Decent Health Care section for additional data about choosing a health plan.)

Among Medicare beneficiaries with disabilities surveyed in 2002, 28 percent said they had sought information about Medicare, Medicaid, Medicare HMO or supplemental insurance, to learn about coverage.\(^{68}\)

**Relatively Few Strive to Minimize Health Care Outlays**

Information about a health plan’s provider network, formulary, covered benefits and member cost-sharing terms can help people take into account potential out-of-pocket expenditures when they have to make a medical decision. Yet, a large majority (two-thirds or more) appears to take a passive approach.

About one-third of Internet users checked their health plan’s coverage for a treatment before going to the hospital or verified that the hospital accepted their insurance.\(^{44}\)

Even with health plan coverage, people can struggle with paying for needed medical care. Many families affected by cancer have had serious financial difficulties due to medical expenses, reduction in job earnings and other costs.
Actions taken to deal with the financial burden include:

- Borrowing from relatives (13 percent).
- Seeking charity or public assistance (11 percent).
- Getting a loan (7 percent).
- Declaring bankruptcy (3 percent).  

Medical bills can quickly add up, especially for the uninsured. Yet in 2009, seven in 10 uninsured Americans had not asked about the price of a treatment.  

In recent years, insurers have developed high-deductible health plans that are designed, in part, to make individuals more cost-conscious in obtaining health care.

In a survey of people covered by high-deductible health plans, those who were aware of applicable deductible expenses reported altering their care-seeking behaviors due to out-of-pocket costs.
5 Make Good Treatment Decisions

What must people do to benefit?

- Gather additional expert opinions on any serious diagnosis prior to beginning any course of treatment
- Ask about the evidence for the efficacy (risks and benefits) of recommended treatment options
- Evaluate treatment options
- Negotiate a treatment plan with the provider(s)

What’s at stake?

People who understand what their treatment is, how it is supposed to work, and the risks and benefits it poses will have greater confidence that the treatment plan is the right one for them, i.e., that it balances their health needs with their personal preferences and conforms to a standard of evidence acceptable to them. And they have a greater likelihood of adhering to the treatment, working with their provider on modifications to the plan and realizing a positive outcome.⁸ ⁹

What actions do people now take?

Highlights

In the past two years, 82 percent of adults age 40 and older have made a significant medical decision.⁷² Yet, their participation in making treatment decisions is hardly explored in national health surveys. The limited data show that:

- One in four people turn to the Internet to supplement information from a health care provider about a specific preventive screening, medication or elective surgery.⁷² A large majority of people make decisions primarily based on their doctors’ recommendations.⁴⁴,⁷²,⁷³
- Among Internet users who have been prescribed drugs, two in three have not compared available treatments.⁴⁴
- Men were asked about their discussions with health care providers regarding the prostate-specific antigen (PSA) screening test. In 74 percent of the discussions, the provider recommended PSA testing. Of the men who received a recommendation for testing, 86 percent opted to have the test. ⁷²

Use of Second Opinions to Inform Decisions

In a limited survey conducted with women in Los Angeles and Detroit who had breast cancer surgery, 19 percent of the patient sample reported getting a second opinion when choosing between breast conservation surgery or mastectomy as part of their treatment. Thirteen percent of women with a high school diploma or less sought a second opinion, compared with 28 percent of college graduates.⁷⁴
6 Participate in Treatment

What must people do to benefit?

- Learn about any newly prescribed medications and devices, including possible side effects or interactions with existing medications and devices
- Fill or refill prescriptions on time, monitor medication effectiveness and consult with prescribing clinician when discontinuing use
- Maintain devices
- Evaluate and receive recommended diagnostic and follow-up tests in discussion with health care providers
- Monitor symptoms and conditions (e.g., for diabetes—monitor glucose regularly, check feet; for depression—medication and/or counseling and monitor symptoms; for hypertension—measure blood pressure regularly, maintain blood pressure diary), including danger signs that require urgent attention

What's at stake?

The implementation of treatment recommendations blended with patient perspectives creates a mutually agreed upon treatment plan. This plan is the vehicle through which a clinician’s knowledge and experience and a patient’s values and behaviors will affect the course of the patient’s disease.

Treatment participation is most commonly measured as compliance with physician directives. Low adherence to prescription drug treatments and chronic disease management regimens increases the risk of ill health, the need for hospital services and death.75-79

What actions do people now take?

Highlights

Following treatment plans, including lifestyle changes, can entail a range of activities. Available data consistently indicate large groups of people are not following recommendations for prescription drugs or their providers’ treatment or discharge plans.

- A majority of adults (about 55 percent) do not consistently read information about a new prescription or follow medication directions.44,58 One in three adults say they have never confirmed that their medication from the pharmacy matches their doctor’s script.50
- One in four chronically ill people age 50 and older have not complied with their doctor’s recommendations. Common lapses are related to filling prescriptions, scheduling a follow-up appointment and making a lifestyle change.62
- Self-reports of carefully following their regimens range from 25 percent of people being treated for asthma to 66 percent of people being treated for stroke.52 Notably, the higher the medical stakes (e.g., risk for serious complications), the better the adherence.80
A Snapshot of People’s Engagement in Their Health Care

**Highlights**

- A majority of adults who have been diagnosed with high blood pressure or another heart condition (56 percent) do not regularly check their blood pressure. Also, one in five adults who have been diagnosed with diabetes (19 percent) admit they have never monitored their blood sugar, and an additional 15 percent check it infrequently.63

**People are Casual in their Adherence to Medication**

When asked in abstract terms in 2009, three quarters of adults (75 percent) said they were confident that their medications are effective. People’s actions tell a different story.

- Just 40 percent of Internet users indicated that they always take medications as directed.44
- 30 percent of adults had never compared a medication they received from a pharmacist against their doctor’s order.50

Twenty-one percent of Medicare beneficiaries had qualms about their ability to recognize signs they are experiencing medication side effects. Data from the same survey, though, suggest that many more older people may lack the basic knowledge to identify side effects. As shown in Figure 3, a large group of Medicare beneficiaries—31 percent—indicated that they never or just sometimes read information about a new prescription, such as side effects and precautions. Only 44 percent always do so.58

**Figure 3. Medicare Beneficiaries and How Often They Read New Prescription Information, 2004**

<table>
<thead>
<tr>
<th>Frequency of Reading New Prescription Information</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>14%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>17%</td>
</tr>
<tr>
<td>Usually</td>
<td>24%</td>
</tr>
<tr>
<td>Always</td>
<td>44%</td>
</tr>
</tbody>
</table>

Figures may not add up to 100 percent due to rounding. Source: Data are from Medicare Current Beneficiary Survey, Patient Activation Supplement, 200458

About half of the people with an asthma diagnosis have reported experiencing symptoms at least once a week, which can be a sign of persistent or poorly controlled asthma.81 In a regional survey about asthma, 45 percent of people with asthma said they had not taken a prescription asthma medication in the previous 30 days. The other 55 percent used their medications, but not always on a daily basis: 20 percent said they took their medication 14 or fewer days per month; 3 percent estimated they took their medication 15 to 24 days per month; and 31 percent said they took their prescription asthma medication all or nearly all days in the previous month.81
Adherence to Recommendations for Chronic Disease Care is Sporadic

Given the complexity of managing some chronic conditions, acquiring new skills and knowledge may be necessary. A small majority (55 percent) of adults who have diabetes reported they have taken a class about self-care for their condition.81

Among privately insured adults age 21-64 who report having a specific chronic condition, adherence to treatment recommendations varies.52 Between 25 and 66 percent of respondents strongly agreed that they follow their treatment regimens very carefully, as depicted in Figure 4.

Figure 4. Percentage of Privately Insured Adult Internet Users Who Follow Treatment Regimens Very Carefully, 2008

<table>
<thead>
<tr>
<th>Medical Condition Being Treated</th>
<th>Percent Reporting They Very Carefully Follow Treatment Regimen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allergies</td>
<td>25%</td>
</tr>
<tr>
<td>Arthritis</td>
<td>31%</td>
</tr>
<tr>
<td>Asthma, emphysema or lung disease</td>
<td>37%</td>
</tr>
<tr>
<td>Depression</td>
<td>38%</td>
</tr>
<tr>
<td>High cholesterol</td>
<td>44%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>50%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>57%</td>
</tr>
<tr>
<td>Hypertension or high blood pressure</td>
<td>59%</td>
</tr>
<tr>
<td>Cancer</td>
<td>61%</td>
</tr>
<tr>
<td>Stroke</td>
<td>66%</td>
</tr>
</tbody>
</table>

Source: Employee Benefit Research Institute (2008)52

Among adults (age 18-64) who have been diagnosed with high blood pressure or another heart condition, 56 percent do not regularly check their blood pressure, according to a telephone survey conducted in English and Spanish. Also, 19 percent of adults (age 18 and older) who have type 1 or 2 diabetes admit they have never monitored their blood sugar, and an additional 15 percent check their blood sugar only once or twice every two weeks.82

These survey results about people and adherence to treatment plans correspond with a meta-analysis by researchers at the University of California, Riverside. They found that people tend to adhere to prevention or treatment when they perceive a disease or condition to be a serious threat, such as cancer or a heart attack. Adherence is lower when the condition is considered to be less severe.80

One in four people age 50 or older with chronic illness (27 percent) conceded they do not follow their clinician’s recommendations. Figure 5 shows that some common lapses included not filling a prescription, not scheduling a follow-up appointment and not making lifestyle changes.62
### Figure 5. Percentage of Chronically Ill Persons Age 50 and Older Saying They Did Not Follow Health Professional's Recommendation, 2008

<table>
<thead>
<tr>
<th>Type of Medical Recommendation</th>
<th>Percent Reporting Noncompliance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fill a prescription</td>
<td>30%</td>
</tr>
<tr>
<td>Schedule a follow-up appointment</td>
<td>18%</td>
</tr>
<tr>
<td>Adopt a healthy lifestyle practice</td>
<td>18%</td>
</tr>
<tr>
<td>Undergo a medical test</td>
<td>12%</td>
</tr>
<tr>
<td>Have surgery</td>
<td>4%</td>
</tr>
<tr>
<td>Any type of noncompliance</td>
<td>27%</td>
</tr>
</tbody>
</table>

7 Promote Health

What must people do to benefit?

- Set and act on priorities for changing behavior to optimize health and prevent disease
- Identify and secure services that support changing behavior to maximize health and functioning and maintain those changes over time
- Manage symptoms by following treatment plan, including diet, exercise and substance use agreed upon by the individual and the provider

What’s at stake?

Daily habits have a profound influence on individuals’ health and the prevention, onset and management of acute and chronic conditions. There is considerable evidence that increased excise taxes on tobacco products, enactment of helmet and seat belt laws, and greater access to fresh fruit and vegetables, and safer streets for walking make it more likely that people will act in ways to promote their health.\textsuperscript{83,84} There is also evidence that clinicians’ recommendations and referrals can influence an individual’s willingness to use community-based programs, such as Alcoholics Anonymous and Weight Watchers, or drugs for smoking cessation and appetite control.\textsuperscript{85,86} The hard work of changing health habits and maintaining new ones over time rests with individuals, as do the considerable potential benefits of doing so.

What actions do people now take?

Highlights

People differ in the degree to which they believe their actions can prevent illness and improve their health, and they vary in their ability and willingness to act consistently to decrease their risks.

People generally follow a few of the main recommendations to prevent illness and accidents, such as not smoking and always wearing a seat belt.\textsuperscript{64,65}

- Twenty-four percent of Americans adults eat at least five fruits and vegetables a day.\textsuperscript{66}
- About half the population does not get enough physical activity on most days.\textsuperscript{66}
- Poor eating and activity habits contribute to excess weight, a problem affecting two in three Americans.
- In behaviors that must be practiced most days to get health benefits, the majority has trouble. Between 50 and 75 percent have not done any of the following: kept their weight down, eaten enough fruits and vegetables, and been physically active.\textsuperscript{87,88}

Uneven Performance of Basic Health Behaviors

When asked in abstract terms, a majority of Internet users indicated they do not make an effort to improve their health. In 2009, 44 percent of survey respondents said they were eating more healthy foods. A health-oriented minority were also striving to manage their weight (39 percent) and exercising (35 percent).\textsuperscript{44}
In terms of specific health behaviors that experts recommend, Figure 6 shows uneven performance, as reported by the Centers for Disease Control and Prevention and Harris Interactive. At the low end of participation is eating the recommended amount of at least five fruits and vegetables a day, which only 24 percent of Americans do.\(^8^8\) About half of the population does not get enough physical activity on most days.\(^8^8\) Poor eating and activity habits contribute to excess weight, a problem affecting two in three Americans. Just 37 percent keep their weight in the healthy range.\(^8^7\)

The vast majority of Americans are not smokers or heavy drinkers, but the 18 and 16 percent who do smoke or binge drink, respectively, are increasing their risk—and the risk of others around them—for disease and injury.\(^8^9\) More widespread adoption of healthful behaviors is possible, as demonstrated with seat belt use. Nine in 10 Americans reported buckling up in the car.\(^9^0\)

**Figure 6. Percentage of Adults at Select Educational Levels Practicing Various Health Behaviors, 2007—2009**

<table>
<thead>
<tr>
<th>Health Behavior (Year Collected)</th>
<th>All Education Levels</th>
<th>Less than High School Diploma</th>
<th>College Graduate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat five or more servings of fruits and vegetables per day (2007)(^8^8)</td>
<td>24%</td>
<td>18%</td>
<td>30%</td>
</tr>
<tr>
<td>Maintain a healthy weight (2008)(^8^7)</td>
<td>37%</td>
<td>35%</td>
<td>40%</td>
</tr>
<tr>
<td>Get 30 or more minutes of moderate physical activity on five or more days per week (2007)(^8^8)</td>
<td>50%</td>
<td>40%</td>
<td>54%</td>
</tr>
<tr>
<td>Do not smoke cigarettes (2008)(^9^7)</td>
<td>82%</td>
<td>70%</td>
<td>91%</td>
</tr>
<tr>
<td>Avoid binge drinking(^a) (2008)(^8^7)</td>
<td>84%</td>
<td>89%</td>
<td>82%</td>
</tr>
<tr>
<td>Always wear seat belt when in the front seat of a car (2009)(^9^0)</td>
<td>91%</td>
<td>not available</td>
<td>not available</td>
</tr>
</tbody>
</table>

\(^a\)Binge drinking for men is having five or more drinks on one occasion; for women it is having four or more drinks. Sources: National Center for Chronic Disease Prevention and Health Promotion (2008)\(^8^7,8^8\); Centers for Disease Control and Prevention (2008)\(^9^1\); Harris Interactive (2009)\(^9^0\)

In recent years, the proportion of Americans who practice the health behaviors featured in Figure 6 has remained stable or even declined, with the exception of seat belt use, which has gradually risen over 25 years.\(^8^7,9^0\)
Get Preventive Health Care

What must people do to benefit?

- Evaluate recommended screening tests in discussion with health care provider
- Act on referrals for early detection screenings (e.g., breast cancer, colon cancer)
- Get recommended vaccines and participate in community-offered screening and wellness activities as appropriate

What’s at stake?

Considerable evidence points to the population benefits of regular use of a range of preventive services administered by clinicians, from cancer screenings to cholesterol-reducing drugs to flu vaccines.92

While none of these interventions is 100 percent effective, those that are strongly recommended by the US Preventive Services Task Force decrease the likelihood of poor outcomes for individuals who practice the ones appropriate to their age, sex and health history.92

What actions do people now take?

About half (52 percent) of adults do not receive routine care, such as physical examination or check-up.86 Nonetheless, people are more likely to obtain recommended clinical services than to practice a healthy lifestyle.

Highlights

- About 40 percent of people do not get preventive health care that reduces the risk of infections and detects disease early, when treatment can be most effective.87-89

Figure 7 shows that, as reported by the CDC, the majority of adults get some type of preventive care from a health professional. About half of older people have been vaccinated against seasonal flu or pneumococcal infections. Two in three mid-life and older adults have been screened for colorectal or breast cancer. Finally, three in four people have had their blood cholesterol levels checked or have been screened for cervical cancer.87,89

Figure 7. Percentage of Adults by Select Income Groups and Receipt of Various Clinical Preventive Services, 2005—2008

<table>
<thead>
<tr>
<th>Clinical Preventive Service (Year Collected)</th>
<th>Population</th>
<th>Percent Receiving</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>All Incomes</td>
</tr>
<tr>
<td>Influenza vaccination during previous 12 months (2008—09)</td>
<td>Adults 50 and older</td>
<td>50%</td>
</tr>
</tbody>
</table>
A Snapshot of People’s Engagement in Their Health Care

<table>
<thead>
<tr>
<th>Clinical Preventive Service (Year Collected)</th>
<th>Population</th>
<th>Percent Receiving</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>All Incomes</td>
<td>Below 100% of Poverty</td>
<td>200% or More Above Poverty</td>
</tr>
<tr>
<td>Pneumococcal vaccination, ever (2006)³⁹</td>
<td>Adults 65 and older</td>
<td>57%</td>
<td>45%</td>
<td>60%</td>
</tr>
<tr>
<td>Colorectal cancer screening ever via sigmoidoscopy or colonoscopy (2008)³⁷</td>
<td>Adults 50 and older</td>
<td>62%</td>
<td>52%&lt;sup&gt;a&lt;/sup&gt;</td>
<td>67%&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Mammogram within the past 2 years (2005)³⁰</td>
<td>Women age 40 and older</td>
<td>67%</td>
<td>49%</td>
<td>73%</td>
</tr>
<tr>
<td>Cholesterol screening within the previous 5 years (2008)³⁸</td>
<td>Adults 18 and older</td>
<td>75%</td>
<td>66%&lt;sup&gt;a&lt;/sup&gt;</td>
<td>82%&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Pap smears within the past 3 years (2005)³⁰</td>
<td>Women age 18 and older</td>
<td>78%</td>
<td>69%</td>
<td>82%</td>
</tr>
</tbody>
</table>

Notes: <sup>a</sup>Annual household income less than $15,000; <sup>b</sup>Annual household income $50,000 or more

Sources: National Center for Health Statistics (2008),³⁹ National Center for Chronic Disease Prevention and Health Promotion (2008),³⁷ National Center for Chronic Disease Prevention and Health Promotion (2007)³⁸

The flip side of Figure 7 is that millions of Americans are not getting the preventive care they need to protect their health and identify diseases early. Half of the population could readily be protected against influenza and pneumococcal disease but does not arrange to receive the appropriate vaccines. More than 25 percent of Americans have not been screened for various types of cancer or had their blood cholesterol levels checked in recent years.³⁷,³⁹
9 Plan for the End of Life

What must people do to benefit?

- Complete advance directives and medical power of attorney; file with personal records
- Discuss directives with family physician and other health care providers, appropriate family and/or significant others
- Review documents annually; update and distribute as needed

What's at stake?

Legal forms that document the wishes and preferences of individuals for health care can help guide decisions, in the event that they are not able to speak for themselves, and reduce the likelihood of receiving care that is inconsistent with their wishes.93

What actions do people now take?

Highlights

- Two in three older people have told their adult children how to handle their medical care if they can no longer make their own decisions.63
- One in three Americans have a living will or a legal document covering their preferences for palliative care.94,95
- The majority of people relying on a caregiver have not shared their preferences for future treatment with that caregiver.61

Most people have not documented their wishes about treatment during the last stages of their lives. Two in three older people (63 percent) have discussed with their adult children how to handle their medical care if they can no longer make their own decisions, according to a Pew Research Center survey of adults age 65 and older. A smaller majority of older people—55 percent—has talked to their adult children about what to do if they can no longer live independently. In contrast, 76 percent have talked with their children about their wills and family belongings.63

Many chronically ill persons who rely on a caregiver have not discussed with their caregiver their preferences for future treatment. In 2001:

- 46 percent of (Internet-using) caregivers were unsure what their care recipient wanted in terms of future treatments as their illnesses progressed.
- 49 percent of care recipients had signed a durable power of attorney, and 45 percent had signed a living will.61

The vast majority of people surveyed in a regional study in California—83 percent—viewed written
end-of-life wishes as important to their stage of life. Yet, just 36 percent have acted on these beliefs by developing a living will, advance directive or other written document.\textsuperscript{95}

In 2005, just 29 percent of adults (age 18 and older) had a living well. Figure 8 shows that the likelihood of having a living will increases with age and education.

**Figure 8. Select Adult Groups and Rates of Having a Living Will, 2005**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percent Having a Living Will</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Young adults (age 18–29)</td>
<td>12%</td>
</tr>
<tr>
<td>Older adults (age 65 and older)</td>
<td>54%</td>
</tr>
<tr>
<td><strong>Educational Attainment</strong></td>
<td></td>
</tr>
<tr>
<td>High school graduate or less</td>
<td>26%</td>
</tr>
<tr>
<td>College graduates</td>
<td>35%</td>
</tr>
<tr>
<td><strong>Experience Helping Decide Treatment for Seriously Ill Loved One</strong></td>
<td></td>
</tr>
<tr>
<td>Inexperienced</td>
<td>26%</td>
</tr>
<tr>
<td>Experienced</td>
<td>45%</td>
</tr>
</tbody>
</table>

Source: Pew Research Center for the People and the Press (2006)\textsuperscript{90}
10 Seek Health Knowledge

What must people do to benefit?

- Assess personal risks for poor health, disease and injury, and seek knowledge about health and disease prevention
- If diagnosed with a chronic disease, understand the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health and or disease knowledge.
- Know personal health targets (e.g., target blood pressure)

What's at stake?

As individuals take on more responsibility to deliver care to themselves and their loved ones, finding trustworthy, accurate sources of information to guide health-related actions is critical.

What actions do people now take?

Highlights

- Although people prefer to get information from their doctor, the majority turn to other sources.\(^{58,96}\)
- Traditional sources of health information dominate even though online information is available on demand 24 hours a day, seven days a week. People seek information from a wide variety of traditional sources, including newspapers, magazines, television, doctors, friends, family, health plans and employers.\(^{40,42,52,96}\)
- Online information tends to supplement these traditional sources.\(^{40,42,52,96}\) The Internet is used by 61 percent of all adults for finding out about medical options and treatments.\(^{40}\)
- About half of those who seek information report that they act on what they have learned.\(^{42,97}\)
- Sources of information vary for different generations and by education.\(^{96}\) Topics vary by stage of life.\(^{51}\)
- People with more education and higher health literacy levels have a greater likelihood of seeking health information than others.\(^{98-100}\)
- Half of all adults do something to educate themselves, most often by getting information about a specific health concern.\(^{44,58}\) Medical treatments and fitness activities are other popular topics. This information may be for ourselves for someone we are helping.\(^{40,42}\)
Health Information Sources

Most people use a variety of traditional and online sources of information, according to the Pew Research Center’s Internet & American Life Project. Its lead analyst, Susannah Fox, concludes that Internet users increasingly:

[T]reat the [I]nternet as a supplement to traditional sources of information, using blogs, podcasts, and other online resources to deepen their understanding of a condition and sharpen their questions for a health professional.40

Traditional Sources

Two in three Americans (67 percent) said they highly trust information from their doctor.96 This far exceeds the trust they place in other sources of health information. About 20 percent of respondents agreed they trust the Internet, television, family, magazines or newspapers “a lot” as a health information source. The least trusted source: only 12 percent said they highly trust information they hear on the radio.96

Although adults have a strong preference for information from their doctor, whether for costs, convenience or other factors, they rely on other sources as well. For example:

- Two-thirds of Internet users read online health information at least once a month.96
- More than half of Medicare beneficiaries (56 percent) said they always or usually read about health conditions in newspapers, magazines or Internet sources.58
- Each year the National Cancer Institute’s toll-free Cancer Information Service assists more than 100,000 callers.101

Figure 9 shows that the Internet was a common source in respondents’ most recent search for cancer information, particularly with college graduates. Of respondents with less than an high school diploma, they preferred obtaining information about cancer from health care providers and printed materials.96

Figure 9. Most Recent Source of Cancer Information for All Adults and by Select Education Levels, 2005

<table>
<thead>
<tr>
<th>Source of Cancer Information</th>
<th>Percent Using Source</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All Education Levels</td>
</tr>
<tr>
<td>Internet</td>
<td>48%</td>
</tr>
<tr>
<td>Health Care Provider</td>
<td>24%</td>
</tr>
<tr>
<td>Printed Materials (e.g., books, brochures, magazines, newspapers)</td>
<td>16%</td>
</tr>
<tr>
<td>Information Specialist (e.g., librarian, cancer organization information hotline)</td>
<td>8%</td>
</tr>
</tbody>
</table>
A Snapshot of People's Engagement in Their Health Care

<table>
<thead>
<tr>
<th>Source of Cancer Information</th>
<th>Percent Using Source</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All Education Levels</td>
</tr>
<tr>
<td>Interpersonal Source (e.g., family, friend, co-worker)</td>
<td>5%</td>
</tr>
<tr>
<td>Other (e.g., radio, television and other)</td>
<td>1%</td>
</tr>
</tbody>
</table>

Figure columns may not add up to 100 percent due to rounding.
Sources: National Cancer Institute (2007)

Cancer information sources vary by educational attainment. Health care providers were the most common recent source (40 percent) for people with less than a high school education, followed by printed materials (21 percent) and the Internet (17 percent). In contrast, a majority of college graduates (59 percent) turned first to the Internet, with health care providers and printed materials sources trailing at 15 percent.

There are also generational differences in sources. Young adults (age 18-34) heavily relied on the Internet (64 percent) for cancer information, while seniors age 80 and older turned to printed materials (38 percent) and health care providers (29 percent).

Getting Health Information Online

The Internet can be a quick, easy channel for getting health and medical information, although the quality and relevance of the information varies widely. Interactive features to obtain tailored information are popular. Increasingly, Internet users are connecting and conversing with other people about health or medical issues.

In the 2008 Pew Internet & American Life Project survey, 61 percent of all adults reported going online to get health information. Longitudinal Pew data indicate that more people are augmenting expert sources with online health-related information, experiences, reviews and answers to questions posted by other consumers. Internet users are applying this information to compare options, solve challenges or make a major decision. In other research, we have noted the rising use of consumer-to-consumer sources of information, which Americans increasingly trust as credible.

Beyond getting online reviews and ratings of health care providers, people have used the Internet for information about medical issues and healthy living, according to the Pew survey. Figure 10 shows that half the adult population (49 percent) has searched the Internet to find information about a specific health condition. Other popular health-related topics are treatments, physical activity and medications.

**Figure 10. Percentage of US Adults Seeking Health Information Online by Topic, 2008**

<table>
<thead>
<tr>
<th>Type of Online Information Sought</th>
<th>Percent of Adults Seeking Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific disease or medical problem</td>
<td>49%</td>
</tr>
<tr>
<td>Medical treatment or procedure</td>
<td>41%</td>
</tr>
</tbody>
</table>
A Snapshot of People’s Engagement in Their Health Care

<table>
<thead>
<tr>
<th>Type of Online Information Sought</th>
<th>Percent of Adults Seeking Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise and fitness</td>
<td>38%</td>
</tr>
<tr>
<td>Prescription or over-the-counter drugs</td>
<td>33%</td>
</tr>
<tr>
<td>Alternative treatments or medicines</td>
<td>26%</td>
</tr>
<tr>
<td>Weight loss or control</td>
<td>24%</td>
</tr>
<tr>
<td>Depression, anxiety, stress or mental health issues</td>
<td>21%</td>
</tr>
<tr>
<td>Experimental treatments or medicines</td>
<td>15%</td>
</tr>
</tbody>
</table>

Source: Fox, S., Jones, S. (2009)

Challenges to Finding Good Information

Interest in health topics varies across populations. Older (65 and older) online Californians are more likely to sometimes or often seek information about specific medical conditions or prescription drugs on the Internet (66 percent) than are young and midlife adults. Notably, people seek information not only for themselves, but also for friends and family. Respondents estimated that half of their health-related Internet queries are for someone else.

In 2005, 68 percent of adults said they were completely or very confident in their ability to get needed information. Respondents also reported challenging experiences with accessing cancer information.

- 48 percent of respondents strongly or somewhat agreed they had concerns about the quality of cancer information in their most recent search.
- 37 percent strongly or somewhat agreed their search took a lot of effort.
- 27 percent strongly or somewhat agreed they felt frustrated during their search.
- 24 percent strongly or somewhat agreed they found cancer information that was difficult to understand.

Finding Information Does Not Always Mean Using It

Half of health-information seekers say they acted on what they learned. Fifty-one percent indicated that the information (whether from traditional or online sources) had an impact on how they maintain their health. However, the sources and quality of the information respondents were using were not surveyed.

The 2008 Pew Hispanic Center survey went further in exploring information impact. It found health information from media sources influenced how a plurality of Hispanic adults approached health and health care. Among those getting health information from television, radio, Internet or print media:

- 41 percent of Hispanic adults said the information affected a treatment decision concerning an illness or medical condition.
- 57 percent said it prompted them to ask a health professional some new questions.
- 64 percent said it changed their thinking about diet and exercise.
A Snapshot of People’s Engagement in Their Health Care

Cross-Cutting Findings

Americans do not actively and consistently perform the actions directly linked to benefiting from available health care. This report has described wide variation in performance that exists among engagement behaviors. When survey data are viewed in aggregate, a clear gap appears between what individuals must do to benefit fully from their care and the actions they actually take.

This review of national surveys found that for the majority of engagement behaviors for which data were available:

- One-third of American adults are actively engaged at this time.
- About one-third of people can be characterized as disengaged or passive.
- A final third are tentative participants.

Because data came from 31 different surveys, it is impossible to analyze the extent to which individuals perform consistently across all behaviors. For example, it is not known whether those who are assiduous about adhering to their heart medications are also likely to use comparative quality information to choose their health plan and physician.

Figure 11 highlights some patterns of participation. People are more active — relative to other engagement behaviors — in finding health information, getting preventive health care, having a personal doctor, checking their health plan’s covered benefits and talking about preferences for end-of-life care. And people are less likely, in general, to use objective information to make health care decisions, take steps to communicate with health care providers, actively organize their health care, create legal documents about end-of-life care and make informed treatment decisions.

Note that even among behaviors with higher rates of participation in Figure 11, many people — often in the range of 30-50 percent — do not consistently perform them.

Figure 11. Relative Levels of Participation in Various Types of Behaviors

<table>
<thead>
<tr>
<th>Participation is Less Likely</th>
<th>Participation is More Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proactively communicate with health care providers</td>
<td>Have a personal or regular provider</td>
</tr>
<tr>
<td>Organize health care</td>
<td>Check that health plan will cover care</td>
</tr>
<tr>
<td>Make treatment decisions</td>
<td>Discuss potential benefits of a medical test or treatment with provider</td>
</tr>
</tbody>
</table>
A Snapshot of People’s Engagement in Their Health Care

<table>
<thead>
<tr>
<th>Participation is Less Likely</th>
<th>Participation is More Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow treatment plans for:</td>
<td>Follow treatment plans for:</td>
</tr>
<tr>
<td>- Allergies</td>
<td>- Cancer</td>
</tr>
<tr>
<td>- Arthritis</td>
<td>- Diabetes</td>
</tr>
<tr>
<td>- Lung conditions</td>
<td>- Heart disease</td>
</tr>
<tr>
<td>- Depression</td>
<td>- Hypertension</td>
</tr>
<tr>
<td>- High cholesterol</td>
<td>- Stroke</td>
</tr>
<tr>
<td>Promote health by eating plenty of fruits and vegetables, maintaining a healthy weight and being moderately active</td>
<td>Obtain immunizations, screenings and other preventive care from a health care provider</td>
</tr>
<tr>
<td>Put end-of-life plans into written or legal documents</td>
<td>Talk to adult children about what to do if one can no longer make decisions about care</td>
</tr>
<tr>
<td>Use objective information to:</td>
<td>Seek information about specific health conditions and medical care</td>
</tr>
<tr>
<td>- Select a health care provider or health plan</td>
<td></td>
</tr>
<tr>
<td>- Make a medical decision</td>
<td></td>
</tr>
<tr>
<td>- Compare treatments</td>
<td></td>
</tr>
</tbody>
</table>

Several patterns emerged when examining the survey data within and across the behavior sets.

- More people appear to perform simpler tasks (e.g., make a list of medications) than more complex actions (e.g., make informed treatment decisions).
- The depth of participation in any engagement behavior set tends to be shallow. For example, many more people seek out information about a provider or health plan than actually use the information to make a choice.
- People appear to defer information- and advice-seeking until they have a specific need. Thus, participation takes place “just-in-time.”
- Commonly reported barriers to participation include poor health as well as insufficient knowledge, skills, confidence, external support and insurance.
- Data show people of all ages use the Internet to help them learn about their health and health care. It is unknown, however, if Internet use has altered engagement performance levels or whether it merely supplants traditional modes of information-seeking and record-keeping such as telephone calls, doctor visits and paper-based records.

Many People are Reactive, not Proactive

When it comes to managing their health care, people tend to be more reactive than proactive. Most can be described as “just-in-time” participants who defer involvement until illness or injury strikes or appears imminent.

Just-in-time approaches reported in one 2009 survey, in which 90 percent of Internet users said “they would become active in improving their health if they were diagnosed with a chronic illness” (emphasis added). Based on this finding and other research, survey analysts concluded that demand for external support — such as education, resources and decision-making tools — is low until people get sick. At that point, “the needs curve soars.”

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Seeking health knowledge is a specific area in which surveys have documented just-in-time approaches. According to the 2007 national survey, half of Americans without any chronic conditions (50 percent) said they sought health information in the previous year. In contrast, 66 percent of people with two or more chronic conditions looked for health information over that period.\textsuperscript{41}

Even when health information is at their fingertips, relatively few Internet users go online daily — or even weekly — for a health-related purpose. The vast majority, 81 percent, of online adults turn to the Internet less than once a week as a resource to learn about health or health care, as reported in the 2008 Pew Internet & American Life Survey.\textsuperscript{40} When Internet users do go online for their health, Pew’s Susannah Fox reports that this group is seeking tailored information that answers a specific question or need at a time proximate to their actual need.\textsuperscript{40}

**Who Is Less Likely to Participate?**

When people are disengaged or hesitant in their care, it is sometimes because of sociodemographic characteristics that constitute barriers to understanding and action. All engagement behaviors require motivation, time, energy and attention to perform; many also require knowledge, skills and resources. Individuals with lower engagement levels tend to be people with one or more of the characteristics in Figure 12.

**Figure 12. Characteristics Related to Low Active Participation in Care**

<table>
<thead>
<tr>
<th>Observed Patterns in National Survey Data</th>
<th>Characteristics Related to Low Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consistently Low Participation</td>
<td>• Low education (a high school diploma or less)</td>
</tr>
<tr>
<td></td>
<td>• Marginal health literacy</td>
</tr>
<tr>
<td></td>
<td>• Low incomes</td>
</tr>
<tr>
<td></td>
<td>• Multiple chronic conditions or poor health</td>
</tr>
<tr>
<td></td>
<td>• No health insurance</td>
</tr>
<tr>
<td></td>
<td>• Low numeracy</td>
</tr>
<tr>
<td></td>
<td>• No Internet access</td>
</tr>
<tr>
<td>Low Participation, but Some Exceptions</td>
<td>• Older age</td>
</tr>
<tr>
<td></td>
<td>• Marginal health literacy</td>
</tr>
</tbody>
</table>

Appendix C provides a detailed account of the characteristics of participation for each of the behavior sets.

As the data in Appendix C indicate, individuals who almost always are less likely to perform engagement behaviors are those with one or more of these characteristics: low educational attainment, marginal health literacy, low incomes, multiple chronic conditions or poor health, no health insurance and low numeracy. Overall, individuals with older age or marginal health literacy tend to have lower engagement levels than younger adults and the health literate, but variations exist.

In general, older people appeared to experience more barriers or need help for many of the behaviors.
As individuals age, they increasingly rely on adult children for help paying bills, completing paperwork, getting to appointments and taking care of errands.\textsuperscript{63}

Nonetheless, older adults are more active than younger adults in obtaining a usual source of care or a living will.\textsuperscript{51, 94} With regard to other behaviors, different generations can have similar performance levels but may participate in different ways. For example, older people tend to rely more on traditional information sources, while younger generations turn more to Internet sources.\textsuperscript{96} Low health literacy also can interfere with the ability to adhere to prescribed medications and self-care. Adults with marginal health literacy tend to have less knowledge about their health conditions, and be less skilled in managing those conditions, than peers with better health literacy.\textsuperscript{99, 100, 103, 104}

However, studies comparing treatment adherence by health literacy levels present a varied picture. Some studies found associations between low health literacy and low compliance with providers’ recommendations. In other studies, people with low health literacy appeared to follow self-management regimens better than peers with higher literacy. It may be that once people with lower health literacy levels gain the skills to manage a condition, they are more likely to adhere to directions.\textsuperscript{99, 100, 103-105}

Millions of Americans have at least one of the Figure 12 characteristics (see Figure 1 in the Introduction for detailed statistics). This means that many US adults may be unable to meet the health system’s expectations without assistance. Yet, many national surveys do not ask whether respondents need or use external support; further, most surveys do not drill down to collect and examine response rates by these sociodemographic characteristics. Without these types of data, it is impossible to describe the nuances of participation in care by populations with potential disadvantages (such as those listed in Figure 12).

### National Surveys Provide a Partial Picture

Data about participation in engagement behaviors are scattered across the many surveys reviewed. The review of the 31 surveys make it possible to provide only a rough estimate of participation levels in each of the ten sets of engagement behaviors.

Major gaps exist in what national surveys reveal about how people act to make good use of available health care. No single survey queried subjects on all of the engagement behaviors. Figure 13 shows the information gaps that exist for eight sets of behaviors. The behavior sets relevant to promoting health and getting preventive health care are omitted because survey data are relatively extensive in these two areas. Four behavior sets were particularly sparse in data: communicate with health care providers, organize health care, make good treatment decisions and plan for the end of life.

<table>
<thead>
<tr>
<th>EBF Behavior Set</th>
<th>Major Gaps in Survey Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Find Safe, Decent Care</td>
<td>• Find provider who fits personal criteria and accepts new patients with health insurance plan</td>
</tr>
<tr>
<td></td>
<td>• Get appropriate health care when needed</td>
</tr>
</tbody>
</table>

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39
## EBF Behavior Set

### Communicate with Health Care Professionals
- Prepare questions and medication lists before appointment
- Report current symptoms and medical history
- Ask questions, discuss concerns and communicate so next steps are clear
- During acute illnesses, take other steps as needed to promote effective communications with health care professionals

### Organize Health Care
- Maintain a personal health record summarizing services received, treatment plans, test or screening results and providers seen
- Bring a summary of health/medical record to appointments
- Coordinate exchange of important information between providers
- As needed:
  - Arrange for assistance if facility is not accessible
  - Have a trusted person assist during the appointment

### Pay for Health Care
- Select coverage that meets personal needs, values and preferences
- Learn about benefit coverage before seeking care
- Keep records and fill out forms to obtain reimbursements, tax deductions or health plan authorizations
- As needed or as applicable:
  - Apply for and maintain public insurance coverage
  - Maintain or adjust coverage for changes in job, eligibility or family status
  - Track payments and reimbursements
  - Negotiate payments for medical bills

### Make Good Treatment Decisions
- Get a second opinion when diagnosis is serious
- Ask about risks and benefits of treatment options
- Evaluate treatment options
- Negotiate a treatment plan with provider(s)

### Participate in Treatment
- Learn about newly prescribed medical devices
- Monitor medication effectiveness and identify possible side effects or interactions with other prescriptions
- Consult with prescribing health professional when discontinuing use
- Maintain devices
- Evaluate proposed diagnostic and follow-up tests in discussion with health care providers; obtain tests as applicable
- Build knowledge and skills to enact treatment plan
<table>
<thead>
<tr>
<th>EBF Behavior Set</th>
<th>Major Gaps in Survey Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan for the End of Life</td>
<td>• Complete legal documents about preferences for end-of-life care</td>
</tr>
<tr>
<td></td>
<td>• Discuss directives with health care professionals, family, caregivers and significant others</td>
</tr>
<tr>
<td></td>
<td>• Review documents annually; update and distribute as needed</td>
</tr>
<tr>
<td>Seek Health Knowledge</td>
<td>• Assess personal risks for poor health, disease and injury</td>
</tr>
<tr>
<td></td>
<td>• Increase knowledge about health and self-care in traditional (and online) sources of information and education</td>
</tr>
<tr>
<td></td>
<td>• Develop understanding of diagnosed condition(s)</td>
</tr>
<tr>
<td></td>
<td>• Know personal health targets and what to do to meet them</td>
</tr>
<tr>
<td></td>
<td>• Apply new knowledge in health care decisions</td>
</tr>
</tbody>
</table>

**Limitations of this Review**

The aim of this effort is to provide a rough picture of the prevalence of engagement behaviors among adults in the United States. Some specific limitations of this review include the following.

Beyond the incomplete content derived from the surveys reviewed, survey methods represented another challenge. Data were drawn from telephone, pen and paper, in-person and online surveys. Some were conducted nationally, some by state, others by region. Sample sizes varied. Each of these limits conclusions that can be definitively drawn in the analysis.

For example, of the small subset of surveys that were conducted online, Internet users tend to have higher incomes and more education than people who do not go online. By reaching only a select population, online surveys can inflate the participation levels of behaviors because those who face barriers to using the Internet share a number of characteristics with those who are less likely to be involved in their care. This exaggeration in participation levels is apparent when responses to similar survey questions fielded via the Internet were compared with those from telephone surveys.

Similarly, as phone ownership patterns evolve, the state of representative sampling is in flux. Land telephone line surveys suffer from skewing towards an older, traditional population instead of balancing with more transient or younger populations who are likely to have only mobile phones.
A Snapshot of People’s Engagement in Their Health Care

Goals and Recommendations

There has never been a more critical nor more opportune time for attention to be paid to our critical role as individuals in realizing the promise of health care to improve our health and the health of the nation. Health care reform will increase our access to care, but without our active, knowledgeable participation — from both the currently and newly insured -- reform will yield only sporadic and modest improvements. On the other hand, reform provides a window of opportunity to put in place new policies, practices and procedures that could provide considerable guidance and support for our participation in our care if they are designed with this objective in mind.

While each of us must — along with our caregivers and families — take on these responsibilities if we are to benefit optimally from our health care, we cannot do so without the cooperation of every stakeholder in the health care enterprise. Performing these behaviors requires that health professionals, institutions and organizations fully recognize the centrality of our role in effective health care and are organized to welcome and support our participation at every step along the way.

This review shows that a sizable majority of us do not perform many of behaviors required to find and make good use of the health care available to us. It does not explain why we do or don’t perform each of these behaviors when it is in our interest to do so; it doesn’t shed light on the individual, cultural, institutional or resource-related barriers we face in doing so; and it doesn’t prescribe interventions to ameliorate the barriers. Rather, it provides information critical to taking strategic actions to increase support for engagement — resources allocated, priorities established, research conducted and problems solved.

While the snapshot of the depth and range of our current participation in care appears discouraging, it is important to remember that we have made significant changes in health-related behavior before. Hibbard’s research shows about 40 percent of Americans express confidence that they can actively participate in their care. Americans smoke less than in the 1960s, people with high-deductible health plans have altered how and when they seek care, and people with chronic diseases have improved their self-care.

Increasing People’s Engagement in Their Care:

We propose the following three goals to increase and support individual engagement.

Goal #1: More effective actions by individuals

Most of us are mostly healthy most of the time and are thus unaware of the constant changes in health care delivery and their implications for our own actions. Further, there is little continuity across delivery settings. We are often unaware of many of our new responsibilities which, if not fulfilled, cause confusion and waste time and resources.

Make responsibilities clear. Providers, plans, practices, hospitals and professional societies such as the American Academy of Pediatrics, the American Academy of Family Physicians and American College of Physicians can encourage their members to make explicit the terms of engagement: Providing basic information to us about how we can most effectively interact with a practice and discussing with us our responsibilities and those of our doctor or care team is necessary for us to
work well with a practice and emphasizes our role in the shared enterprise of our care.

The introduction of new health care models such as Accountable Care Organizations and Primary Care Medical Homes will also present new challenges for patients and caregivers as they adjust to changes in practice and delivery. Information, guidance and support for users will be critical factors in the implementation and adoption of these new systems of care.

Support the development and implementation of new effective strategies. The National Institutes of Health, the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Disease Control and Prevention (CDC) should invest in assessing the barriers we face in actively participating in our health care. Research should be conducted to develop and test both targeted and broad strategies to support our performance of specific engagement behaviors in all relevant settings — individual, provider, institutional, employer, plan and community.

Goal #2: Better tools for individuals

The proliferation of tools and applications to help us manage our health care assume that many of us are hungry to take on the multiple tasks that constitute the Engagement Behavior Framework. This assumption is not supported by the findings reported above. Nevertheless, there is tremendous potential for Web-based, device-based and print-based tools to help us to fulfill our responsibilities with ease and accuracy

Build tools that help us solve our problems. Developers of tools — electronic, Web-based or print-based — should ask us to identify specific health-related or care administration problems we think are important and that we struggle to solve on our own. Tools, portals and applications should be designed in concert with us to require a modest investment of time and skill to learn to use and to communicate with our provider if relevant. An effort to systematically understand and address the barriers we experience in using different tool technologies is long overdue.

Provide just-in-time information and guidance. Providers, plans, clinics and hospitals should organize information and support that is tailored to meet the needs that emerge over the course of an illness or episode. The finding that we are most likely to seek and attend to information at the point we need it suggests integrating tools and information into care delivery processes. Our diverse literacy and language needs and preferences for quantity and type of information mean that information must be both available and adaptable for the needs and capabilities of each of us at each step along the continuum of care decisions.

The proposed meaningful use rules of the Office of the National Coordinator of the Department of Health and Human Services, which are tied to the receipt of federal electronic medical record incentives, offer an opportunity to implement staged approaches to the adoption of tools that will be truly useful for patients and caregivers. Guidance from patients and caregivers in both the development and evaluation of various new tools will be essential for maximizing their potential.

Goal #3: Care that is more accountable to and with individuals

The strong predominance of survey questions about the services we receive and the overall lack of attention to how we act relative to our care means that only general and fragmented information is
available about those of us who do not engage in our care and the barriers we face.

**Monitor engagement behaviors.** The CDC and the AHRQ should track these behaviors among adults by including specific engagement questions in regular national surveys and oversampling for groups at high risk for not engaging. Identifying and measuring specific behaviors is an effective driver of quality improvement. Data about what we do and don’t do:

- Are vital to assessing the size and scope of the problem: to what extent are we performing the specific actions that are linked to benefiting from our health care?
- Provide focus for stakeholder efforts to be accountable for supporting efforts by their constituents, members or patients to care for ourselves and our loved ones
- Enable strategic tailoring and targeting of efforts to support the capacity of all of us to engage in our health and health care
- Can track progress in our effective engagement in our health care

**Incorporate engagement into quality performance measures or accreditation standards or both.** National Committee on Quality Assurance, URAC and other review organizations should continually review and refresh existing standards and measures and create new processes for accountability related to how provider and plan performance affects our specific engagement behaviors, whether we are members or patients. New measures would aim at improvement in interactions by individuals with the health care system and would demonstrate more efficient and effective use of health care resources by patients.

Of course, the potential of health care to improve health rests in part on having access to the professional counsel and armamentarium of technologies now available. It depends in part on the solid evidence and sound clinician judgment that together shape the deployment of the tools of medicine. But these potent, complex, expensive solutions depend on us to have an impact. We have to show up for the tests. We have to take the pills, lose the weight, monitor our blood sugar and recover from the surgery.

As our responsibilities for our health care mount, the stakes of our participation rise.

This report shows that while some of us are willing and able to take on these new challenges, many of us have yet to do so. Our lack of participation results in unnecessary suffering and wasted resources and will contribute to disparities in health outcomes.

We must bring to the challenge of increasing our engagement in our care the same focus, energy, commitment and resources as have been devoted to increasing access and improving quality.

The health of each of us — mine, yours, my mom’s, your son’s, our neighbor’s — and the health of the nation depend on both our ability and our active, knowledgeable and willing participation in our care.

It’s time for policy makers, health care providers, researchers, government agencies, foundations and the private sector, to join forces to ensure that all Americans have the support we need to fully benefit from the health care available to us.
Appendix A

Engagement Behavior Framework

Introduction

The Engagement Behavior Framework (EBF) is based on interviews with 210 individuals, a comprehensive review of the peer-reviewed and gray literature, a survey of national conference agendas and interviews with 57 key health stakeholders. It consists of the actions individuals must take in order to achieve the optimal benefit of the care available to them.

The EBF was developed to ground the idea of “engagement in health care” in concrete, measureable terms in order to facilitate strategic, practical efforts to support people’s ability to participate effectively.

Health care is one of many strategies individuals enlist in their effort to live life free of pain. The EBF focuses on this modest piece of the overall challenge of self care for four reasons:

- First, because individuals face a growing number and complexity of requirements in finding safe, decent care and then making good use of it. Not engaging causes preventable suffering and wastes time and resources.
- Second, because the increased demands on individuals to engage in their care disadvantages those who are unable to do so and contributes to health disparities.
- Third, because while health care is responsible for only modest improvements in population health, its impact on individual health can be considerable, as can be its expense to them. Effective engagement will maximize the former and minimize the latter.
- Fourth, because health care reform has sparked a multitude of new, well-funded efforts, many of which are directed to be “patient-centered,” there is an opportunity to institutionalize support for individuals’ engagement in their care in the new policies, measures and practices that are developed.

Performance of each of the behaviors listed here is influenced by a variety of factors: community and cultural norms, institutional and professional practices, and individual characteristics and preferences, such as literacy, motivation, resource availability, social support and health status. Effective support for greater participation in care (policies, interventions, practice organization, tools, materials, for example) will be based on a nuanced understanding of these determinants.

1. Find Safe, Decent Care
   - Find provider(s) who meet personal criteria (e.g., performance, cost, geographic access, personal style), will take new patients and accept personal insurance
   - Use all available comparative performance information (including cost data) to identify prospective providers
   - Establish a relationship with a health care professional or group
• Use all available comparative performance information (including cost data) to identify prospective health care facilities
• Seek and use the appropriate health care setting when professional attention is required

2. Communicate with Health Care Professionals
• Prepare in advance of appointments a list of questions and issues for discussion with the health care professional
• Bring a list of all current medications (including supplements and alternative products) and be prepared to discuss their benefits and side effects
• Report accurately on the history and current status of physical and mental symptoms
• Ask questions when any explanations or next steps are not clear and express any concerns about recommendations or care experiences

3. Organize Health Care
• Make appointments; inquire about no-show policies; arrive on time
• Assess whether the facility can accommodate unique needs (e.g., physical navigation, hearing or visual impairment, translation services) and arrange for assistance
• Bring documentation of health insurance coverage
• Bring another person to assist if the patient is frail, confused, unable to move around or unable to remember the conversation with the provider
• Bring a summary of medical history, current health status and recent test results to visits as appropriate
• Ensure that relevant medical information is conveyed between providers and institutions
• Obtain all test results and appointment records and maintain personal health record

4. Pay for Health Care
• Compare coverage options; match to personal values, needs and preferences; and select coverage
• Gather and submit relevant eligibility documentation if applying for or seeking to maintain public insurance (e.g., Medicaid, Medicare, SCHIP); compare coverage options if applicable; match to personal values, needs and preferences, and select affordable, quality coverage
• Before seeking treatment, ascertain benefit coverage restrictions or incentives such as mental health benefits limitations, pre-certification requirements, access restrictions to specialists or adjunct health providers, and variables in co-pays for specific types of care or providers
• Maintain or adjust coverage in the event of changes in employment, eligibility or family status, (i.e., job change, marriage, divorce, birth of child)
• Maintain all receipts for drugs, devices and services; submit any documentation of services or payments upon request or as needed for third-party payers (e.g., private insurance,
medical/flexible health savings accounts or public payers)

5. **Make Good Treatment Decisions**
   - Gather additional expert opinions on any serious diagnosis prior to beginning any course of treatment
   - Ask about the evidence for the efficacy (risks and benefits) of recommended treatment options
   - Evaluate treatment options
   - Negotiate a treatment plan with the provider(s)

6. **Participate in Treatment**
   - Learn about any newly prescribed medications and devices, including possible side effects or interactions with existing medications and devices
   - Fill or refill prescriptions on time, monitor medication effectiveness and consult with prescribing clinician when discontinuing use
   - Maintain devices
   - Evaluate and receive recommended diagnostic and follow-up tests in discussion with health care providers
   - Monitor symptoms and conditions (e.g., for diabetes — monitor glucose regularly, check feet; for depression — medication and/or counseling and monitor symptoms; for hypertension — measure blood pressure regularly, maintain blood pressure diary), including danger signs that require urgent attention

7. **Promote Health**
   - Set and act on priorities for changing behavior to optimize health and prevent disease
   - Identify and secure services that support changing behavior to maximize health and functioning and maintain those changes over time
   - Manage symptoms by following treatment plans, including diet, exercise and substance use agreed upon by them and their provider

8. **Get Preventive Health Care**
   - Evaluate recommended screening tests in discussion with health care provider
   - Follow-up on referrals for early detection screenings (e.g., breast cancer, colon cancer)
   - Get recommended vaccines and participate in community-offered screening and wellness activities as appropriate

9. **Plan for the End of Life**
   - Complete advance directives and medical power of attorney; file with personal records
   - Discuss directives with family physician and other health care providers, appropriate family
and/or significant others

- Review documents annually; update and distribute as needed

10. **Seek Health Knowledge**
- Assess personal risks for poor health, disease and injury, and seek opportunities to increase knowledge about health and disease prevention
- If diagnosed with a chronic disease, understand the condition(s), the risks and benefits of treatment options and personal behavior change(s) by seeking opportunities to improve health/disease knowledge
- Know personal health targets (e.g., target blood pressure) and what to do to meet them
Appendix B  
Background on Major Surveys Used

Our analysis used 31 national surveys and several regional or minor surveys.

National Surveys

A Portrait of Informal Caregivers in America, 2001  
*Robert Wood Johnson Foundation and the Foundation for Accountability*  
In 2001, the Robert Wood Johnson Foundation and the Foundation for Accountability collaborated on an online survey of 1,005 Internet-using caregivers for chronically ill persons.  

Behavioral Risk Factor Surveillance System (BRFSS)  
*Centers for Disease Control and Prevention (CDC)*  
BRFSS is a cross-sectional telephone survey conducted by state health departments, with technical and methodological assistance provided by the CDC. Every year, states conduct monthly telephone surveillance using a standardized questionnaire to determine the distribution of risk behaviors and health practices among noninstitutionalized adults. The states forward responses to the CDC, which aggregates the monthly data, then returns the data to the states and publishes them on the BRFSS Web site. In 2008, seven states conducted the adult asthma history module, and 48 states conducted the diabetes module.  

Chronic Care Surveys, 2008  
*AARP*  
In 2008, AARP designed and Knowledge Networks fielded two online national surveys of Internet-using Americans age 50 and older with at least one serious chronic condition and at least one episode of care at a hospital or other care setting in the preceding three years. The second online national survey polled Internet-using caregivers age 45 and older who provided care to a friend or family member with the same characteristics as participants in the first survey. The surveys used separate samples.  

Commonwealth Fund Health Care Quality Survey, 2006  
*The Commonwealth Fund*  
For the Commonwealth Fund, Princeton Survey Research Associates International fielded this 2006 telephone survey in either English or Spanish. It used a random, nationally representative sample of 3,535 adults age 18 and older in the continental U.S. to ask them about health care access and quality.  

Consumer Access Survey, 2009  
*PricewaterhouseCoopers’ Health Research Institute*  
In 2009, PricewaterhouseCoopers commissioned this online survey of 1,000 Internet users about access to health care.  

Consumer Assessment of Healthcare Providers and Systems (CAHPS)  
*Agency for Healthcare Research and Quality (AHRQ)*  
The CAHPS program develops and supports the use of a comprehensive and evolving family of standardized surveys that ask consumers and patients to report on and evaluate their experiences with...
health care. These surveys cover topics that are important to consumers, such as the communication skills of providers and the accessibility of services.112

Consumer Engagement in Health Care Survey, 2008
Employee Benefit Research Institute
The Employee Benefit Research Institute conducted this online survey using a nationally representative, randomly drawn panel of 4,532 Internet users (age 21 to 64) who have health insurance through an employer or purchased it directly from a carrier. American Express, Blue Cross Blue Shield Association, Hewitt Associates, IBM, John Deere & Co., Kaiser Permanente, Pfizer, Procter & Gamble and the Commonwealth Fund provided financial support for the survey.52,108 The 2007 version was the EBRI/Commonwealth Fund Consumerism in Health Care Survey.113

Kaiser Family Foundation
The Kaiser Family Foundation commissioned this telephone survey in 2008. Fielded by Princeton Survey Research Associates International, the survey had a randomly selected, nationally representative sample of 1,517 adults age 18 and older.50,114

Fall Tracking Survey, 2008
Pew Internet & American Life Project
In partnership with the California Healthcare Foundation, the Pew Internet & American Life Project in 2008 conducted a national telephone survey in English or Spanish of 2,253 adults age 18 and older. The sample included 502 cell-phone interviews.40

Health Information National Trends Survey (HINTS), 2003 and 2005
National Cancer Institute
In 2003 and 2005, the National Cancer Institute conducted this cross-sectional health communication survey with 7,000 U.S. noninstitutionalized civilian adults (age 18 and older) with landlines. With a list-assisted random-digit dial method, they survey used a computer-assisted telephone interviewing system, asking questions in either English or Spanish. The 2003 sample size was 6,369 adults; in 2005, 5,586 respondents participated in HINTS.38,96,115-117

Health Tracking Household Survey, 2007
Center for Studying Health System Change
In 2007, the Center for Studying Health System Change conducted its periodic, nationally representative Health Tracking Household Survey. This telephone survey, sponsored by the Robert Wood Johnson Foundation, had a sample of about 17,800 noninstitutionalized U.S. civilians, of whom 15,500 were age 18 and older.36,42

Hispanics and Health Care in the United States, 2008
Pew Hispanic Center
With support from the Robert Wood Johnson Foundation, the Pew Hispanic Center had ICR field this public opinion survey among people of Latino background or descent. ICR conducted interviews with a nationally representative sample of 4,013 Latino respondents age 18 and older.97
International Health Policy Survey of Sicker Adults, 2008

The Commonwealth Fund

The Commonwealth Fund commissioned this survey, which was conducted by Harris Interactive. The survey was fielded by telephone in eight industrialized countries: Australia, Canada, France, Germany, the Netherlands, New Zealand, the United Kingdom and the United States. Initially screened adults met at least one of the following criteria: health is fair or poor; serious illness in previous two years; or was hospitalized or had major surgery in the previous two years. The US sample had 1,205 sicker adults. 60

Medical Expenditure Panel Survey (MEPS)

Agency for Healthcare Research and Quality

MEPS is a set of large-scale surveys of families and individuals, their medical providers and employers across the US. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage. 118

Medicare Current Beneficiary Survey

Centers for Medicare & Medicaid Services

The Centers for Medicare & Medicaid Services (CMS), through a contract with Westat, conducts the Medicare Current Beneficiary Survey. This is a continuous, multipurpose survey of a representative national sample of aged, disabled and institutionalized Medicare beneficiaries selected from Medicare enrollment files. A sample person participates in computer-assisted personal interviews three times per year over a four-year period with the beneficiary or a proxy respondent if the sample person is not available for the interview. Survey questionnaires are tailored to the residence of the sample person — community or long-term care facility. If the sample person moves from one setting to the other during the period covered by an interview, a separate interview is administered for the time spent in each setting. About 11,000 beneficiaries are followed continuously over time regardless of where they live. 37, 58, 68

National Health and Nutrition Examination Survey (NHANES)

CDC

NHANES is a program of studies designed to assess the health and nutritional status of adults and children in the United States. CDC analyses of NHANES data are published in the annual report, Health US. 27, 89, 119

National Health Interview Survey

CDC

NHIS has monitored the health of the nation since 1957. NHIS data on a broad range of health topics are collected through personal household interviews. It includes the National Longitudinal Study of Aging. For over 50 years, the US Census Bureau has been the data collection agent for CDC. Survey results have been instrumental in providing data to track health status, health care access and progress toward achieving national health objectives. 120


Kaiser Family Foundation and AHRQ

This telephone survey was conducted between July 31 and October 9, 2000, among a randomly selected nationally representative sample of 2,014 adults 18 years or older. Representatives from both organizations worked together to develop the survey questionnaire and to analyze the results. 121
National Survey of Enrollees in Consumer Directed Health Plans, 2006  
*Kaiser Family Foundation*  
This Kaiser survey looks at the views and experiences of people enrolled in consumer-directed health plans as compared to people with traditional health insurance. The survey was conducted among 1,389 people, including 272 who are enrolled in consumer-directed health plans, plans with a high deductible that also involve a Health Savings Account or Health Reimbursement Arrangement, and 715 with more traditional employer-sponsored insurance.122

National Survey of Households Affected by Cancer, 2006  
*USA Today, Kaiser Family Foundation and Harvard School of Public Health*  
In 2006, a partnership of USA Today, the Kaiser Family Foundation and the Harvard School of Public Health conducted a telephone survey with a nationally representative sample of 930 adults (age 18 and older) who self-identified as having had cancer in the previous five years or having a family member with cancer in the previous five years.59

National Survey of Medical Decisions (DECISIONS Study), 2006—2007  
*Foundation for Informed Medical Decision Making*  
With funding from the Foundation for Informed Medical Decisions, the Survey Research Center and the Center for Behavioral and Decision Sciences in Medicine at the University of Michigan conducted this nationwide telephone survey by interviewing 3,010 participants age 40 and older between November 2006 and May 2007.45,72,73,123

National Survey of Midlife Development in the United States (MIDUS)  
*MacArthur Foundation*  
MIDUS (Midlife in the U.S.) is a national longitudinal study of how many factors (behavioral, social, psychological, biological, neurological) come together to influence health and well-being as people age from early adulthood into midlife and old age.124

Pew Social Trends Aging Survey, 2009  
*Pew Research Center*  
In 2009, the Pew Research Center’s Social and Demographic Trends project sponsored a telephone survey with a nationally representative group of 2,969 U.S. adults. The survey oversampled adults age 65 and older, blacks and Hispanics. It also included 552 cell-phone interviews. Princeton Survey Research Associates International directed the survey.63,125

The Public and the Health Care Delivery System, 2009  
*National Public Radio, Kaiser Family Foundation and Harvard School of Public Health*  
Working collaboratively, National Public Radio, Kaiser Family Foundation and Harvard School of Public Health developed and conducted this survey in 2009. Social Science Research Solutions fielded the survey in 2009 among a nationally representative sample of 1,238 randomly selected adults (age 18 and older).69

Public Support for the Right to Die, 2005  
*Pew Research Center*  
In 2005, Princeton Survey Research Associates International conducted telephone interviews with a nationwide sample of 1,500 adults age 18 years and older for the Pew Research Center.94

Survey of Americans with Chronic Conditions, 2009
A Snapshot of People’s Engagement in Their Health Care

National Council on Aging
In 2009, Lake Research Partners conducted a national survey for the National Council on Aging. The 1,109 adults age 44 and older who were surveyed had at least one chronic condition. The study received support from the Atlantic Philanthropies and the California HealthCare Foundation.

Survey of Health Care Consumers, 2009
Deloitte Center for Health Solutions
The Deloitte Center for Health Solutions commissioned an online survey of a nationally representative sample of 4,001 adults age 18 and older. Although titled as “2009,” it polled Internet users in October 2008.

Wall Street Journal Online/Harris Interactive Health-Care Poll, 2007
National Council on Aging
In 2007, the Wall Street Journal Online, Health Industry Edition had Harris Interactive conduct an online survey of a national cross section of 2,673 Internet users age 18 and older.

Supplemental Surveys and Studies

Baltimore Longitudinal Study of Aging (BLSA)
National Institute on Aging
The National Institute on Aging (NIA) conducts research to learn about the changes related to aging. One goal of NIA research is to help us understand medical problems that are common in older people. The NIA supports the BLSA, America’s longest-running scientific study of human aging, begun in 1958. BLSA scientists are learning what happens as people age and how to sort out changes due to aging from those due to disease or other causes. More than 1,400 men and women are study volunteers. They range in age from their 20s to their 90s.

California General Public Survey, 2007
California HealthCare Foundation
In 2007, Harris Interactive conducted a telephone survey using a random sample of Californians age 18 and older for the California HealthCare Foundation.

Consumer Use of the Internet to Manage Care, 2008
California HealthCare Foundation
The California HealthCare Foundation commissioned Harris Interactive to survey the state’s consumers to gain insight into who the seekers of health information are, what kind of information they use and what actions they take after seeing that information.

Consumers and Health Care Quality Information, 2001
California HealthCare Foundation
This survey, the largest of its kind at that time, was conducted by RAND between November 1999 and January 2000. The survey sampled more than 4,000 Californians and, in addition, allowed a close-up view of difficult-to-reach and traditionally underserved populations: the elderly, the chronically ill, the uninsured, low-income populations and Hispanics.
Death and Dying in California, 2006
*California HealthCare Foundation*
This survey examined changing attitudes about death and dying and potential trends through the lens of demographics, the cost and nature of end-of-life care and cultural norms.95

Health Literacy and Patient Activation among Medicare Beneficiaries, 2004
*AARP Public Policy Institute (sponsor)*
In 2004, University of Oregon researchers conducted an exploratory study for the AARP Public Policy Institute with a convenience sample of 293 Medicare beneficiaries in the Eugene and Springfield, Oregon, area. The participants, age 65 years and older, responded to a questionnaire administered by a trained interviewer.129

Mastectomy for Treatment of Breast Cancer
*Memorial Sloan-Kettering Cancer Center (lead)*
As part of a research study examining appropriate use of mastectomy, Monica Morrow, MD, and her colleagues at Memorial Sloan-Kettering Cancer Center surveyed 1,984 women in Los Angeles and Detroit who had breast cancer diagnoses. The samples, designed to be representative of each metropolitan area, came from the National Cancer Institute’s Surveillance, Epidemiology, and End Results program registries. The surveys were mailed and available in both English and Spanish. Funding from the National Cancer Institute supported the study.74

Measuring Trust in Health Care
*Hopkins Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health*
As part of a research study, the Hopkins Center for Health Disparities Solutions tested measures of mistrust in health care organizations and explored whether mistrust is a factor in use of health care services. The telephone survey used a random sample of households in Baltimore. The 401 respondents were primarily African Americans. The Agency for Healthcare Research and Quality, Russell Sage Foundation and the National Center on Minority Health and Health Disparities supported the study.130
Appendix C

People’s Engagement Attitudes

This appendix provides supplementary data from national surveys about people’s attitudes over interacting with the health care system and managing their health.

Most People in the US Have Hesitant or Passive Attitudes

About one-fifth (22 percent) of adults feel helpless and say they are unable or unwilling to manage their health, as reported by researcher Judith Hibbard, a professor in health policy at the University of Oregon, who analyzed a 2007 nationally representative survey conducted by the Center for Studying Health System Change. Her analysis, shown in Figure 14, also indicates 59 percent of Americans are passive, inhibited or vulnerable, facing significant knowledge and confidence barriers to caring for themselves. Only two in five adults felt able to self-manage their care, but they were unsure if they could maintain their confidence under stress.

Figure 14. Adults’ Readiness to Manage Their Health

<table>
<thead>
<tr>
<th>Ability and Willingness to “Play an active role in their own health”</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive (“Level 1/Least Activated”) People who tend to be inactive and lack sufficient confidence in their ability to manage their health</td>
<td>7%</td>
</tr>
<tr>
<td>Inhibited (“Level 2”) People who lack basic knowledge and self-confidence</td>
<td>15%</td>
</tr>
<tr>
<td>Vulnerable (“Level 3”) People who make some effort to be active in their health, but whose confidence and skills may not be adequate to support self-management</td>
<td>37%</td>
</tr>
<tr>
<td>Participating (“Level 4/Most Activated”) People who are active in managing their health, but have unknown ability to sustain their participation with increased life stressors</td>
<td>41%</td>
</tr>
</tbody>
</table>

The descriptive labels in this figure (i.e., passive, inhibited, vulnerable, participating) are characterizations by the Center for Advancing Health; the authors’ original terms are provided in quotation marks.


Of Medicare beneficiaries, a plurality—44 percent—appear to be unmotivated to play an active role in health care decisions, according to an analysis by the Centers for Medicare & Medicaid Services. Figure 15 shows that 30 percent of these older adults believe they have the knowledge, skills and motivation to make informed health care decisions. An interesting segment, “high effort” beneficiaries, report trying to get information and participate in their health care decisions, but they are hampered by the lack of appropriate skills.
Figure 15. Medicare Beneficiaries’ Skills and Motivation to Make Informed Health Care Decisions

<table>
<thead>
<tr>
<th>Medicare Audience Segments</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive Unskilled and unmotivated</td>
<td>17%</td>
</tr>
<tr>
<td>Complacent Skilled but unmotivated</td>
<td>27%</td>
</tr>
<tr>
<td>High Effort Moderately high motivation, but moderately low skills</td>
<td>26%</td>
</tr>
<tr>
<td>Active Skilled and motivated to make informed health care decisions</td>
<td>30%</td>
</tr>
</tbody>
</table>


Engagement Attitudes Vary by Education, Health Status and Insurance Coverage

Educational attainment, health status and insurance coverage may correlate with people’s readiness to actively participate in their care. In Hibbard’s 2008 analysis, survey respondents who were most likely to be passive or inhibited were those who lacked a college education, had poor health or were enrolled in Medicaid or a state health plan. Figure 16 provides some of these data.

Figure 16. Select Adult Groups and Readiness to Self-Manage, 2007

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percent Assessed as Passive or Inhibited in Managing their Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education (age 18 and older)</td>
<td></td>
</tr>
<tr>
<td>0-11 years</td>
<td>31%</td>
</tr>
<tr>
<td>16 or more years</td>
<td>15%</td>
</tr>
<tr>
<td>Health Status (age 18 and older)</td>
<td></td>
</tr>
<tr>
<td>Fair or poor</td>
<td>38%</td>
</tr>
<tr>
<td>Excellent</td>
<td>15%</td>
</tr>
<tr>
<td>Insurance Coverage (age 18–64)</td>
<td></td>
</tr>
<tr>
<td>Medicaid or state health plan</td>
<td>30%</td>
</tr>
<tr>
<td>insurance</td>
<td>16%</td>
</tr>
</tbody>
</table>


The Medicare survey data suggest that education is a risk factor for, not a determinant of, having a passive approach to engagement. One in four Medicare beneficiaries may be relatively unskilled, but they are actively interested in both making shared decisions about their care and in seeking health information.

Another national survey also found that health status correlates with perceived problems with participating in health and health care. In 2009 survey of chronically ill adults age 44 and older, many
people with multiple chronic conditions reported experiencing pain, fatigue, emotional struggles and other limitations that hinder self-care. Figure 17 shows that 62 percent of adults with four or more chronic conditions doubted their ability to make healthful changes. Even among people with one chronic condition, 24 percent did not believe they could take better care of themselves.38

Figure 17. Adults with Chronic Conditions Expressing Doubts about their Ability to Improve Self-Care

<table>
<thead>
<tr>
<th>Number of Chronic Conditions</th>
<th>Percent of Respondents Agreeing that “I wish I can change and do things that are healthier, but I just don’t think I can”</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 chronic condition</td>
<td>24%</td>
</tr>
<tr>
<td>2 chronic condition</td>
<td>33%</td>
</tr>
<tr>
<td>3 chronic condition</td>
<td>40%</td>
</tr>
<tr>
<td>4 chronic condition</td>
<td>62%</td>
</tr>
</tbody>
</table>

Source: Lake Research Partners (2009)38
Appendix D

Who Is Less Likely to Perform Engagement Behaviors?

Individuals who almost always are less likely to perform engagement behaviors are those with one or more of these characteristics: low educational attainment, marginal health literacy, low incomes, multiple chronic conditions or poor health, no health insurance and low numeracy. Overall, individuals with older age or marginal health literacy tend to have lower engagement levels than younger adults and the health literate, but variations do exist.

In general, older people appeared to experience more barriers or need help for many of the behaviors. As individuals age, they increasingly rely on adult children for help paying bills, completing paperwork, getting to appointments and taking care of errands.63

Nonetheless, older adults are more active than younger adults in obtaining a usual source of care or a living will.53,94 With regard to other behaviors, different generations can have similar performance levels but may participate in different ways. For example, older people tend to rely more on traditional information sources while younger generations turn more to Internet sources.96

Low health literacy also can interfere with the ability to adhere to prescribed medications and self-care. Adults with marginal health literacy tend to have less knowledge about and be less skilled in managing their health conditions than peers with better health literacy.99,100,103,104

Following is a detailed summary of the findings from this analysis.

1. Who Is Less Likely to Act to Find Safe, Decent Care?

Among Internet users, people with lower levels of education and income are less likely to seek objective information about health care providers than are people with more education and income.

- As income and education levels rise, so does the likelihood that Internet users will seek online information about health professionals, hospitals and medical facilities, according to the Pew Internet & American Life Project.50
- About 17 percent of college-educated people have seen and used information comparing the quality of health plans or providers, as reported by the 2008 Kaiser Family Foundation (KFF) survey. In contrast, 11 percent of people with a high school degree or less did so.50
- In the KFF survey, 63 percent of people with a high school education or less preferred going to a familiar hospital, as compared to 52 percent of college graduates. This group with less education also was more likely than college graduates to prefer health plans recommended by friends and surgeons who have treated a family member or friend.50
- Pew survey data also indicate that women and younger generations are more likely than men and older people to seek information about health care providers.40

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2. Who Is Less Likely to Effectively Communicate with their Health Care Providers?

People with low numeracy and marginal health literacy levels have difficulty communicating with their care providers. Specifically, stigma associated with marginal health literacy can interfere with providing an adequate medical history, asking questions and understanding what a doctor or provider is saying. Vocabulary and speech complexity differences between health professionals and low health literacy patients can further complicate communications.

3. Who Is Less Likely to Act to Organize Care?

Surveys reviewed shed little light on this question. As people age, many rely more on adult children for help getting to appointments and taking care of errands. One in three (32 percent) of adults age 65-74 and 46 percent of people age 75-84 have received this assistance. For seniors age 85 and older, two in three (64 percent) had this help.

4. Who Is Less Likely, Because of Barriers, to Pay for Health Care?

As individuals age, they increasingly rely on adult children for help paying bills or completing insurance forms or other paperwork, according to a Pew Research Center survey of adults age 65 and older. Nine percent of adults age 65-74 and 22 percent of those age 75-84 have received this assistance. For people age 85 and older, 44 percent have had this help.

About 11 million working-age adults have chronic conditions but lack health insurance coverage. Without affordable options for health care, this group reported (at varying rates) forgoing or delaying care, leaving a prescription unfilled and relying on emergency departments as their standard source for care.

Increasingly, insurance-related tasks can be done online, but people with low educational attainment (high school diploma or less) are less likely than college graduates to use this tool. The 2007 California HealthCare Foundation survey found that 28 percent of low-education online adults used Internet services to review claims or obtain benefits information, compared with 35 percent of Internet-using college graduates. One in four Internet users with low education (24 percent) went online to find a physician in the health plan’s network versus 36 percent of college graduates. Interestingly, 10 percent of each group reported buying their health insurance plan via the Internet.

In Massachusetts, community outreach workers have helped vulnerable populations obtain health insurance over the two years since state policy makers enacted health reform. Their clients’ greatest barriers to getting and maintaining coverage is confusion, according to community health workers participating in a limited, exploratory survey by Community Partners’ Access Network. Three in four (78 percent) community outreach respondents identified confusion about enrollment paperwork as a top barrier, and 50 percent cited the health coverage system. Affordability was a third top barrier, selected by 38 percent of respondents.
5. Who Is Less Likely to Make Informed Treatment Decisions?

Obtaining a second opinion appears to be less likely among breast cancer patients with low education. Internet use to get health information — some of which may be applicable to a medical decision — varies by age and education. The Pew Internet & American Life Project reports that within the online adult population:

- 42 percent of online seniors (age 65 and older) have used the Internet to get information about a specific medical treatment or procedure. A much larger group — 60 percent — of 30-49 year olds has done so.
- Only 43 percent of online adults without a high school diploma, compared to 63 percent of college graduates, say they have sought information on the Internet about specific medical interventions.

6. Who Is Less Likely to Participate in Treatment?

Money, confidence and knowledge barriers can inhibit the ability of people with low incomes to manage their chronic conditions, according to a 2009 national survey for the National Council on Aging. Among adults age 44 and older who have one or more chronic conditions, two in three (65 percent) of individuals with annual household incomes of $20,000 or less report lacking the money to act to improve or manage their health, compared with 22 percent of their peers in households with $50,000 or more in annual income. While 59 percent of respondents with four or more chronic conditions describe their health problems as making it difficult to care for themselves, a much smaller group, 14 percent, of their peers with one chronic condition, feel this way.

Following a treatment plan often requires basic numerical abilities, so individuals with low numeracy are at risk for non-adherence. Specific problem areas can include reading and interpreting medication dosages, filling out insurance forms, knowing when to schedule a follow-up appointment and reading a bus schedule to get to an appointment on time.

Low health literacy also can interfere with ability to adhere to prescribed medications and self-care. Adults with marginal health literacy tend to have less knowledge about and be less skilled in managing their health conditions than peers with better health literacy.

However, studies comparing treatment adherence by health literacy levels present a varied picture. Some studies found associations between low health literacy and low compliance with providers’ recommendations. In other studies, people with low health literacy appeared to follow self-management regimens better than peers with higher literacy. It may be that once people with lower health literacy levels gain the skills to manage a condition, they are more likely to adhere to directions.

Among adults age 44 and older who have one or more chronic conditions, 50 percent of low-income adults said they seldom receive any help or support them. The National Council on Aging’s survey also found a plurality (44-57 percent) of all survey respondents who said their doctors and other health professionals rarely:
Provide information about assistance available in the community (e.g., self-care classes or patient support groups).

- Asked about help available at home.
- Planned to follow up with them after an appointment.
- Sought their ideas about caring for their health.\(^\text{39}\)

### 7. Who Is Less Likely to Act to Promote Health?

As Figure 8 shows, compared with college graduates, adults who have not finished high school were more likely to smoke and not get enough physical activity, fruits or vegetables. On the positive side, Figure 8 also indicates people with low educational attainment were less likely to binge drink.\(^{87,88}\)

Marginal health literacy is another factor associated with low participation in health behaviors. Almost 60 percent of Americans 65 and older have inadequate or marginal health-related print literacy, according to an analysis by Ian Bennett, MD, PhD, and colleagues at the University of Pennsylvania.\(^{132}\) A small study using a convenience sample of Medicare beneficiaries found those with lower health literacy skills appeared to practice fewer health behaviors than did Medicare beneficiaries with higher health literacy skills.\(^{129}\) Other studies have found people who have low levels of health literacy practice health behaviors at lower rates than peers with adequate health literacy.\(^{99}\)

Confusion or ambiguity about expert recommendations is associated with lower levels of practicing healthy behaviors and getting cancer screenings.\(^{38,41,133,134}\) People with high levels of ambiguity about cancer prevention were most likely to be physically inactive, smoke, not use sunscreen, eat few fruits and vegetables, and not be screened for colon cancer.\(^{38,41,134,135}\)

Cross-sectional analyses of the Health Information National Trends Survey revealed widespread ambiguity about expert recommendations for reducing risk for cancer.\(^{38,134,135}\) For example:

- 71 percent of Americans agreed that “there are so many recommendations about preventing cancer, it’s hard to know which ones to follow.”\(^{38,134}\)
- Only 33 percent of adults knew that individuals should get 30 or more minutes of moderate physical activity at least five days a week.\(^{41}\)

Ambiguity about expert recommendations was especially common among people with low education levels.\(^{38,41}\)

### 8. Who Is Less Likely to Act to Get Preventive Health Care?

The data show a clear pattern in which low-income adults are much less likely than higher income groups (a 24 percentage point difference) to have a mammogram for breast cancer. About a 15 percentage point gap is present for cholesterol screenings, various cancer screenings and pneumococcal vaccination. Rates for influenza immunizations are closer, but low-income groups still appear to lag behind.\(^{87,89}\)

Studies have also found that people with low literacy levels get fewer clinical preventive services than do those with adequate health literacy. For example, older adults with low health literacy levels are less
likely to have received these three preventive services in the past year: influenza vaccination, dental checkup or a mammogram. Other researchers have reported comparable findings.

9. Who Is Less Likely to Plan for the End of Life?

In the 2009 Pew Research Center survey, older Hispanics (65 and older) were least likely (44 percent) to say they had talked with their adult children about what to do when they could no longer live independently. Half of older black adults (50 percent) and 56 percent of older whites had done so.

A review of 33 empirical (but often small) studies on end-of-life decision making found African Americans were less likely than whites to have advance directives. Some of the studies also reported advance directives were less common among frail Hispanic, Asian and Native American older people in community or long-term care settings.

10. Who Is Less Likely to Seek Health Information?

Educational attainment appears to have a strong influence on seeking health information from online and traditional sources. At each higher level of education, information-seeking behaviors rise. Similar to the pattern presented above for seeking cancer information, 42 percent of people without a high school diploma looked for health information on any subject, while 72 percent of people with graduate education did, according to the Center for Studying Health System Change’s 2007 Health Tracking Household Survey.

Marginal health literacy can impede seeking and acting on health information. People in this group can have trouble understanding health information, in part because they have low levels of knowledge about health, disease management and basic medical terms. Also, stigma may keep them from asking for help finding health information or having it explained.

Internet access and use are relevant because variations still exist in who has access and actually uses the Internet (for any purpose). According to the 2008 Pew Internet & American Life Survey of adults age 18 and older about the Internet and health care, Internet use for any purpose:

- Is highest among young adults (87 percent of people age 18-29), tapering to 41 percent of people age 65 and older.
- Rises with educational attainment (35 percent of people with less than high school versus 95 percent of college graduates).
- Increases with income (57 percent of people in households whose annual income is less than $30,000 versus 94 percent in households earning $75,000 or more per year).

In the Health Information National Trends Survey, both people age 80 and older and Spanish-speaking Hispanics reported more problems with accessing cancer information than other adults. People with low education levels or low incomes were two other groups that had disproportionately high rates of challenges.
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Endnotes

A Snapshot of People’s Engagement in Their Health Care


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Personal communication from National Cancer Institute staff received on Aug. 26, 2009, via e—mail.

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