

Snapshot of People's Engagement in Their Health Care

A review of 31 national surveys found that Americans do not actively and consistently perform the actions directly linked to benefiting from available health care.

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

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

Why focus on engagement in health care?

Health care is one of many strategies we enlist in our effort to live life free of suffering. This study focuses on our engagement in our health care for three reasons:

First, in order to benefit from the care available to us, we and our caregivers face a growing number of responsibilities to find good care and make the most of it.

Second, because the increased demands on us to participate in our care disadvantages those of us who are unable to do so and contributes to disparities in health outcomes.

Third, because health care reform has sparked a multitude of new efforts, many of which are directed to be "patient-centered," there is an opportunity to institutionalize support for our engagement in our care in the new policies, measures and practices that are developed.

What is at stake?

Those of us who are unable or unwilling to participate actively and knowledgeably in our care are more likely to suffer preventable illness, receive less effective care, pay more out-of-pocket costs, experience poor outcomes and suffer a diminished quality of life. From a societal perspective, non-engagement wastes public and private resources, contributes to unnecessary suffering and erodes the health of the population.

What constitutes engagement in health care?

Here, engagement is defined as "actions we must take over time to obtain the greatest benefit from the health care services available to us."

In 2007, the Center for Advancing Health (CFAH) launched an initiative to develop a behavioral definition of engagement. The Engagement Behavior Framework (EBF) was derived from interviews with 210 individuals, 57 professional health stakeholders and comprehensive reviews of the peer-reviewed and advocacy literature. It consists of such actions as ensuring that relevant medical information is conveyed between our providers and institutions, asking questions of your provider when any explanations or next steps are not clear and evaluating recommended tests and treatments in discussion with your health care provider. There are a total of 42 specific behaviors that fall into one of the following ten categories:



The full framework can be viewed at www.cfah.org.

Approach

CFAH reviewed 31 publicly available national surveys conducted from 2001-2009 to identify items that matched the 42 behaviors in the EBF. Data from those items were aggregated across studies.

Findings

For the majority of the behaviors for which data were available, one-third of adults performed them regularly, one third did so inconsistently and one-third did not do so at all.

This is a rough approximation because even within a set of behaviors, individuals' performance of specific actions may vary significantly. Because data came from 31 surveys, it is impossible to analyze the extent to which people behave consistently across different behaviors.

When data were examined within and across the behavior sets, some patterns emerged:

- More of us appear to perform simpler tasks (e.g., make a list of medications) than complex actions (e.g., make informed treatment decisions).
- The depth of participation in any engagement behavior set tends to be shallow. For example, more of us seek out information about a provider or health plan than actually use that information to make a choice.
- We appear to defer information and advice-seeking until we have a specific need: our participation takes place "just in time."

For any single behavior, those less likely to participate are those with little education, marginal health literacy, low incomes, multiple chronic conditions and lack of health insurance.

While such barriers affect a sizable number of people, lack of participation is also common among those who face none of them.

We Are Less Likely to	We Are More Likely to
Proactively communicate with health care providers	Have a personal or regular provider
Organize health care	Check that health plan will cover care
Make treatment decisions	Discuss potential benefits of a medical test or treatment with provider
Follow treatment plans for: <ul style="list-style-type: none"> ▪ Allergies ▪ Arthritis ▪ Lung conditions ▪ Depression ▪ High cholesterol 	Follow treatment plans for: <ul style="list-style-type: none"> ▪ Cancer ▪ Diabetes ▪ Heart disease ▪ Hypertension ▪ Stroke
Promote health by eating plenty of fruits and vegetables, maintaining a healthy weight and being moderately active	Obtain immunizations, screenings and other preventive care from a health care provider
Put end-of-life plans into written or legal documents	Talk to adult children about what to do if one can no longer make decisions about care
Use objective information to: <ul style="list-style-type: none"> ▪ Select a health care provider or health plan ▪ Make a medical decision ▪ Compare treatments 	Seek information about specific health conditions and medical care

Goals and Recommendations

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 improvements.

While each of us must - along with our caregivers and loved ones - 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. CFAH proposes the following three goals to increase support for people's engagement in their health care, along with highlights of suggested strategies to accomplish them and recommendations for leadership.

Goal #1: More effective actions by us

Make our 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 are instrumental partners in this effort.

Support the development and implementation of new effective strategies

We will look to government partners for this support, including the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Disease Control and Prevention (CDC).

Goal #2: Better tools for us

Build tools that help us solve our problems

Developers and disseminators of tools - electronic, Web-based or print-based - are key partners.

Provide just-in-time information and guidance

We'll count on clinicians, plans, practices and hospitals.

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

Monitor engagement behavior of American adults

We look for leadership from NIH, CDC and AHRQ to perform this job.

Incorporate measures of our engagement behaviors into quality performance measures and accreditation standards

This is an opportunity for private health care oversight agencies to play a role: National Committee on Quality Assurance, URAC and JCAHO.

It is time to bring to the challenge of increasing our active, knowledgeable participation 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.

About the Center for Advancing Health

The Center for Advancing Health (CFAH), founded in 1992, is a non-partisan, Washington-based research and policy institute that works to ensure that each of us is able to find and make good use of the health care available to us. CFAH is a non-profit organization originally funded by the John D. and Catherine T. MacArthur Foundation and the Nathan Cummings Foundation and now supported by a number of foundations - principally the Annenberg Foundation and the W. K. Kellogg Foundation - and individuals.



Evidence. Engagement. Equity.

**For extended versions of
the Snapshot of People's Engagement in Their Health Care report
and the Engagement Behavior Framework,
visit us online at www.cfah.org.**

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