

A New Definition of Patient Engagement: What is Engagement and Why is it Important?

Acknowledgements

We gratefully acknowledge the many contributions to this report by Margaret Holmes Rovner, PhD, of Michigan State University; Molly French, MP of Potomac Consulting; Shoshanna Sofaer, DrPh, of Baruch College, City University of New York; Dale Shaller, MS, of Shaller Consulting; Denis Prager, PhD, of Strategic Consulting Services and David Kanouse, PhD, RAND. Each has participated in aspects of formulating the conceptual approach, testing it, challenging it and endlessly reviewing the whole and parts of the Engagement Behavior Framework.

We deeply appreciate the generosity of the hundreds of people who agreed to be interviewed about their experiences finding and making use of health care as well as the many health professionals, advocates and researchers whose insights provide the solid ground upon which the Engagement Behavior Framework was built.

Abstract

The purpose of the Engagement Behavior Framework is to present a realistic and comprehensive picture of what individuals must do in order to benefit from the health care available to them. Specifying these behaviors allows the public and other stakeholders to understand the magnitude and scope of the challenges people face in finding and using safe, decent care. This framework provides a basis for concrete, measurable expectations for individuals' behavior that should guide the reorientation of care toward patient-centeredness. It constitutes the first step in an effort to track and monitor engagement in the nation and among vulnerable subgroups. Better information about who does and does not perform each of these behaviors will allow stakeholders to make strategic decisions about the kind of information, guidance and support that are needed by their patients, members or constituents to participate effectively in their care and thus to benefit optimally from it.

This White Paper contains excerpts from: Gruman J, Holmes-Rovner M, French ME, Jeffress D, Sofaer S, Shaller D, Prager DC. From patient education to patient engagement: Implications for the field of patient education. *Patient Education and Counseling*. March 2010 (Vol. 78, Issue 3, Pages 350-356, DOI: 10.1016/j.pec.2010.02.002)

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Introduction

Advances in medicine, technology and health care services promise increases in the length and quality of life for many Americans. However, obtaining the benefit of these advances to prevent, manage and cure disease depends increasingly on individuals' energy, knowledge and skills, regardless of whether they are sick or well. For example:

- Improved surgical techniques mean that people return home from the hospital quicker but sicker (1,2,3). To heal optimally, they must themselves take on tasks associated with managing pain, symptoms, feeding and rehabilitation formerly performed by professionals (4,5,6).
- New drugs make it possible for those with diabetes, asthma, cancer, heart disease and HIV/AIDS to live long and well with these conditions, but to do so, they must maintain complex drug and lifestyle regimens over time (7,8,9,10).
- New evidence about treatments and information about professionals who deliver them mean that in order to ensure they are receiving effective treatment that meets their needs and preferences, people must learn about their diseases, possible treatments and a variety of physician attributes in order to weigh complex trade-offs when making decisions about their care (11,12).

Some of these new responsibilities result from the drive to make care more efficient by delivering equivalent or superior care while minimizing demands placed on professionals (13, 14). Others arise from a fragmented care delivery system that hasn't kept pace with emerging needs to coordinate information (15,16). And some of the new responsibilities are products of the change away from a paternal, authoritative style of medicine toward a model that has demonstrated that patients do better when they have a say in their own care (17, 18).

Despite signals that individuals should participate more actively in their health care, the public's behavior appears not to have kept pace with the demands of these advances. In a national sample, Judith Hibbard at the University of Oregon found that while 23 percent of respondents had adopted new behaviors related to their health care, they were not confident they could maintain them in the face of stress or a crisis. The remaining 77 percent ranged from thinking they could remain passive recipients of care (12 percent) to not having basic facts or being able to understand their recommended regimens (29 percent) to having some facts but lacking the confidence and skills to act on them (36 percent) (19). A similar analysis from the Medicare Current Beneficiary Survey found that only about 30 percent of older people report feeling that they possess both the motivation and skills to participate fully in their care (20).

Employers, government payers, politicians, health plan administrators, technology developers, labor leaders and patient advocates have noted the need for the public's involvement in health care and have labeled the phenomenon patient or consumer "engagement." They have joined efforts of researchers and patient educators to address and promote engagement using a range of strategies.

These strategies have included changes in practice design and provider behavior (21) through the patient centered care and medical home movements (22, 23) and implementation of the Chronic Care Model. More patient involvement has also been encouraged in treatment decisions through provision of tools and provider training aimed at supporting more meaningful provider-patient interactions (24,25). The call for increased public reporting on the comparative quality of health plans, hospitals and other health facilities has produced web-based and printed tools designed to support more informed choices. Chronic disease self-management (26) and provisions of incentives for behavior change (27) are other popular approaches used by payers. And behavioral researchers have developed interventions for cross-cutting individual health care-related behaviors, such as patient-provider communication and medication adherence (28,29).

These commitments demonstrate widespread understanding that individuals must become more active in their care and concern that many have not done so.

In this paper we ask: What is the full range of actions individuals are now expected to perform if they are to optimally benefit from their health care? We describe a multi-stage initiative to assemble a comprehensive framework of measurable behaviors that individuals must perform in order to benefit from their care.

In planning this initiative, we built on the work of those who measure health care quality. They have learned that identifying and measuring specific behaviors that in themselves constitute better quality care is the most effective way to drive quality improvement efforts. To borrow a phrase from this movement, "what gets measured gets done."

Approach

Definitions

We define engagement as "actions 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, rather than the actions of professionals or policies of institutions.

Engagement is not synonymous with compliance. Compliance means an individual obeys a directive from a health care provider. Engagement signifies that a person is involved in a process through which he harmonizes robust information and professional advice with his own needs, preferences and abilities in order to prevent, manage and cure disease.

The definition is agnostic about the many factors that have been shown to influence these behaviors, although we recognize that they are complex and many and include individual characteristics (e.g., age, self-efficacy, literacy), disease characteristics (e.g., acuity, co-morbidities, treatment demands), characteristics of the setting (e.g., type of provider; information availability) and cultural norms.

Building the Engagement Behavior Framework

A specific list of "engagement" behaviors was developed by Judith Hibbard in 2004 (30). Hibbard's list of behaviors served as the core of the Engagement Behavior Framework and was supplemented by behaviors identified through the activities described below. Her aim was to develop a parsimonious survey instrument by identifying the fewest key behaviors that could indicate attitudes and intentions toward engagement. In contrast, our aim was to expand this list for the purposes of assembling a detailed, comprehensive picture of the implicit and explicit demands posed to individuals by current health care delivery practices.

A variety of health stakeholders use the term "engagement," so we used a number of strategies to collect meanings of this term and to identify the behaviors those meanings imply:

1. We interviewed 210 individuals and caregivers about their experience with health care following a serious diagnosis.
2. We reviewed a) the advocacy literature; b) research topics in the published literature; and c) relevant systematic reviews.

3. We conducted 57 key informant interviews.
4. After assembling a draft list of 73 behaviors, the Engagement Behavior Framework (EBF) was constructed by the authors and reviewed by an external review group consisting of 30 people: 15 physicians and nurses, eight researchers and seven individuals with no professional connection with health care. Their comments were integrated by a subgroup of the authors.
5. The draft list of behaviors was organized into the EBF (Table 1).

The appendix provides a detailed description of the approach.

Findings

Interviews of Individuals

Many interviewees spontaneously mentioned the unexpected difficulty of performing some of the practical tasks of finding health care. For example, calling for appointments (e.g., trouble following sequential recorded messages; lack of access to an operator); requesting accommodation for hearing, vision, and mobility deficits; mastering and then maintaining devices; finding a physician who takes personal insurance; deciding which doctor to consult for which symptoms; staying on top of the paperwork; and refilling prescriptions were each mentioned dozens of times. Many people identified behaviors that they perceived as challenging to their physicians' authority as an important part of getting care. For example, asking questions; seeking additional opinions on diagnoses and treatment; asking to revisit treatment plans and discussing with their doctors treatment information found online or on TV.

Literature Reviews

The patient advocacy literature review tended to focus on behaviors related to care navigation, information-seeking, informed decision-making, and behaviors linked to getting access to care (e.g., choosing a health plan) and maintaining personal health records.

Through a general health literature topic review, we identified a range of engagement behaviors on which research has been conducted. In order of frequency, the focus of research was on behaviors related to mental health and substance abuse treatment adherence, chronic disease self-management, health promotion and disease prevention, and patient representation in health policy and planning.

A review of the Cochrane Library review topics suggested that the most highly developed interventions related to engagement are directed at modifying patient medication compliance, chronic disease self-management, and traditional behaviors associated with promoting health and preventing disease such as: smoking, diet and exercise. Interventions directed at enhancing clinical encounters have largely focused on encouraging patients to ask questions through coaching or written encouragement.

The review of the Coulter and Ellins report on systematic reviews of patient-focused interventions found mostly interventions to increase general self-care, health literacy and clinical decision-making (29). Few trials or systematic reviews described interventions to support finding and choosing plans, doctors or hospitals or managing the administrative aspects of using care and maintaining care records.

Key Informant Interviews

Behaviors identified through key informant interviews varied by stakeholder perspective and expanded the list derived from the literature reviews:

- Consumer and advocacy groups and labor representatives equated engagement to behaviors related to

- access (choice of plan and provider), information-seeking and shared decision-making.
- Purchasers (government payers and employers) identified these behaviors as well as participation in screening and disease management.
- Health plan representatives identified compliance with health promotion, disease prevention and disease self-management recommendations as key.

Construction of the EBF

The comments of external reviewers and the multiple iterations of the EBF that were reviewed and commented on by the authors over a period of 14 months resulted in a detailed, comprehensive list of behaviors that characterize the typical demands on adults in the U.S. when seeking and using health care.

The behaviors that emerged from this initiative were grouped by the authors into 10 types of tasks that together constitute the Engagement Behavior Framework.

Commentary

The Engagement Behavior Framework is a qualitative description of the behaviors that individuals in the United States must perform to optimally benefit from their care. This behavioral definition of engagement has the potential to serve three broad purposes.

First, it is a necessary precursor to assessing the size and scope of the challenges that engagement poses to individuals. We need to learn to what extent people currently perform the specific actions that are linked to benefitting from their health care. Such an effort could be extended to monitor and report on changes in the public's engagement behavior over time. This would serve two other important aims: It would provide a focus for stakeholder initiatives to support their constituents', members' or patients' efforts to care for themselves and their families, and it would enable the strategic tailoring and targeting of interventions to support the capacity of all individuals to engage in their health and health care.

Second, a behavioral definition of engagement can help those who plan, fund and conduct health behavior research to identify gaps in knowledge, set priorities for new research and commission reviews to consolidate knowledge. As patient and consumer responsibilities grow, so does the need for basic, applied intervention and evaluation research and its implementation through policies and programs that ensure effective support for individuals to perform specific behaviors on their own behalf.

Third, listing the behaviors expected of all individuals raises concern about who is unable to perform these actions. Who is at increased risk of preventable illness and suffering as a result of their own inability or unwillingness to act or from penalties imposed by the structure of health plans (31, 32)? The existing patient engagement literature is replete with examples demonstrating that people who are at increased risk for poor health are also less likely to perform specific health behaviors: those without insurance (33,34,35), those with fewer resources (36), those with less education (37) and low health literacy (38,39), older people (40) and many of those who are already ill (41). The requirement that all individuals actively and knowledgeably participate in their health care to obtain the benefits of safe, decent care further disadvantages such individuals and may contribute to increased disparities in health outcomes (42).

Changes in the delivery, financing and organization of health care will only increase the demands on individuals to participate knowledgeably in their care. Regardless of the outcome of health care reform, most people will need to perform most of the behaviors listed in the Engagement Behavior Framework at some point if they are to optimally benefit from the health care available to them. Many will willingly make the effort, but many others will not be able to do so without guidance and support. Some will go in and out of being able to perform them because of illness. Some will never do most of these tasks.

The consequences of inaction are borne most heavily by individuals and their families in the form of preventable suffering and high financial, social and emotional costs. And the losses that accrue to society by ignoring the challenges posed by health care whose success increasingly depends on individuals' effective participation are high: wasted resources, suboptimal outcomes and increases in health disparities.

For health care to deliver on its promise of improved health and better quality of life, a renewed commitment by all stakeholders is required to ensure that each person has the opportunity to participate knowledgably and effectively in their care to the extent they are able.

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ENGAGEMENT BEHAVIOR FRAMEWORK TABLE 1

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 available comparative performance information (including cost data) to identify prospective providers
 - Establish a relationship with a health care professional or group
 - Use 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 out-patient and in-patient contact a list of questions/issues for discussion with the health care professional
 - Bring 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 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 patient if 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 insurance 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 patient's own values, needs and preferences, and select coverage
 - Before seeking treatment: ascertain cost, benefit coverage restrictions and incentives such as mental health benefits limitations, pre-certification requirements, access restrictions to specialists or adjunct health providers, variables in co-pays for specific types of care or providers
 - Maintain or adjust coverage in the event of unemployment, eligibility or family status changes (i.e., change of job, 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 third-party payers (e.g., private insurance, medical/flexible health savings accounts or public payers) and submit payment; negotiate schedule and amount if necessary

ENGAGEMENT BEHAVIOR FRAMEWORK

TABLE 1 - CONTINUED

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 of recommended treatment options (risks and benefits)
 - 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 before discontinuing use
 - Maintain devices
 - Evaluate and receive recommended diagnostic/follow-up tests in discussion with health care providers
 - Monitor symptoms/condition including danger signs that require urgent attention (e.g., for diabetes - monitor glucose regularly, check feet; for depression - medication and/or counseling and monitor symptom; for hypertension - measure blood pressure regularly, maintain blood pressure diary)
7. **Promote Health**
 - Set priorities for changing behavior to optimize health and prevent disease and act on them
 - 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 the patient and his or her provider
8. **Get Preventive Health Care**
 - Evaluate recommended screening tests in discussion with health care provider
 - Act on referrals for early detection screenings (e.g., breast cancer, colon cancer), and follow up on positive findings
 - Get recommended vaccines and participate in community-offered screening/wellness activities as appropriate
9. **Plan for the End of Life**
 - Complete advance directives and medical power of attorney, file with personal/home records
 - Discuss with/deliver to 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 knowledge about maintaining health and caring for one's self
 - 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

Approach Detail

Because “engagement” is a word that many stakeholders use, we used a broad-ranging strategy that combined reviews of the research, advocacy and systematic review literatures and key informant interviews to capture its diverse meanings and the range of behaviors explicitly or implicitly linked to those meanings. We then assembled and refined the list. Thirty diverse stakeholders then reviewed and commented on it. This version of the Engagement Behavior Framework was constructed based on the comments and suggestions that were adjudicated by three authors of the reference paper that appears on the abstract page of this report (JCG, DDJ, MHR).

Individual Interviews

Our aim was to get a general idea of how people find and use health care in response to a serious diagnosis. We interviewed 210 individuals who were within three years of receiving or caring for someone with what they defined as a serious medical diagnosis. Interviews were conducted over the course of 2005-2006: 186 individuals who had been ill and 24 individuals who served as a primary caregiver for an ill family member or friend. Interviewees were identified through personal contacts throughout the US, advertisements in local *Pennysaver* newspapers, and person-on-the-street requests. The average age of interviewees was 63 and the majority of interviews were conducted by telephone. This was not intended to be a representative sample from which population-level conclusions could be drawn but rather a way to draw on the experiences of many individuals to identify the tasks that people identify as key to getting health care.

Interviewees were asked to “tell the story of their diagnosis and treatment,” including how they were diagnosed; how they responded; how they found their doctors; how the treatment plan was developed; and how they managed the treatment plan. All interviews were recorded and the specific health care behaviors mentioned by interviewees were added to a cumulative list.

Literature Reviews

Advocacy literature. We performed an environmental scan of 20 patient and consumer advocacy organizations such as Consumers Union and Families USA and reviewed their Web sites to collect language and white papers relevant to engagement. Organizations were selected based on a stated purpose that they advocated on behalf of the public for health and health care. Disease-specific organizations were not included in the sample. The review sought to answer two questions: a) what do those who claim to represent the interests of patients and consumers mean when they use the word engagement?, and b) what are the specific behaviors those meanings imply?

Research literature. Using the three databases most likely to cover the core research publications in individual health behavior, we searched for articles related to engagement in the years 1997-2008 using search terms specific to the relevant databases. In CINAHL, we used key words of health AND behavior AND patient engagement (50 sources). In PUBMED, we used key words patient engagement AND health behaviors (231 sources). In PSYCH INFO we used health AND behavior AND patient (84 sources). Articles from non-English journals were excluded. Each study that was consistent with our definition of patient engagement was classified as describing (a) an intervention to increase engagement (either a specific behavior or general participation), (b) determinants of general or specific types of engagement, (c) descriptions of engagement generally, and (d) measures of engagement. Studies describing the physiological impact of behavioral interventions, clinician-focused interventions and professional development were excluded. Abstracts for all articles retrieved using this search algorithm were reviewed. We reviewed the resulting 365 articles to identify behaviors to be included in the draft list.

Systematic review literature. The Cochrane Library was first searched using the terms, "patient participation, patient engagement, and patient activation." Then, the full list of reviews in the Cochrane Consumers Group library was hand-

searched to find systematic reviews that were relevant to the broad definition of engagement. The relevant reviews were then searched for behaviors identified in the research literature. These behaviors were then also added to the draft list.

To ensure that we had not overlooked any behaviors in our broad search of the research literature, we also reviewed the comprehensive collection and analysis of systematic reviews of patient-focused interventions by Coulter and Ellins (29).

Key Informant Interviews

We identified 57 key informants through the advocacy and literature reviews media reports and referrals from interviewees in response to requests for names of "key leaders in patient and consumer engagement." We conducted semi-structured telephone interviews with representatives of consumer/patient groups, labor unions, purchasers, and health plans and universities who had conducted research, and/or written or spoken professionally publicly about patient or consumer engagement. The aim was to obtain interviewees' definitions of engagement and to ask them to identify the behaviors that constitute engagement.

Construction of the Engagement Behavior Framework

Starting with a comprehensive list of 76 items compiled from these diverse activities, the authors participated in a series of iterative telephone and in-person meetings to winnow and organize the list. In order, the aims of the gatherings were to a) identify duplications in the draft list; b) combine and explicate draft items to ensure continuity of detail; c) identify a meaningful organizational framework; and d) revisit the organizational framework, item assignment and wording of behaviors. Face validity of the draft framework was tested by obtaining reviews from 30 people: 15 physicians and nurses, eight researchers and seven individuals with no professional connection with health care. These reviewers were asked to eliminate, combine and add items and to suggest wording changes. Three authors of the reference paper listed on the abstract page (JCG, DJ, MHR) adjudicated the reviewers' comments and were unanimous in agreement on the final list.



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