

Here to Stay

What Health Care Leaders Say About Patient Engagement



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FOREWORD by Jessie Gruman

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“What are people talking about when they say *patient engagement*, anyway? That phrase encompasses so many concepts and ideas that it’s become meaningless.”

I have heard this comment dozens of times recently: during conversations where everyone seems to be talking about a different leg of the same elephant of patient engagement; at the start of one of the many conferences convened to recommend how to increase the phenomenon; indeed, any time some consensus in meaning might be useful. So for example, you hear:

- Patient engagement is what happens between a patient and his/her clinicians.
- Patient engagement improves adherence and health outcomes.
- Patient engagement relies on having access to electronic health records.
- Patient-centered care is impossible without patient engagement.
- Patient engagement is key to transforming health care delivery.

We are about fifteen years into the professional use of *patient engagement* as good solid jargon and those of us who were rooting around at its beginnings are delighted at its current traction. A thundering chorus of clinicians, educators, administrators, consultants, employers and patients has joined us to enthusiastically make sure that more of us are able to interact in more meaningful ways with our health and health care.

And so with the convergence of the phrase’s longevity, the familiarity of its use and the cascade of resources tipped toward its aims, it is worthwhile to check in with some of the major users of the phrase to hear how they describe “patient engagement” and how that description informs their own efforts.

This report presents the Center for Advancing Health’s effort to gather the reactions of key health care stakeholders to the CFAH definition of patient engagement — “Actions people take to support their health and benefit from their health care” — and to explore areas of consensus that can be instrumental in increasing the extent that patients are engaged in their care. The report also collects stakeholder perspectives on various investments in engagement interventions and barriers encountered.

We use the CFAH definition of patient engagement and the CFAH Engagement Behavior Framework (EBF) as reference points for our interviews because:

- a. This definition and the EBF were developed through an interactive process that included interviews with patients, families and other stakeholders, as well as a review of the empirical, gray and advocacy literatures and reviews of current research. For a description of its development, see [this paper](#).
- b. The EBF identifies measurable behaviors that are directly linked with the outcome of interest: making good health and health care choices. The CFAH emphasis on specific actions of individuals as the dependent variable means independent variables (interventions and conditions that increase the likelihood of specific engagement behavior changes) can be strategically targeted.
- c. This definition is clean and parsimonious. Using a common definition of patient engagement as a basis for discussion allowed the additions and suggestions by interviewees to be clearly identified and considered.

Our aim was to discover how various stakeholders use this phrase, how its use influences the factors they pay attention to, what interventions they prefer and what outcomes they measure (if any), and to describe the current landscape of the patient engagement discussion.

Those working in the field of patient engagement may well be frustrated with the “Wild West” cacophony in which our conversations take place. It is our hope that this report helps you to find a vocabulary and set of common assumptions that can clarify and strengthen your work.



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INTRODUCTION

Advances in medicine promise better health outcomes while simultaneously conferring additional responsibilities on patients and caregivers. New surgical procedures mean we come home from the hospital quicker but sicker and must attend to symptom management, medications, wound care, rehabilitation, and mobility, all of which were previously performed by professionals. Similarly, new medications mean that those of us with chronic conditions like HIV, cancer, and transplants can live long and well if we can accommodate the complex drug regimens and lifestyle changes necessary to make them work. Many of us are unprepared to take on what is now required of us to benefit from our health care. Some of us don't want to and others have no choice in the matter; we are too ill or impaired or isolated to act on our own behalf. These and other new responsibilities make our participation in our care increasingly central to individual and population outcomes.

The likelihood that we are willing and able to assume these responsibilities is influenced by a variety of factors, some of which are characteristics of individuals (e.g., cognitive status, culture, literacy, numeracy, confidence), and some of which are characteristics of health care (e.g., absence of meaningful cost/quality information, complexity of health benefits and explanations thereof, poor clinician communication skills). While these responsibilities are now ours, we are largely unaware of them; we are mostly healthy most of the time, and we are rarely told how doing them will benefit us. Further, it's not clear that health professionals, employers, or health plans fully recognize the growing demands on us and the skills we must acquire to meet them.

Although new legislation, policies, and models for health care delivery (such as the Affordable Care Act, patient-centered medical home, accountable care organizations, etc.) often include objectives for patient and family engagement, engagement is at best loosely defined and at times may even be construed as equivalent to compliance. The identification of best practices and interventions that promote engagement is scarce.

In the spring of 2013, the Center for Advancing Health (CAH) started interviewing key health care stakeholders to gather perspectives on patient engagement. The results of the year-long study follow.

METHODOLOGY

The purpose of this small study was to explore both how different health care stakeholders describe “patient engagement” and what strategies each stakeholder uses or promotes to support (or facilitate) engagement. To collect data, CFAH conducted structured interviews with key informants from seven groups with an interest in patient engagement: patients, clinicians, employers, health plans, community health programs, governments, and health care consultants and contractors.

CFAH developed and used a set of eight questions to interview informants. The topics included patient engagement definitions, behaviors associated with engagement, the impact of patient engagement on various stakeholders, organizational and stakeholder credibility to facilitate engagement, barriers that hinder people’s engagement, interventions to overcome engagement barriers, overall support for engagement by their stakeholder peers, and ways to build more support for engagement. Given the breadth of patient engagement conceptualizations, interview questions referenced both the CFAH definition of patient engagement and the CFAH *Engagement Behavior Framework*¹ to provide a common reference point for analysis.

CFAH assembled a convenience sample by asking its board of directors, William B. Ziff Fellows, and colleagues to recommend individuals who were knowledgeable about and affected by patient engagement. At least six individuals per stakeholder group were invited to participate in the study, with a goal of interviewing at least four per group.

As shown in Figure 1, CFAH interviewed 35 individuals in 29 organizations for the study. Nearly all interviews were conducted by telephone (just one informant opted to submit written comments). After the interviews, informants received written draft summaries of their interview. Staff invited each informant to clarify, correct, or extend their comments. CFAH incorporated informant feedback, and the final interview summaries are in the appendix, which omits one summary to respect an informant’s request for anonymity.

¹ The CFAH *Engagement Behavior Framework* is a comprehensive list of measurable actions that individuals and/or their caregivers must perform in order to maximally benefit from the health care available to them. The framework is available at:

<http://www.cfah.org/engagement/research/engagement-behavior-framework>

Figure 1. Number of Organizations and Individuals Interviewed as Key Informants by Stakeholder Group

Stakeholder Group	# of Organizations Interviewed	# of People
Clinician	4	4
Community Health Programs	5	7
Employer/Purchaser*	4	5
Government	4	4
Health Plan	4	7
Patients**	4	4
Health Care Consultants and Contractors	4	4
TOTAL	29	35

* Counts include one senior leader from an employer who declined to be identified in the interview compilation.

** Most patient advocates conducted the interview from their individual perspective, but for counting purposes in this report, we also considered them as an organization.

CFAH used the full set of edited interview summaries for the qualitative analysis. The primary method was a simple content review of two interview compilations: one organized by informant and the other by interview question. (The small sample size precluded quantitative analysis.) Staff used these compilations to identify themes and recurring patterns among the comments.

The next section provides the results of this analysis. Each theme is illustrated with informants' comments on that topic.

RESEARCH FINDINGS

Patient engagement is a rapidly growing movement according to the 35 health care stakeholders that CFAH interviewed. Although specific concepts of “patient engagement” varied across informants, all were enthusiastic and optimistic about the benefits that they believe will accrue when people are engaged in their health and health care. These stakeholders regard patient engagement as an essential strategy for improving health outcomes and the quality of health care experiences, and in some cases for reducing health care costs.

CFAH analysis of the interviews uncovered six broad themes.

Engagement is active.

Informants agreed that the core of patient engagement is individuals' *active* participation in their health and health care. Although the health care field has yet to coalesce around a specific "patient engagement" definition, informants did concur that engagement entails about 10 different sets of behaviors, as conceptualized by CFAH's *Engagement Behavior Framework*.

The health care system doesn't make engagement easy.

Even the most active, capable individuals require support from other people and health organizations to engage in their health and health care. Informants noted that the culture, delivery, and financing of health services in the U.S. often obstruct people's active participation in their care. Environmental context, lifestyle, and social norms are additional barriers that interfere.

Everyone benefits from engagement.

Patient engagement makes a positive difference for all seven stakeholders. Most *non-patient* stakeholders agree that it is important to increase patient engagement.

Engagement is demanding, and many are unprepared.

Consumers' views are still evolving about participation in their health and health care. Many have only a partial understanding of what it takes to be actively engaged and how engagement would make a difference. Also, many are unprepared to be active in their care because they lack the basic building blocks of engagement (such as health literacy).

Partnerships are required.

Patient engagement is a shared responsibility that requires ongoing partnerships among different sets of stakeholders.

It's like the Wild West.

In part due to the depth and breadth of behaviors that represent engagement, no single strategy can boost engagement. Each stakeholder representative noted that they use a variety of interventions to encourage patient engagement. However,

their efforts to promote engagement often lack a systematic approach to ground their investment of time and resources. Even so, informants called for all stakeholders to do more.

Engagement Is Active

Informants agreed that the core of patient engagement is individuals' active participation in their health and health care. Although the health care field has yet to coalesce around a specific "patient engagement" definition, informants did concur that engagement entails about 10 different sets of behaviors, as conceptualized by CFAH's *Engagement Behavior Framework*.

Across the interviews, informants repeatedly described patient engagement as people being involved and active in both their health and health care. Janice M. Prochaska, Pro-Change Behavior Systems, portrayed:

... [A]n engaged patient as someone who is a proactive health consumer. To that end, we have designed programs to help people get ready to make informed health care choices, share decisions with their providers, engage in healthy practices, and be responsible about health care costs.

No one volunteered a specific definition of engagement, and a few informants commented that "patient engagement" is a relatively new term. Further, definitions vary depending on one's perspective. For example, when community health groups, employers, health plans, and providers say "patient engagement," they're referring to efforts to encourage people to participate in their care. Gordon K. Norman, xG Health Solutions, pointed out that, "The field is gradually evolving. 'Patient compliance' used to be the going term and now it's 'patient adherence.' Compliance infers hierarchy, presuming that patients should do what their doctors tell them."

Several informants felt that engagement implies having support from other people and health care organizations. That is, engagement is compromised at least or prohibited at worst without such support.

Some informants spoke of multiple levels of engagement. At the micro level, engagement is about how individuals interact with their clinicians. Others spoke about engagement in terms of what people do day in and day out, such as what they choose to eat, if they take their medications, and more. Finally, a few mentioned a systems level of engagement in which people are involved in improving health care.

A related concept is that patient engagement has a continuum of involvement. As described by Michael Vittoria, MaineHealth:

People can do things to support their health and benefit from their health care that don't require much active engagement. For example, they can make a doctor's appointment, but not actually be engaged during and after the appointment or follow through on their doctor's advice. So, they may be passively present and go through the motions, but not be actively participating, such as thinking critically about the doctor's recommendation, asking about alternatives, and working with their care team to make the best decisions and get the best outcomes.

Views on CFAH Definition

The CFAH definition of patient engagement is "actions people take to support their health and benefit from their health care." When asked whether/how they would change this definition, informants expressed overall agreement with CFAH. For example, Art Franke, National Kidney Foundation of Michigan, commented, "I don't know that our definition would be that different. We feel that activated/engaged patients are going to be more involved in their health care and will be more likely to take action for their own health."

Informants described the CFAH definition as action-oriented and noted that it encompasses more than just participation in medical care. Cindy Brach, Agency for Healthcare Research and Quality, and Carolyn Thomas, patient advocate and founder of the blogs *Heart Sisters* and *The Ethical Nag: Marketing Ethics for the Easily Swayed*, both reported using the CFAH definition in their professional writing. Some informants felt the definition could be tweaked to further convey *active* participation. Laurel Pickering, Northeast Business Group on Health, said, "One question I would ask is why you chose the word 'support' vs. 'improve' their health. While it makes sense that health status might not always improve, at first glance 'support' seems passive."

Four modifications to the CFAH definition were suggested by several informants. First, some informants disagreed with the use of "patients." For example, Marc Pierson, PeaceHealth's St. Joseph Medical Center, said:

... [T]he first word that concerns me about this definition is the use of the word 'patient.' Few or no people I have met define or refer to themselves as patients. They understand that a patient is less than a whole person, is less than what they are. I would prefer thinking of 'people' engaged in their health and health care.

Second, informants recommended adding family members and caregivers to the definition because people may be unable or unwilling to become engaged. As Jean Moody-Williams, Centers for Medicare and Medicaid Services Quality Improvement Group, reflected, “Families and caregivers are important because they often have to facilitate, remind, and support decisions made in care planning.” Candace Goehring, Aging and Disability Services Administration (Washington State), likewise noted that, “caregivers are also affected by engagement” and cautioned that, “They need to know how to contribute to engagement and that those actions can make a positive difference in a person’s health.”

Third, some informants wanted the CFAH definition to convey that engagement has a collaborative element. Rushika Fernandopulle, Iora Health, said:

Our actions need to reflect our own goals, our values and preferences, and what we are willing and able to do to achieve them. But often we do need help and support to reach our goals and to take action.... [Also, the health] system must align itself with that aim.

In a similar vein, Moody-Williams encouraged CFAH to “add ‘with the support of providers’—to give people the message that they aren’t in this alone—those who provide the care are also part of their effort.”

Fourth, a group of informants suggested CFAH modify the definition so it explicitly refers to decisions or decision-making as a specific action that engagement entails. Kelly Young, Rheumatoid Patient Foundation, said, “I’d want to be sure that ‘actions’ include decisions.” Several informants noted that when people participate in making decisions, they feel they have a stake and are more likely to follow the care plan.

Agreement with CFAH Set of Engagement Behaviors

[CFAH Engagement Behavior Framework](#)

The CFAH *Engagement Behavior Framework* consists of a comprehensive list of 42 measurable actions that individuals and/or their caregivers must perform in order to maximally benefit from the health care available to them. The behaviors are collected under the following 10 major headings:

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

When asked about CFAH's set of engagement behaviors, informants expressed overall support. They thought the set captured major aspects, and no one identified a behavior that was not relevant. Some looked at the full *CFAH Engagement Behavior Framework* and remarked that the complete list of 42 behaviors could be overwhelming for most stakeholders to try to address. Only one informant, Dave "e-Patient Dave" deBronkart, patient advocate and author of the book *Let Patients Help*, recommended adding a behavior—"design and create a safe, effective, and caring system"—to recognize that people can be involved in system-level changes.

Are some engagement behaviors more important than others? A few informants raised this question. Some felt that health behaviors could have a higher priority than behaviors relating to health care. Norman reflected, "A few actions in this set are probably more important markers of engagement than others." Thomas L. Simmer, BlueCross BlueShield of Michigan, said, "The priority should be having people become better stewards of their health, with becoming better consumers of health care as secondary. People have limited bandwidth and interest to do the first, let alone the second."

Some informants liked that the CFAH framework is based on people's behaviors. As Eve Harris, patient advocate and navigator, said, "Actions are measureable." Prochaska, in reference to her own research, commented that when her team "began to define the stages of change, we started with smoking because it was the easiest to study and measure. Either you are smoking or not." Throughout the interviews, informants emphasized that quality measures drive a lot of provider and health plan behaviors. Norman added, "The CFAH framework could be used to assess engagement, and such performance measures would prompt changes in the delivery system."

The Health Care System Doesn't Make Engagement Easy

Even the most active, capable individuals require support from other people and health organizations to engage in their health and health care. Informants noted that the culture, delivery, and financing of health services in the U.S. often obstruct people's active

participation in their care. Environmental context, lifestyle, and social norms are additional barriers that interfere.

No matter how prepared people are to be active in their health and health care, systemic problems often obstruct their participation. Further, some of the foremost barriers to people being actively involved in their care are the same ones that curtail other stakeholder groups' efforts to support patients. Frequently identified systemic barriers for both patients and non-patients include:

- The health “system” is fragmented, complex, and opaque.
- People live their lives outside of clinical settings.
- Stress is high, in part due to many demands on personal, professional, and institutional resources.
- Trust and communications between various stakeholders can be suboptimal.
- The “old school” culture—that providers are the experts, and patients should be submissive—persists.
- Habit (or inertia for institutions) is a mighty force to overcome.

With regard to the last challenge, Norman remarked, “Habits are particularly enduring, and bad habits are the hardest to break. Emotions often overpower intellect as determinants of our behaviors. Long-term, important health goals are easily undermined by short-term gratifications.”

Some personal barriers to patient engagement mainly affect individuals. Informants highlighted these challenges:

- Insufficient prerequisites (see Building Blocks section, below)
- Health problems, including depression, pain, poor health, and disabilities, to name a few
- Non-health complications in life from financial instability to abusive relationships to unemployment, and other difficulties associated with what Amber Haley, Virginia Commonwealth University Center on Human Needs, called “low-resource, high-stress environments”
- Language and cultural differences

A few informants noted that being the only person in the exam room who is unclothed often makes patients feel vulnerable or subordinate to clinicians. Such emotions discourage activism.

With regard to barriers specific to providers, informants reported that some clinicians have limited skills in encouraging their patients to play an active role. Clinicians are also under

intense pressure to see many patients each day because of health care payment structures, which often provide few incentives—or may even discourage—clinicians from taking time to encourage their patients to participate in decision-making.

Everyone Benefits from Engagement

Patient engagement makes a positive difference for all seven stakeholders. Most *non-patient* stakeholders agree that it is important to increase patient engagement.

Again and again, informants emphasized the many benefits of patient engagement. As Alexandra Drane, Eliza Corporation, enthused, “Ultimately, better health feels good, costs less, and increases productivity—a win for all.” Most informants asserted that people’s active participation in their care improves health outcomes; enhances quality of care, including patients’ experiences of it; and lowers medical expenses. These outcomes—often referred to as the Triple Aim²—affect all seven stakeholder groups. Society also benefits “because [people/patients] can be more productive and don’t consume as many health care resources,” as Arthur Southam, Kaiser Foundation Health Plan, explained.

In the interviews, informants did not seriously question the ability of engagement to produce positive outcomes. Their beliefs, though, varied about the strength of the evidence supporting claims that engagement has a positive impact. Some had temperate views, saying existing evidence is positive, but more research is needed. Others noted that some interventions yield greater effects than others. A few informants suggested the evidence base is robust, while others felt anecdotes could be convincing. On this matter, Daniel Z. Sands, Zev Enterprises, commented:

We need more evidence in the peer-reviewed literature that participation makes a difference. Doctors care about the time it’s going to take. They need evidence that it doesn’t increase time or, if it does, that it translates into better outcomes or reduced costs.

Informants asserted that patient engagement has important psychosocial benefits for consumers and their caregivers as well as their providers. For patients, engagement gives people a sense of control, especially when their views and values shape their care plan. As compared with people who have low engagement, those with higher levels may have a reduced

² The Triple Aim for population health entails the application of “integrated approaches to simultaneously improve care, improve population health, and reduce costs per capita,” as described by the [Institute for Healthcare Improvement](#).

sense of helplessness and powerlessness, according to some informants. They may feel more invested in achieving treatment goals than do people who are less engaged.

Professional satisfaction is a foremost psychosocial benefit for clinicians who have engaged patients. Roseanne DiStefano and Joan Hattem Roi, Elder Services of the Merrimack Valley, commented that, “When [nurses and care managers] have a participating client, they are also more engaged. It’s more of a conversation, and it makes everyone’s work more rewarding.” Tom Ewing, PacificSource Health Plans, finds that engaged patients “are much more gratifying for me to work with [as a clinician].”

Not all clinicians, though, prefer engaged patients. Brach explained:

How clinicians and other professionals feel about engaged patients varies a lot. Some feel it makes their job harder: They have to negotiate and recognize different preferences. This makes it more complex to deliver care. On the other hand, clinicians want patients to engage because they understand that nothing will happen if they don’t. They know the statistics about adherence and health behavior. The understanding is growing that you need to partner with patients to get better outcomes.

Individuals benefit the most when their health improves, which can also enhance quality of life and extend life. Families can minimize out-of-pocket expenses by averting costly complications and hospitalizations. These positive outcomes are helpful to family members and caregivers. Susan Black, BlueCross BlueShield of South Carolina, and her colleagues have observed that, “Patient engagement also makes a difference for the person’s family, especially if people take better care of themselves, then caregivers have a lighter burden. Poor self-management can really affect the family.”

To the extent that patient engagement lowers per capita health care costs, it makes a difference to employers and health plans. Informants said that employers can benefit in additional ways. Per capita disability outlays can go down and employee productivity can go up.

Widespread Buy-In

Within stakeholder groups, many informants perceive most of their colleagues and peer organizations as backing patient engagement. For example, Black and colleagues remarked, “Everyone is gradually getting the idea that engagement makes a difference.” This widespread acceptance that patient engagement matters is likely to endure and continue to influence health systems. For example, Prochaska commented:

At the end of the day, there is a growing recognition that we need people to take better care of themselves. Too much money is being spent on the consequences of unhealthy choices and on health care. We don't think that patient engagement is just the flavor of the week. The concept of how we can take more responsibility for our health and health care is not going away.

Among non-patient stakeholders, informants viewed clinicians as a second group in which more members had yet to be convinced about the merits of patient engagement.

Health care stakeholders report that in recent years they have expanded efforts to support patient engagement. However, a few informants hinted that some of their peers' commitment to patient engagement could be skin-deep. That is, the peer stakeholders may "talk the talk", but their actions convey limited understanding of or commitment to patient engagement. For example, employers or health plans may use the term "engagement," but their interventions center on compliance with providers' care plans. As Ewing commented, "Unfortunately, many health care institutions/providers just think of engagement as a synonym for adherence."

At the other end of the spectrum, some informants mentioned groups that are fully committed to supporting engagement but lack the resources or capacity to intervene deeply. In particular, Lisa Ferretti, University at Albany School of Social Welfare, characterizes the community health sector as being "tragically underfunded." Similarly, smaller employers lack the resources and knowledge to assist their employees with tools or information that would support informed participation in their health care.

Engagement Is Demanding, and Many Are Unprepared

Consumers' views are still evolving about participation in their health and health care. Many have only a partial understanding of what it takes to be actively engaged and how engagement would make a difference. Also, many are unprepared to be active in their care because they lack the basic building blocks of engagement (such as health literacy).

Gradually, consumers are realizing that they need to be involved in their health care. According to informants, relatively few people know their involvement can make a difference, and they act accordingly. Informants in the patient advocate stakeholder group personally exemplify this engaged group. Others understand at least a few things they should do (especially in core health behaviors like eating well and being active, learning medication side effects, and getting second opinions), but there's a gap between knowing and doing. Finally, there is another group of people who have little understanding of how much they can improve their well-being and

who take a passive role in health care. Lygeia Ricciardi, Office of the National Coordinator for Health Information Technology, reflected:

Ours is in many ways still a paternalistic system. ... People aren't used to questioning the medical establishment, and they need to be encouraged to push back in a constructive way, to tell about personal goals as well as provide information about their bodies and their behaviors. At the same time we all need to take greater ownership of our own behaviors on a daily basis—they impact our health more than anything else.

Building Blocks: Internal and External Prerequisites for Engagement

To become actively involved in caring for their health, people need to possess some basic building blocks that prepare them.

One widespread perspective was that many people lack the prerequisites for actively contributing to their care. As noted by June Simmons, Partners in Care Foundation, “Actions are indeed the big outcome, but readiness is key.” To be prepared to participate in their care, people need the following building blocks:

- *Mindset*: viewing yourself as having a role, being able to make a difference in your health, caring about that difference, and being willing (or motivated) to participate in care
- *Knowledge*: knowing how the health system operates and what your insurance benefits are; understanding that variances in quality and cost exist; and having both general and health literacy
- *Skills*: being able to ask questions, “comparison shop,” navigate a highly fragmented system, get helpful information, and more

These personal building blocks are essential to engagement, but external support is also needed. Specifically, access is foundational to engagement. Informants described access as having a means to obtain not only health care services, but also community-based health programs and services, reliable health information, information in medical records, and tools.

Trusting relationships are an additional external prerequisite that many informants emphasized. Simply put, engagement requires trust between patients and their individual clinicians. This is because people who mistrust their health plan, employer, or a community health group will be less receptive to the engagement support that these stakeholders offer. This view is reflected in Linda Smith-Wheelock's, National Kidney Foundation of Michigan,

comment that, “[People] have to feel trust in the system in order to even have the kinds of conversation with their medical team that will help them care for themselves.” In a similar vein, Mary Minniti, Institute for Patient and Family Centered Care, declared:

Right now I believe there is a lot of misunderstanding about the intention of each player. We judge each other harshly—patients aren’t compliant; doctors don’t listen. When we understand and honor the importance of healing relationships between members of the health care team, I become hopeful. When a partnership is established and everyone is engaged in working with patients and families, I see wonderful outcomes and am hopeful we can all have a different experience.

Partnerships Are Required

Patient engagement is a shared responsibility that requires ongoing partnerships among different sets of stakeholders.

Most informants emphasized that patient engagement does not happen in isolation but rather requires multiple stakeholders working together to support patients. As described by Steven E. Weinberger, American College of Physicians, “To get better engagement, a push needs to come from both the clinician and the patient side—each interacts with the other.” Similar views appear throughout the interviews.

Often the obstacles that hinder engagement are systems issues, according to Weinberger and others. Fernandopulle noted that the macro health system must align itself to support patient engagement. This realignment will require health care providers and health plans to work more closely with community health organizations than in the past. Employers, together with health plans and companies offering disease management and other assistance, can influence consumers’ and providers’ behaviors. Likewise, consumers and community health groups can push for system changes.

It’s Like the Wild West

In part due to the depth and breadth of behaviors that represent engagement, no single strategy can boost engagement. Each stakeholder representative noted that they use a variety of interventions to encourage patient engagement. However, their efforts to promote engagement often lack a systematic approach to ground the investment of time and resources. Even so, informants called for all stakeholders to do more.

Extensive efforts are underway to facilitate patient engagement. All stakeholder groups, including patient advocates, shared multiple ways they try to help people become more involved in caring for their health. Which interventions are appropriate, according to informants, depends on your stakeholder group. For example, employers are willing to educate employees about health plan benefits and provide informational resources to aid participation in clinical decisions. However, they steer clear of making treatment decisions for employees and their dependents.

Few informants articulated a systematic approach—such as one guided by a particular theoretical framework or body of evidence—that directs their investments in patient engagement. Rather, “scattershot” or “Wild West” might characterize how different stakeholders are trying to improve engagement. As Simmer observed, “I see a lot of zeal among health plans, perhaps akin to a Tower of Babel.” Simmons has found that “Whatever works to get people thinking and talking and sorting it out with peers is of interest.”

At a population level, trending interventions to support engagement include the following (not in any particular order):

- Stanford’s suite of Chronic Disease Self-Management Programs
- Interventions informed by behavioral science, especially as applied to the design of patient and provider incentives
- Health coaching, especially models that deliver in-person services instead of wholly relying on telephonic or online support
- Technology, especially online portals that facilitate patient-provider communications, mobile technology apps, access to reliable medical information, social media, and online patient communities
- Peer support, especially when provided by lay health workers, disease support groups, trained peer mentors, or other participants in health promotion groups

In individual patient interactions, some providers use Patient Activation Measure assessments or motivational interviewing techniques. Others apply the Transtheoretical Model of Change (a.k.a. Prochaska’s stages of change) to encourage patient engagement.

At the system level, many health systems are adopting the patient-centered medical home model and adding care coordination teams. One strength of these types of interventions, according to Minnitti, is “Care [is] no longer oriented just to the exam room.” But she cautioned that as care delivery evolves, providers must explain to patients:

...why their involvement is essential and [set] the context for this change in relationships [to help] invite more participation. To build confidence with new roles, patients and families need encouragement and support for these expectations and new behaviors.

Several informants noted that some health care providers are involving patients as advisors to help guide how they deliver care and to support engagement.

Systemic change is essential in the eyes of some informants. Haley said, “Small-scale changes are important, but systemic changes are critical to address this issue.” Ferretti believes that the key is “to create community and clinical linkages that activate people to engage in ways that enhance their overall health and well-being.” Likewise, Simmons noted that community groups could do a lot, especially if they partner with health systems. He added that community health groups and providers are “just beginning to learn to work together.”

Other informants suggested that the place to start is changing people’s and providers’ mindsets about their roles in protecting health. Norman has found:

[D]elivery systems get the best engagement results if they have systems to support and encourage patient involvement in their care. Clinical systems are needed to support engagement because even “good” physicians inconsistently deliver optimal care unless they have systems to support that process.

Simmer envisions “a major transformation to reverse the current relationship between patients and providers... [such that] patients [will] say their doctors helped them understand their health and guided them in making changes to improve health.” Some informants referred to the Affordable Care Act as catalyzing changes in health systems that will ultimately increase patient engagement.

Doing More

Informants often viewed other stakeholders as having a bigger stake—and more capacity—to influence patient engagement than they have. At a minimum, Larry Boress and Cheryl Larson, Midwest Business Group on Health, urged, “Each stakeholder... be accountable for patient engagement.” Other informants expressed similar views.

DISCUSSION

This study provides a partial picture of current thinking about and approaches to patient engagement by representatives from the major stakeholders in health care. One limitation is the use of a convenience sample. The key informants were all involved in actively promoting patient engagement and thus may have been predisposed to participate in the study. Also, the scope did not enable a large number of stakeholders to be interviewed. Even so, the breadth and diversity of the study participants has produced a composite of the field from multiple angles and from different regions in the country. CFAH was unable to find prior studies gathering the range of perspectives about patient engagement that this one generated. Thus, this study makes an important contribution to the field.

CONCLUSIONS

On the whole, informants view the patient engagement movement as having taken root in all health care stakeholder groups. It's a movement with staying power, not an overnight fad.

Although not explicitly noted by informants, the field is clearly moving forward without an established definition of patient engagement. Stakeholders share a common, broad understanding of engagement defined as people's active participation in their health and health care, done in partnership with other stakeholders. These partnerships are critical to work around barriers to engagement within the current U.S. health care system.

Efforts to support patient engagement are plentiful. Stakeholder groups are investing broadly in patient engagement, and informants believe that these efforts will pay dividends to all stakeholders. Even so, they called for more to be done to improve people's preparedness—and efforts—to actively participate in their care.

The interviews depict what is still a Wild West landscape of patient engagement. Although it may be too late to corral health care stakeholders around a single definition of patient engagement, current agreement about its general principles is sufficient to move the field forward. A key opportunity for improvement is for stakeholders to adopt systematic approaches to support and measure the actions people take to participate in their care.

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APPENDIX

CFAH Interviews with Health Care Stakeholders on Patient Engagement

DISCLAIMER

The views expressed in the following interviews are those of the informant(s) and do not necessarily reflect the position or policy of the Center for Advancing Health (CFAH), the interviewers (Jessie Gruman, Dorothy Jeffress or Molly French) or the project supporter, the Robert Wood Johnson Foundation.

Any attributions to specific individuals, publications, projects or organizations are those of the individual key informants and have not been verified by CFAH.

All informants were provided with copies of their interview summaries prior to publication and were allowed to edit their responses.

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- Tom Ewing, MD—Executive Vice President and Chief Medical Officer, PacificSource Health Plans, Springfield, OR
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CLINICIANS

RUSHIKA FERNANDOPULLE, MD

Rushika Fernandopulle, MD, is the cofounder and CEO of Iora Health, which offers innovative primary care practices in Las Vegas, NV; Hanover, NH; Boston, MA; and Brooklyn, NY. Iora focuses on a totally redesigned primary care model with the goal of drastically reducing overall health care costs and improving health outcomes down the line. Fernandopulle was the first executive director of the Harvard Interfaculty Program for Health Systems Improvement and served as a managing director of the Advisory Board Company. He serves on the faculty and earned his AB, MD, and MPP from Harvard University, and he completed his clinical training at Massachusetts General Hospital.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

FERNANDOPULLE: It is important to start with the premise that for an individual their goal is health, *not* health care. Health care is only one of many means to achieve health. Our behaviors, including lifestyle, are critical. Our decisions about health care and how we use and navigate it are important too.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

FERNANDOPULLE: Being engaged in our health and health care makes the most difference to us as individuals. Our actions need to reflect our own goals, our values and preferences, and what we are willing and able to do to achieve them. But often we do need help and support to reach our goals and to take action.

The notion that a doctor or health care professional can manage your health is foolish. At most, we only see an individual for a couple of hours per year. So being engaged has to matter most to individuals and the system needs to align itself with that aim.

Some in the provider community don’t buy in to this perspective. But really that doesn’t matter. Decisions about health mostly take place outside health care.

Q3. CFAH: As a clinician leader, have you ever tried to help your constituents with any of the engagement challenges in the list below? Are there any that you think clinicians have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

FERNANDOPULLE: Of this group, these four stand out as challenges that clinicians have standing and credibility to address:

- 1) Find good clinicians and facilities
- 2) Make treatment decisions
- 3) Participate in treatment
- 4) Make and sustain lifestyle behavior changes

People have lots of distractions in their lives. As a doctor, I can help them sort through information and start to figure out what are the best choices for them. Sometimes people need help understanding why some action or behavior is important. Sometimes there are specific treatments or therapies I can recommend that will help. Sometimes they need to discuss risks and benefits of different decisions like back surgery, for example.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

FERNANDOPULLE: The current model of Monday through Friday, 9-to-5 health care driven and organized by clinicians can't do enough to help people engage. We have to move beyond that paradigm. Health and health care is not just about the doctor. Support for many of the engagement challenges you describe can be done better by others. I am especially encouraged by programs like ours that coordinate health coaches in concert with clinicians. Health coaches can provide support in everyday life and go beyond what takes place in just health care encounters. The best coaching helps to create a continuity of care and respects existing clinical relationships.

In the past, some coaching or disease management programs were organized by condition or disease, which was silly. We need to organize by patient, by providing one primary contact that can triage to others as needed.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

FERNANDOPULLE: The current payment model (mostly fee for service) encourages fragmentation of care. Since care is mostly oriented toward making a diagnosis and providing isolated treatment for that condition, a lot of the support and help people need just isn't reimbursable.

And many think that if people were more engaged in their health, then use of health care might go down. So the incentives are misaligned too. We need to shift the culture of health care so it serves the patient, not the clinicians.

Q6. CFAH: To what extent do you think that efforts by clinicians can reduce these barriers/increase the capacity of people to engage?

FERNANDOPULLE: Clinicians should be on board with efforts to both transform the culture of health care *and* to realign payments to support more patient engagement. But most are distracted by demands of the current system, so few are actively working in this direction. If you were to ask most clinicians why they became a doctor or health care professional, they would reply with "to help people" or something very similar. Yet, many clinicians would say they feel trapped by current payment and delivery system models. Some patients are beginning to seek out and find the clinicians and practices that have made the shift and started new models of care. The more this happens, the more impact it will have.

As for making changes within health care systems, it can be very hard to do because just a few bad apples can ruin it. In some cases, you just can't do it with the people who are on the bus [in the system]. I would ask other clinicians to step back over and over and get clear about the goals of their practice. Is it self-preservation or is it patients? Getting clarity and keeping it is rare.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

FERNANDOPULLE: To the patients we serve and the purchasers writing the check, patient engagement makes a lot of sense. They get it. They are with the program.

Health plans are variable with regard to supporting patient engagement. Most of them talk about it, but their playbook relies heavily on long-distance relationships like using a nurse/coach from a call center in Idaho. While those programs may not directly harm patients, they don't really cultivate the right connections. And health plans really don't do a good job of maintaining relationships with patients/members. In part, because they just don't have long-lasting relationships.

We need to find more effective ways to identify people who would benefit from extra support, those whom we should pay more attention to, and how we can help them with their efforts to change behavior and improve health. While data and reports are useful, they rarely prompt change.

We need to get closer to actual patients and actual care, find more “bottom up” ways to engage. This is today's land war in Asia. What are people interested in doing? What are their interests? We have to get to know these things.

Q8. CFAH: Some clinicians are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution's behavior to support PE?

FERNANDOPULLE: The only thing that will get clinicians' and health care systems' attention is for patients to vote with their feet; many will only change when patients demand it. There are a few encouraging trends pointing in that direction. Over the past two years, over 7,000 patients have left old practices to join our delivery model. We are already seeing the practices they are leaving start to pay attention and focus more on engagement. Our goal is to eventually hit a tipping point when care will be more patient-centered everywhere—patients will be more engaged as a result.

From a policy perspective however, there are barriers for new models of care. Policies often tend to support existing models or encourage larger models, such as accountable care organizations (ACOs), to emerge to deal with new regulations and oversight. As a result, in many markets there is less competition, less variety, more narrow choices for patients. That is worrisome.

But in closing, supporting patient engagement in health and health care is critical for our future. The sheer magnitude of an aging population and growth in numbers of people with chronic conditions mandates it.

MARC PIERSON, MD

Marc Pierson, MD, was the vice president of clinical information and quality for PeaceHealth's St. Joseph Medical Center in Bellingham, WA, for 17 years. Pierson led the development of a community-wide electronic medical record system, the "Community Health Record," and intranet in the mid- and late-1990s. He spent more than five years listening to patients and implementing their vision for a personal health record that is shared with family, friends, and providers—with patient permission. PeaceHealth's Shared Care Plan is capable of being a complete health care management and communication system for consumers in Whatcom County, WA. This Shared Care Plan platform inspired the development of Microsoft's HealthVault and is fully integrated with it. The Shared Care Plan and the Whatcom vision also inspired Washington State's AccessMyHealth health record bank projects.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): "Actions people take to support their health and benefit from their health care." What's missing from this definition? What would you add, subtract, or word differently?

PIERSON: Is the current physician-centric idea of engagement something we merely want to improve, or are we ready to radically depart from the current asymmetric relationship in favor of more activated engagement? Defining engagement is very much the product of who is doing the defining. If from within health care, then the key question becomes for what or for whom is "patient" engagement primarily intended to benefit?

So for that reason, the first word that concerns me about this definition is the use of the word "patient." Few or no people I have met define or refer to themselves as patients. They understand that a patient is less than a whole person, is less than what they are. I would prefer thinking of "people" engaged in their health and health care.

However, I do like that this definition recognizes that both health and health care require people's active participation and that by having both mentioned, it opens up the necessary dialogue for exploring how they are different and how they are related. The tension between the two views is important. Medical care is not the same as health. Health is much more than the lack of illness.

My friend and colleague Ed Wagner made a mistake, understandable for the time, when he designed his Chronic Care Model looking only at research from inside health care. We need to incorporate more perspectives from real people and ask them what they need to become more engaged with their medical conditions, their health, and their well-being.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

PIERSON: Typically, engagement is defined by health care insiders as paying attention to what you are told to do and being compliant with “orders.” The current non-system of health care plays into this by being disconnected and difficult for people to understand or navigate. The current situation is a form of domination or asymmetry of power, and the move is in the opposite direction of real engagement.

Health care offers technology and knowledge but is set up for the people that work inside it, not for its clients’ ease, safety, or affordability. Payment for health care is based on professionals managing clients’ ill health, not on engaging with people to prevent illness, create well-being, or for self-care of illnesses and chronic conditions.

People are scared of what they are not allowed to know or understand. They don’t want to be more dependent. They don’t want to end up going to an emergency room. Their primary relationships are with family, friends, neighborhood, and community—not professional service providers.

Thinking is evolving about health. People have strengths—internal qualities like individual resilience—and resources outside of health care like external safety nets. We can improve health care when we help people get in and get what they need, when we make sure that people have access to information about their health and health care, and when we offer ongoing training or lifelong learning opportunities.

For example, in our county, we hired nurses and social workers who understood how to help people navigate care. Their job was to understand the context of each client’s daily life and where they needed support and then to help translate between the world of the client and the professional health care system. They became trustworthy guides who helped people understand their situation better and avoid emergencies and hospitalizations.

Q3. CFAH: As a clinician leader, have you ever tried to help your constituents with any of the engagement challenges in the list below? Are there any that you think clinicians have more or less credibility to address?

[PIERSON: *comments are in italics*]

Find good clinicians and facilities. *As an emergency physician, I did this on a daily basis. I still do this with my friends. Our navigator coaches also did this on a daily basis.*

Communicate with clinicians (doctors, nurses, others). I know that people need health and health care translators. Some clinicians do connect with clients and really communicate effectively.

Organize care (appointments, records, referrals). *The health care system is a mess, not a system at all. A major re-engineering problem/opportunity exists to connect and align the independent parts.*

Pay for health care. *In our county, Whatcom Alliance for Healthcare Advancement has been helping citizens obtain insurance and care for 12 years. But we are primarily paying for reactive illness care. Public health is the only notable counter-example. Almost all our resources are funneled into illness care...preventable causes of death. [We] need more emphasis on learning about healthy choices/behaviors in schools, workplaces, and neighborhoods.*

Make treatment decisions. *People need more peer support in their decision-making. The unavoidable biases of doctors are too strong. We need to help people connect with other people in the same situation. Over the next five years, diagnosis and treatment choices will change dramatically due to genomic and proteomic testing.*

Participate in treatment. *Navigator coaches who are not employees of the prescribing physicians are needed to help people participate in treatment. Make and sustain lifestyle behavior changes. This is the big one. No one has this answer... positive psychology has much to offer here, particularly Barbara Fredrickson and Rhonda Cornum. More practical research on learning how people become more resilient is needed. We need to understand how to support people in taking action on their own behalf.*

Get preventive health care. *We need to decouple lifestyle and preventive health screening and education from doctors and hospitals. We can thus make it more affordable and much less intimidating. Judy Hibbard and Bill Mahoney have shown that patient activation, measured with the Patient Activation Measure® (PAM®), frequently goes down when they see their doctor. Like Jonkoping County, Sweden, we should place basic pediatric care in the schools, managed by nurses.*

Plan for the end of life. *The number one cause of bankruptcy in the US is medical costs at end of life. We, in Whatcom County, WA, are learning from La Crosse, WI, and engaging the whole population in proactive end-of-life planning with getting living wills in place and ensuring that they are honored by hospitals. A second thing that is important and doable is to organize acute care, chronic care, and social care around the 3% of the community that account for 30% plus of the total cost of*

medical care. Atul Gawande named these the “hotspotters.” For these people, lots of social workers and broad community support are needed. We must do whatever is needed for these very expensive patients. We must especially try to keep them at home. We also should support hospice and palliative care. When we do a better job here, we will solve some of the economic crisis caused by medical care.

Seek health knowledge. *Participatory research with end-users, citizens, is needed to learn how to develop abundant communities that foster health and well-being among neighbors; we have lost our prior know-how. (See *The Abundant Community* by Block and McKnight.) The relationships, knowledge, and behaviors for well-being and health originate and are sustainable only in neighborhoods, certainly not primarily by professional service providers with dependent clients.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

Q4. CFAH: What are some interventions that you’ve heard of that show promise in helping people to engage in their health and health care?

PIERSON: There is great promise in having professional navigators, health coaches, or what I call health care translators. They can help people get in and out of medical care more efficiently and hopefully with the least harm and much lower costs. Pilot projects that focus on extra help during transitions of care (when someone is being discharged from a hospital or surgery center or needs a new level of self-management skill) offer promise too.

Some work has been done with offering telephonic support for hotspotters, the people who are recurrent users of medical care. This approach saves money and resources. Online resources are promising, too. The Web can offer more information and support than was formerly possible.

Understanding a person’s level of activation is key. PAM® scores should be monitored for all people receiving medical care, in my opinion. We need to know where the person is and not lump everyone together. People who are very sick and those who have very complicated medical, social, or financial problems need extra support.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

PIERSON: There are two pieces to consider. One is the affective state, actually the ratio of positive to negative affective experiences, of the patient. If mostly positive, a ratio greater than 3.0, then most of the time they can call up personal reserves of resilience. Even when

experiences are negative, available resilience gets them through. Twenty percent of people with a significant number of adverse childhood experiences do really well. They are resilient. We urgently need to understand how they accomplish this and then do what we can to support others with what we learn. We need more research about nurturing people's resilience. The Robert Wood Johnson Foundation is beginning to invest here. Brigadier General Rhonda Cornum is a great resource as well.

And secondly, we need to make sure people have good information about their health and health care and in the right doses. Too much information and too many directions can be a burden, especially for people who have low patient activation scores.

Q6. CFAH: To what extent do you think that efforts by clinicians can reduce these barriers/increase the capacity of people to engage?

PIERSON: I don't think that hospitals/providers can be trustworthy stewards of these efforts. They are trained and paid to diagnose and treat. Coaches who are affiliated with, but not employed by, physicians and hospitals are needed to reduce barriers to people's engagement in their health and health care. There are too many conflicts of interests between individuals and professionals and the companies that now employ professionals. There is a deep mindset within the health care community that patients are dependent. It is a self-fulfilling worldview.

I would suggest that learning about and exploring the role and responsibilities of engagement in health and health care should be deployed from *outside* the health care system—with seniors, in communities, and within the cultural context, and especially in schools. Maybe in employment settings next—perhaps we should think small and local.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

PIERSON: Look to the community at large. They actually can solve this problem. Professionals just seldom think of such approaches.

These three rules are a good guide when introducing something new into a professional community.

- First, vet the idea with someone else. Find a colleague.
- Then be sure to invite everyone in: "Want to play?" Don't close the door to naysayers. Remember that people like to be safe and seek situations where they are professionally and socially comfortable. Don't try too hard to persuade them. They will only become

concerned with engagement (outside the more common compliance definition) if and when they are convinced themselves that it is both important and possible.

- Finally, when some people and organizations decline to be involved, proceed anyway (the “no veto” rule) and remain open to their joining later if there is success.

Q8. CFAH: Some clinicians are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

PIERSON: Money talks. Financial incentives have to change. For example, most clinicians feel like they have no time for interacting with patients.

If there are limited resources, then I would bet all money on putting in place navigator coaches within health care. Patients are so disadvantaged because the mismatch in power is off the chart. But a translator/coach/concierge approach can help rebalance the situation. It will become increasingly clear that it helps to match people’s choices to their values—not the professional’s nor the institution’s—when considering health options.

DANIEL Z. SANDS, MD, MPH

Daniel Z. Sands, MD, MPH, is a health IT consultant at Zev Enterprises based in Newton, MA, working with several companies, including Kinergy Health, SeniorLink/Caregiver Homes, and Best Doctors, as well as a frequent speaker at health care conferences. Sands is also a primary care physician at Beth Israel Deaconess Medical Center, assistant clinical professor of medicine at Harvard Medical School, and co-founder and co-chair of the Society for Participatory Medicine. Prior to joining Zev Enterprises, Sands worked for six years as chief medical informatics officer at Cisco, providing both internal and external health IT leadership. He works to advance health care transformation, non-visit based care, collaboration, and participatory medicine.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

SANDS: The reason it’s not right is because patient engagement is a noun and actions are verbs.

I’m stuck on the linguistic point. This list of things consists of patient actions that demonstrate patient engagement. Engagement is a state of doing things or a state of mind. We can do things as a health care system to change people’s minds.

If you say these are actions that demonstrate patient engagement, it gets to the same point.

In other words, “Actions demonstrating patient engagement are X.”

To me, patient engagement is a state of mind. Maybe the point is that you can measure engagement—or at least activation—through the Patient Activation Measure® (PAM®), but we can *really* measure the actions that people take on their own behalf.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

SANDS: It makes a difference to all the stakeholders in health care. I believe it makes a difference—some supported by data and some not—because it improves health outcomes, quality of care, reduces cost, and improves satisfaction. This should matter to all the stakeholders. Key are patients, providers, and payers of health care, and it probably matters to the pharmaceutical industry as well.

Q3. CFAH: As a clinician leader, have you ever tried to help your constituents with any of the engagement challenges in the list below? Are there any that you think clinicians have more or less credibility to address?

[SANDS: comments are in italics]

Find good clinicians and facilities.

Communicate with clinicians (doctors, nurses, others). *Also must be a good collaborator (which is not just about communication).*

Organize care (appointments, records, referrals).

Pay for health care. *Is this important? What if I have no money? I'm struggling with the word "pay." Maybe "manage my health care finances"?*

Make treatment decisions.

Participate in treatment.

Make and sustain lifestyle behavior changes.

Get preventive health care.

Plan for the end of life.

Seek health knowledge. *Reach out to others like me.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

SANDS: Clinicians need to be a part of all of these. We can lower barriers and encourage patients in all areas. Note that this is a primary care doctor's perspective—not a specialist's.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

SANDS: I think that the access to tools and information commonly done through a patient portal has been a very important tool for patient engagement. People can't engage in their care if they don't have the information they need to make decisions. Portals lower the barriers to access to care.

What I mean by access is that frequently a doctor will see a patient and say, "Here's the list of medications. Is this correct?" The patient says, "No. I stopped some." Doctor: "Why?" Patient: "The prescriptions ran out." Doctor: "Why didn't you call?" Patient: "I did but was put on hold..." The same thing happens with appointments.

Allowing patients to conveniently access health care—including information, prescriptions, appointments, and even care—makes it easier to get care. It's not always easy to access by

phone or to come in. When doctors make it easy to send e-mail information about side effects or symptoms, that's another reduction of friction. Overall, I think the portal has been an important tool.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

SANDS: There are three main barriers.

- Lack of access to the practice and lack of information, which has been the rule, not the exception. The opacity of the health care system and amount of friction one has to overcome to get care are big barriers. This isn't going to get better soon.
- The cost of health care for many people.
- General and health literacy.

Q6. CFAH: To what extent do you think that efforts by clinicians can reduce these barriers/increase the capacity of people to engage?

SANDS: If you look at what I said were the biggest barriers, they are driven by clinicians and provider institutions. When they care enough about these things, they will be more likely to reduce barriers. Clinicians need to change their mindset; this will change their behavior and will encourage patient behavior change.

Patient/family behavior is important too. If we change their mindsets, then health behavior improvements will follow.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

SANDS: It's hard to generalize—many clinicians are enlightened. This is a struggle, though. We haven't changed enough minds yet, but it's fascinating to spend the time engaging physician audiences. I spent several months in 2012 visiting Canada and speaking to groups of doctors about patient engagement—how to think about it and why it's important. And I've done the same thing on many occasions in the US and in other countries. And the reactions are interesting to see, ranging from agreement to protest.

Clinicians have to think differently about health care. Unless you are a surgeon and you have a patient who is unconscious and you are performing surgery on him or her, we can't be successful in treating patients without their involvement. Sure, I can tell you to come into a visit

or prescribe medication, etc., but none of this will make a difference unless the patient participates.

We physicians are now increasingly being held accountable for patient outcomes, which will make a difference over time. Doctors complain about non-compliance, but if we can lower barriers and help patients, it will change patients' orientations toward health and health care.

We still think we can do it all, but we can only be successful if our patients participate.

Q8. CFAH: Some clinicians are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution's behavior to support PE?

SANDS: I think there's not a silver bullet here. I find it gratifying when I successfully change one or two doctors' minds using evidence, persuasion, key opinion leaders, etc.

Some of this will happen through education. We need to be teaching these skills to clinicians in training; most places don't do a great job of this. Teachers are often not practicing this way. As a preceptor, I try to bring patient engagement issues to students. And this year I will start formally teaching primary care residents these concepts.

We need more people teaching who understand partnering with patients.

I do believe that the [federal health IT] meaningful use incentives [requiring patient portals] will drive some behaviors, and clinicians will be convinced by that. Right now I find some practices are fulfilling meaningful use requirements by just going through the motions and checking the box. For example, visit summaries in many places are information-free pieces of paper.

For some people, meaningful use may motivate them.

We need more evidence in the peer-reviewed literature that participation makes a difference. Doctors care about the time it's going to take. They need evidence that it doesn't increase time or, if it does, that it translates into better outcomes or reduced costs. And we need to present this information to clinicians.

What can clinicians do to make a difference? I talked about what they can do but not how they can help patients change. Some patients aren't engaged, and they don't want to be engaged. This is a huge problem.

One approach I have been using is the Prochaska stages of change model. It's very useful in changing behavior. I assess where patients are, try to help them move to the next stage, and try to help them not slip back. I use this to help clinicians move too, even though I know that some will just stick in that pre-contemplative phase until they retire.

STEVEN E. WEINBERGER, MD, FACP

Steven E. Weinberger, MD, FACP, is executive vice president and CEO of the American College of Physicians (ACP) as well as an adjunct professor of medicine at the University of Pennsylvania School of Medicine. Prior to joining ACP, Weinberger served on the faculty of Harvard Medical School and Beth Israel Hospital/Beth Israel Deaconess Medical Center for more than 25 years and was executive director of the Carl J. Shapiro Institute for Education and Research. ACP is a national organization of internists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults. It is the largest medical-specialty organization and second-largest physician group in the US and works to enhance the quality and effectiveness of health care by fostering excellence and professionalism in the practice of medicine.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

WEINBERGER: I don’t think there is a single definition. There are both macro and micro levels of patient engagement. The micro level is what happens at the point of contact between doctors and patients in the patients’ health care. The macro level is involvement of patients generically in making the system better in practice and organization at local, regional, and national levels.

Both of these components of patient engagement are important to address, because our system is pretty bad at the moment. As we talk about redesigning the system, it’s important to get patients’ input in a serious way, not just the clinician’s viewpoint of what the patient thinks.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

WEINBERGER: I think it makes a difference in that health care is not delivered *to* someone; it’s delivered *with* someone. It’s a partnership. To accomplish the three things Don Berwick talks about in the Triple Aim [care, health, and costs], the best way to do this is as partners.

Better health needs the patient to have a healthy lifestyle. Better care requires the doctor to do things that are medically appropriate, taking into account patients’ preferences. And patients need to be informed and engaged in their care.

Engagement can make a difference in lowering per capita costs. There needs to be an understanding by patients that more or more expensive care is not necessarily better. This has to be understood within a partnership.

Q3. CFAH: As a clinician leader, have you ever tried to help your constituents with any of the engagement challenges in the list below? Are there any that you think clinicians have more or less credibility to address?

- Find good clinicians and facilities**
- Communicate with clinicians (doctors, nurses, others)**
- Organize care (appointments, records, referrals)**
- Pay for health care**
- Make treatment decisions**
- Participate in treatment**
- Make and sustain lifestyle behavior changes**
- Get preventive health care**
- Plan for the end of life**
- Seek health knowledge**

(This list is from the [CFAH Engagement Behavior Framework](#).)

WEINBERGER: The only one I have discomfort about is paying for care. This gets into whether health care is a right or a privilege. It goes beyond the clinician-patient relationship. I know that it is critical, but I don't view it as a component of patient engagement or something that the patient and clinician are working on with one another. All the other things are.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

WEINBERGER: We're particularly interested in the macro-level approach. We are involved with helping redesign care—helping clinicians to be more patient-centered. To do this, it is important to recognize that being patient-centered means having patients involved in how care delivery should be transformed generally and within individual practices.

At the individual clinician-patient level, we have an initiative that addresses the cost-of-care issue, that is, to help ensure that patients understand what makes a difference. Our High Value Care initiative is focused on this. We are also part of Choosing Wisely—but ACP's High Value Care initiative has an even broader agenda.

At our annual meeting we have a patient fair. The focus is on getting the right amount of care: what's appropriate and advisable? What should people ask their clinicians? Traditional

expectations of patients are not necessarily in their best interests. We are aiming for *rational* care, not *rationed* care.

I am interested in the *Open Notes* concept that Tom Delbanco has been developing, where there is an opportunity for patients to review their notes and for communication with patients about their care.

Another promising area is the opportunity for practice assistance to be built into electronic health records (EHRs). Currently, this requires better computer-based systems that would allow patients to set their up own appointments and do other tasks. This remains aspirational, at least on a broad scale.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

WEINBERGER: I think one of the biggest barriers is *time*. For patients to be able to participate more fully in their care they need to have better understanding of their own health care issues. The problem is that discussing these issues is the responsibility of the health care team. We have to communicate more effectively than we do now. Because of time constraints, health care professionals aren't doing what needs to be done to help patients engage. Clinicians need to be both a catalyst and a resource for engagement. Because of time constraints and churning of patients through the system, it's impossible to communicate the kind of information patients need to engage and to have patients ask the questions that are so critical.

Another barrier is access to care. Patients can be engaged in their care—they may want to be, but this requires bi-directional communication that goes beyond the face-to-face visit, and our system is not aligned to do this yet. The payment system does not yet reward effective communication and the time spent doing it.

Q6. CFAH: To what extent do you think that efforts by clinicians can reduce these barriers/increase the capacity of people to engage?

WEINBERGER: These are systems issues, not individual clinician issues. The time barrier has been imposed by the volume based fee-for-service system. Clinicians feel forced, with high overhead and low reimbursement, to push patients through.

The access issue is interlinked with the time issue, and it is also a systems issue.

One of the opportunities to fix things is at the level of better design of team-based care: to use the appropriate health care professionals that make sense. That is, not having doctors do things

that a nurse practitioner can do. There needs to be a more appropriate allocation of work based on skills as well as the needs and preferences of the patients.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

WEINBERGER: No matter what issue you talk about, clinicians are all over the place. This is true about patient engagement as well. There are many who are very committed, and there are many for whom this hasn't even hit the radar screen.

If the tipping point is at 50%, I'd say we are now at about 30%, at least as far as true patient engagement.

Q8. CFAH: Some clinicians are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution's behavior to support PE?

WEINBERGER: I actually think it will be a few things. There is more discussion about this concept in the media. General awareness of both clinicians *and* the public will help through messages like, "It's appropriate and advisable for you to ask your clinician whether these tests are really needed for you."

At the same time, as we move toward value-based payment systems and part of that value is patient satisfaction, these incentives for physicians will come into play as well.

I don't know how regulation can be persuasive except as it relates to payment. To get better engagement, a push needs to come from both the clinician *and* the patient side—each interacts with the other.

I have concerns about how quickly we can make changes in the amount of time that doctors have with patients these days. I'd love to see team care make possible more time for each patient with the appropriate clinician. And I am convinced that you need to be able to fix the macro-level issues to get the micro-level ones to work on a broad scale.

COMMUNITY HEALTH LEADERS

ROSANNE DISTEFANO AND JOAN HATEM ROY

Rosanne DiStefano is the executive director, and Joan Hatem Roy is the assistant executive director of Elder Services of the Merrimack Valley in Lawrence, MA. Established in 1974, this nonprofit agency serves elders, disabled adults, and caregivers by supporting their desires to make their own decisions, secure their independence, and remain living in the community safely and for as long as possible. Elder Services of the Merrimack Valley was one of the first agencies to be recognized nationally for its work in implementing evidence-based healthy living programs designed to help people become better health care consumers and manage their chronic health conditions. It was also one of the first agencies in the nation to be awarded funding for a partnership with six area hospitals offering transitional care services for patients being discharged from health care settings.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

DISTEFANO & HATEM ROY: With the population we see (older people), it’s not only about the patient. It’s also about their family and their support network. Elders often consult with their families and caregivers to advocate with and for them.

In different settings, you have different expectations. When we are delivering in-home support to an older population, we want to make sure they are as engaged as possible by knowing and understanding their choices and options for services. What kind of services they want and in what location, for example. What motivates them and what are their personal preferences and values? For frailer elders who are nursing-home eligible, it is very important that they understand all choices and options. Choices for a less independent population are still theirs to make, but they are different than for those who are active and more fully independent. For them it is about how to manage and live with their chronic diseases. This is where Stanford’s Chronic Disease Self-Management Programs are so useful.

We believe in activating and empowering our staff to really act on behalf of the elders and older adults we serve. As management, our job is to try to take away the constraints that they face in getting the clients what they need and want.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

DISTEFANO & HATEM ROY: First, it makes a difference to the individual and family. One of the things about self-reported health is that if people feel healthier and more in control of their

illness and environment, they feel better and report that they are healthier. This translates not only into a better quality of life but also benefits their insurers.

Clinicians benefit too. If you are a clinician and you are getting immediate feedback and a response from your patient, you know how you are doing.

The nurse and care manager: When they have a participating client, they are also more engaged. It's more of a conversation, and it makes everyone's work more rewarding.

Engagement really affects all the staff that serves the patient. We spend time with our care management and nursing staff on motivational interviewing and cognitive behavioral techniques. You can do a lot more with an activated patient.

Q3. CFAH: As someone who is active in engaging people in communities in their health, are there any types of behavior listed below that you think community-level leaders have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

DISTEFANO & HATEM ROY: All of these are relevant. We are furthest away from treatment decisions because we are a direct provider of health care. We help to educate people about their choices and to sort through what's important to them. We have a hospital-to-home transition program. We use non-clinical transitional health coaches and often hear that patients are more honest when they think you aren't a medical professional.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

DISTEFANO & HATEM ROY: We are working on health literacy issues. Different cultures/languages and the ability to read medical information can be a real challenge for many that we serve. We have staff who have been trained as medical interpreters. We try to begin and focus on those issues most pressing for the individual, helping them to find solutions to apparent barriers, identify their choices. Maybe they haven't talked with their daughter for years or have a hard time being direct about their preferences, and our staff might help create a safe environment for that conversation. We also do protective services. And we find that in these cases, people can be afraid to ask for what they want. We need to meet with them where they are and create a situation where they feel safe.

The oldest generation we serve sees the doctor as the end-all and be-all. A big part of our job is helping them communicate with their doctor and to advocate for themselves.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

DISTEFANO & HATEM ROY: Not realizing what options they have. It's so basic. This older generation—the one that is now aged 80 to 100—is not used to having choices about their health care and is often not comfortable questioning medical authority. It's very different in the 64- to 85-year-old population. They are used to being better consumers and stronger advocates for themselves. You need to think about these barriers by age, cultural background, and other factors to really understand the barriers that the individual sees.

A barrier for someone at 65 might be depression, finances, transportation—they can feel boxed in. At 85 or 90 they may also feel boxed in and see fewer choices.

One of the things we're doing is medical care coordination. Often the doctor doesn't know what the home situation is like. We provide that information to the doctor, giving him or her eyes and ears on the ground and the opportunity to work on these barriers with their patients if appropriate. We can also let the physician know what barriers we are working on—more suitable housing, for example. We give doctors information they wouldn't get in the 15-minute office visit.

It's important to remember that taking the medication prescribed is not always an issue of non-compliance, but may be an issue of being able to afford the medications or managing them.

Q6. CFAH: To what extent do you think that efforts by community groups like yours can reduce these barriers/increase the capacity of people to engage?

DISTEFANO & HATEM ROY: I think some of the things we do are critical, such as being a patient advocate when we need to, but also giving the patient the chance to see all their choices. We're learning how they can be more empowered (through interventions like the evidence-based programs) and telling them they do have some control over their emotions and pain by using certain tools to get a better quality of life. As a non-medical, community-based organization we can sometimes have greater access to a broad range of elders and older adults; we don't have to rely on any single communication tool to get the word out. We look at everything: volunteers, word of mouth, professionals, paraprofessionals, and the media. If they have the information and knowledge they need, they can be more activated.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

DISTEFANO & HATEM ROY: I think our colleagues now are beginning to really get this. Hospitals are working with our transitional coaches, and this has been rewarding on both sides; they see how our efforts can improve the quality of life for patients, and we appreciate what they need to do in a short period of time. Physician groups too are becoming more receptive. It's hard for clinicians to be resistant in this environment of shared risk.

In this health care environment, where there is such pressure to reduce costs, people are finally realizing that our approach is a resource for cost reduction.

The environment is competitive. Satisfaction is measured by people saying, "I understand my options." The toughest piece is where financial incentives are not aligned. Most of the time better care leads to lower cost. But there are still pockets where, for example, the MRI machine has to be used 24 hours [a day] to pay for itself.

Q8. [not asked]

LISA A. FERRETTI, LMSW

Lisa A. Ferretti, LMSW, is director of the Center for Excellence in Aging and Community Wellness, research assistant professor, and the director of the New York State Evidence-Based Health Program Quality and Technical Assistance Center at the University at Albany School of Social Welfare. Ferretti leads a statewide effort to disseminate several evidence-based health promotion and disease prevention programs including the National Diabetes Prevention Program (NDPP) and the suite of Chronic Disease Self-Management Programs (CDSMP) developed through the Stanford University Patient Education Research Center. Ferretti is a national trainer for the NDPP and the CDSMP programs and has extensive experience developing partner capacity for the delivery of evidence-based programs and building community-clinical linkages to expand access and sustainability efforts.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

FERRETTI: I’m not sure I would change anything about your definition as it is action-oriented. When I think about patient activation, I consider that when people are activated they are doing things in a positive way to change their circumstances. I think activation helps people to become engaged.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

FERRETTI: I think it makes a difference to everyone who is involved in their life. I strongly believe in the Chronic Care Model and the idea that individuals do better when they are supported by their personal and their clinical communities. If someone is engaged, they will look to make positive changes and find good community resources to help them sustain the changes. This helps people on the clinical side too. Engaged and activated patients do better clinically as well. When a person or a patient is a partner in their health care, it makes a difference. The system is more responsive to people who are more engaged. I don’t say this to mean that patients who are not engaged should not receive excellent health care but to point out that engaging and activating patients should be part of the work of clinical communities.

The work I do is to help people to see that their role is different when they engage more directly in their health care. This is especially true for those with a chronic condition or two.

It makes a difference to family members too. If you are engaged, it has an influence on those around you and helps others to be more engaged and helps determine what additional help a

person needs. This is easier to do if someone understands the impact of their behavior on their health.

When people are actively engaged in their health and wellness, we hope it will cost the health care system less money because there will be fewer complications that cost more. Doing a better job caring for yourself potentially means fewer complications, fewer emergency visits, etc. This has the potential to save health care dollars. This hasn't been proven yet but is part of the argument for engagement and prevention.

Q3. CFAH: As someone who is active in engaging people in communities in their health, are there any types of behavior listed below that you think community-level leaders have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

FERRETTI: It's a good list. Every level of this is important to get the best possible care and outcomes. In our work, we have different programs and partnerships where we emphasize some of the items on this list over others, but there is nothing on this list that isn't important to getting the best possible care.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

FERRETTI: I would say that we probably focus our efforts on interventions that empower people to make the changes they decide are important to them. This includes interventions about decision-making, treatment, and preventive care. Also, interventions that are less about increasing knowledge and information and are more about what to do with that knowledge. I

think having greater access to good clinicians and facilities is a must, but if those are available, then empowering individuals is perhaps more important.

As a coalition, we are working on changing the environment to support things like healthy play places, parks, walking paths, grocery stores, farmers' markets, fruit and vegetable trucks, etc.

Our coalition works to better link together the poor with the clinics and organizations providing services to them. We try to give consistent messages about physical activities and are providing evidence-based self-management programs like the Chronic Disease Self-Management Program, National Diabetes Prevention Program, etc. These programs help participants to apply their knowledge to become better patient advocates for themselves. In our evaluations of these programs, we have seen some impact on participants and of course, we have lots of anecdotal evidence. Some of the changes people report are huge.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

I think the barriers vary by population. We recently piloted a lifestyle coaching model, and many of the folks we recruited into the model did great. Those who didn't often had persistent mental health or substance abuse issues that kept them from engaging regularly. Unmanaged substance abuse or mental health conditions impact engagement.

We do a lot of work with older adults. Older adults seem to be a little resistant to the patient activation model. Being influenced by an acute care model, it may take some time to move this population away from that type of thinking. This makes it challenging to help some older adults to understand that they may have different responsibilities living with chronic health conditions than with an acute health issue and that they need to act differently. This *can* be overcome, but it can be tough with some people.

In the health disparities communities that we work in, the fragmentation of people's lives really gets in the way. People may *want* to be involved but they are working one or two jobs, they have child care issues, transportation problems, etc. This makes it hard for many people, and so it's challenging to build and access a supportive community of care.

When we conduct focus groups, everyone *wants* to do better, make healthy lifestyle changes, but when you are working more than one job and your kid is sick, it can be tough to focus on your own health as a priority. Our coalition is composed of providers, community-based organizations, and community residents; this [mix] helps to bring a focus to the change and

provides support that can balance against some of the challenges people in this community experience.

Q6. CFAH: To what extent do you think that efforts by community groups like yours can reduce these barriers/increase the capacity of people to engage?

FERRETTI: If I didn't believe we could make changes, I wouldn't be doing this. I am a firm believer that our work can have a great impact on reducing barriers and challenges. I think we *know* how to do this, we *know* what works. Sometimes the path isn't clear, but I've seen small changes, and I think it is possible for those to be scaled.

At the same time I'm a realist. It can't all be about what we think needs to change in the community or in individuals living there. There are huge institutions with other concerns (cost, quality, availability of care) that have a significant role to play and impact outcomes for everyone in the system. I don't have control over that side of the Chronic Care Model equation. But I know that people on both sides of the equation have to join in for us to be successful.

I believe this can happen. I think the Affordable Care Act is promising and may help. There is resistance to change, but then there always is. I'm patient but I believe that it can—and is—changing.

I would feel like a hypocrite if I worked to help patients change and didn't think it would make a difference. That said, it isn't a one-size-fits-all model—at times it feels like we are building a bridge while we are walking across it.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

I think the thing I find challenging in the resistance piece is that there is a broken trust between people and the health care system that has developed over time. Until recently, doctors and patients each felt they were doing what they could, but neither seemed particularly effective. Doctors were saying, "You are at risk for diabetes. Lose weight!" And patients were saying, "I'm at risk for diabetes—what do I do?" The important thing is to get the conversation on track and to rebuild the trust.

This is where the community side is helpful. On the community side we can help people figure out how to carry out health care recommendations and provide important services that can help the clinical side to better help their patients. Most health care is self-care and does not take place in doctors' offices, so why not acknowledge this and help people to make better self-care decisions.

I recently talked with a director of a physician group about diabetes prevention and self-management. The person asked me, “How will this be paid for in the community?” I said, “The emerging bundled payment system provides resources that can be utilized for the community-level interventions that will help the clinical side and where interventions can be provided where people work and live.” The director said, “My doctors will never do that—they’re not going to share the payment.” I find this short-sighted and frustrating.

If we can’t start finding some common direction, it probably won’t work. It takes both sides. And it takes resources and money. The community side is tragically underfunded. We provide great services that support good clinical care and chronic disease self-management, but we still seem stuck in these turf issues. At some point we really need to work together and recognize and celebrate our strengths.

Recently, I spoke with a physician researcher who was discussing his research, and he stated that his recent research told him that micro-decisions made by patients and their family members outside of the clinical setting seemed to be the most important thing impacting patient outcomes. No disrespect intended, but I was shocked that this seemed such a revelation. We need to do more talking about patient-*driven* care; when that person walks out the door, they are in charge of their care. This isn’t patient-*centered* care. Patient-centered care involves doctors writing care plans that patients don’t follow. *Patient-driven* care is the reality beyond the clinic walls. And that is why we need both sides of the equation to achieve common goals.

Sooner or later we will realize that we are all in this together. The clinical side can’t just keep doing the same things without recognizing the reality that patients are driving their own care. People don’t just engage in their care if they are in good health or have enough money to do it. Everyone is always engaged in their care—daily decisions, micro decisions, impact that experience and potentially outcomes. The question for all of us is how can we leverage that knowledge to create community and clinical linkages that activate people to engage in ways that enhance their overall health and well-being.

Q8. [not asked]

AMBER HALEY, MPH

Amber Haley, MPH, is a project manager and epidemiologist at the Virginia Commonwealth University Center on Human Needs, which was chartered in 2007 to provide the public and policy makers with information about the prevalence of societal distress in the US and its impact on health and well-being. The center is nonpartisan and focuses on rigorous research about societal distress in five domains: food security, housing, health, education, and income. Its mission is to document how many Americans confront hunger, precarious housing or homelessness, inadequate health and health care, inferior education, and inadequate income/poverty. Haley's primary work involves convening a research partnership between community health care providers and various community groups to plan research initiatives based on their identified priorities.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

HALEY: I think engagement may be not the actions people take but the outreach and communication efforts between a health care institution and the people they serve. Engagement has to do with creating a pipeline of communication between groups of people, and the kind of communication you create defines the depth of your commitment.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

HALEY: It impacts the health of the person who is being engaged. When we have engagement with any group, people have the opportunity for self-determination in a way that allows them to participate in the decision-making process and feel more invested in the decision. People who are engaged in the decisions or service are more invested in the results. In health care, it's important for people to feel they have an investment in the results of treatment.

It probably makes a difference to the provider too. Ultimately, the provider wants treatment to have an impact, to be effective. And it probably makes a difference to service delivery—if engagement means true investment, it would lead to better outcomes for providers. This would impact the payer experience. It would decrease costs if treatments were more effective, because it would decrease the need for complicated interventions down the line and mean that primary and secondary prevention are more effective...actually, mostly secondary prevention, I guess.

Q3. CFAH: As someone who is active in engaging people in communities in their health, are there any types of behavior listed below that you think community-level leaders have more or less credibility to address?

[HALEY: *comments are in italics*]

Find good clinicians and facilities.

Communicate with clinicians (doctors, nurses, others).

Organize care (appointments, records, referrals).

Pay for health care. *I would say I'm not sure how that would fit in—with exchanges coming up, though, people will need to be engaged in this process. In our research, "navigating bureaucracy" is a big thing. I think people have lower degrees of self-determination with payment, but [we can be] helping them with administrative burden.*

Make treatment decisions.

Participate in treatment.

Make and sustain lifestyle behavior changes.

Get preventive health care.

Plan for the end of life. *I work in a community-based partnership; I have some exposure to this—not so much [with] end of life. I don't have a saturation of experience in any of this.*

Seek health knowledge.

(This list is from the [CFAH Engagement Behavior Framework](#).)

HALEY: The rest of these, of course, we see as the issues around which we engage patients.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

HALEY: Community-based navigation systems. I work in a low-resource community. People are uninsured, and they face a lot of bureaucratic challenges and fragmented care. Having relationships with people in the community and having them help their peers navigate health care in community settings is key.

We are trying to reach hard-to-reach people who have difficulties with delaying care and compliance. Where I work, they have small community health clinics, and they can get blood pressure screening, sexual reproductive health services, and free medication.

What they do is to employ people in the community to be knowledgeable about common health problems. It's the lay health worker model. They give people lots of information about what services are available. For a hard-to-reach population, community navigation models are exciting, especially if you are employing residents of the community to help with this as well as to think about health promotion.

We find a lot of issues with lack of trust and problems with communication in our communities. Doctors say they can't be sure the person understands their instructions, but usually this isn't as much because the patient can't understand, but that the trust and openness in communication does not exist between the doctor and the patient. Here in the South there are racial issues too. If there isn't trust, it can really hinder good care. People won't disclose and the doctor can't tell whether the person understands or is even willing to do stuff.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

HALEY: A fragmented service environment, discontinuous care, lack of primary care providers, lack of insurance, lack of trust for many reasons, communication problems. Because of the lack of insurance, we see delayed care and people seek care at the emergency room.

For low-income patients, it's not just about compliance; it's about whether people are *able* to comply. People's lives are complicated in low-resource, high-stress environments.

Q6. CFAH: To what extent do you think that efforts by community groups like yours can reduce these barriers/increase the capacity of people to engage?

HALEY: I think that what we're seeing is that the community-based clinics do reduce barriers, but there are a lot more systemic barriers. Small-scale changes are important, but systemic changes are critical to address this issue.

It's hard for clinicians to understand this. The way that people have the experience of going into the health care environment—even in high-resources environments—their clinicians don't have the time to understand the barriers that people face, especially when they have complicated co-morbidities.

The clinicians I work with *care* deeply, and they want their patients to be successful, but they have so little time, how could they even do this? That's why it's so great to see the use of lay health workers who have the time to work with people and talk through their concerns. You need more than just clinicians if you have a high-risk population. Some clinicians understand and some don't, but *none* of them really have the time to address it.

Q7. [not asked]

Q8. CFAH: Some people working in community health are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

HALEY: It really takes time to think about issues around compliance. When you aren’t seeing compliance, how do you understand it? If you can make the argument that a stronger engagement strategy will lead to better compliance, it is useful to clinicians. Taking the time, or having a system where it’s possible, will make it possible for patients to comply, and you will get better outcomes. Absent that, you keep doing the same thing and getting same results.

You have to ask, “Is everything here working?” We know where we’ve looked for solutions before. We know that if we develop systems without talking to users, the system won’t work. You need buy-in from all stakeholders.

JUNE SIMMONS, MSW

June Simmons, MSW, is the founding president and CEO of Partners in Care Foundation in San Fernando, CA. The Foundation develops initiatives and proactive programs to meet the mutual needs of patients, providers, and health care delivery networks to encourage cost-effective, patient-friendly integration of care from hospital to home and community. As CEO, Simmons works to shift the emphasis of health care to prevention, early intervention, and self-management. She takes an active role in the development, testing, and dissemination of high-impact models of care that bring more efficient and effective health and social services to diverse people and communities. These models focus on six main areas: access to care, aging well, end-of-life care, families at risk, education and advocacy, and prevention. Simmons is also a member of the National Advisory Council to the National Institute on Aging.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

SIMMONS: “Deciding” seems to be missing but I guess that’s implied: the idea of getting to the point where you would take action. Actions are indeed the big outcome, but readiness is key.

Engaging means showing interest in what the patient has to say. This is an important element. Finding a way to convey that you are willing and interested is really important.

When I think of patient engagement, I think of a partnership where people work together to figure out what the patient wants and how to support the process. Engagement is the knowledge base, working through the decisions and helping people to become full partners in their health outcomes.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

SIMMONS: It certainly makes a difference to patients. If they feel they can be involved in seeking better outcomes, it reduces their sense of helplessness. And their engagement would result in better outcomes, especially if they have a few resources to support them along the way. Engaging people in their care reduces their sense of isolation and hopelessness and strengthens the partnership, leading to better results. People do better when they are engaged.

The word engagement includes patients but also others—family members and caregivers, for example. I don’t think of it as a solo act. I think engagement helps give people more knowledge and resources to work through internally some of the many issues in their health. What care do

they want? What lifestyle do they want, and what can they achieve? This is better done in partnership.

The Stanford Chronic Disease Self-Management Program is a good platform, and this kind of partnership is also important in making choices about palliative care. Both give people a chance to talk through what they want, how to put it in place, and how to overcome obstacles.

Q3. CFAH: As someone who is active in engaging people in communities in their health, are there any types of behavior listed below that you think community-level leaders have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

SIMMONS: All of these are places where we could be a partner to patients to help them to navigate through to a good result.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

SIMMONS: I like all the methods of peer support, where peers ask one another questions. This is not teaching, but rather interacting with peers where they have an opportunity to have more than one discussion about a concern or topic. There are a number of approaches that help people to talk things through, problem solve, set goals, and gather the wisdom of the group. I think this strategy is really promising.

Engagement has to do with relationships. We are doing work to see how it can be attractive to open up and talk with others to figure out how to have better health results. We have wellness clubs where we put the emphasis on *clubs*. We did an initiative with Microsoft where we

invited people to virtual bowling and dancing, for example. They were competing virtually. They loved it! Then we said, “To continue to participate in the club, you have to participate in a workshop.” This created a pathway that led to more serious engagement through the enticement of fun and relationships.

We need a way to make this kind of group activity really available, or we need to go where peer groups are natural. We’ve been looking at veterans, for example, and housing sites, trying to figure out what we can do to make participating in healthier activities easy, in natural settings, and attractive and engaging. Whatever works to get people thinking and talking and sorting it out with peers is of interest to us.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

SIMMONS: I think it’s hard for people to understand that it’s possible to make a difference in their health outcomes. I don’t know if it’s shyness, or culture (such as where they don’t talk about these personal matters), the remoteness of solutions from their world, the time and thinking it takes to implement the solutions, the barriers like distance and transportation, or natural ambivalence that get in people’s way. We continue to learn and need to discover better how to use invitations that bring such programming to the tipping point where these concerns go viral and you can bring people in.

Patients say they don’t understand engagement and they don’t understand what chronic disease is. We’re going to focus on chronic pain management and diabetes to see if people recognize themselves better there. We see their physicians recognize the issues better there, where they are more familiar and concrete.

We offer a short-term memory loss workshop developed by the University of California, Los Angeles. It seems easier to get people to join this, and it’s easier to get them into A Matter of Balance programs because they understand memory and falling. These are fears that people recognize. It’s also easier to get people to come to exercise classes. “Self-management” as a term is just more foreign.

Q6. CFAH: To what extent do you think that efforts by community groups like yours can reduce these barriers/increase the capacity of people to engage?

SIMMONS: Community groups are key, but partnering with medicine is also so valuable. We need to know who could benefit (medicine knows) and how to reach people (community knows). I think it is a matter of getting out there enough. Everybody is looking for results. If you can

articulate engagement and what it can do for outcomes, the need and value become obvious. I think we're getting enough experience to talk about it, but it is still pioneering territory for both community and medicine that are also just beginning to learn to work together.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

SIMMONS: I think there is plenty of lack of buy-in. There are still a lot of people who think you just do things *to* people—give advice and information. It helps to measure outcomes from our programs, from the activation vs. education approach, and to publish them.

To be successful you need a really trusted doctor who is really credible to other physicians and who steps up to champion these approaches. The same is true in the community. To the degree that we can convert certain people—like thought leaders—it accelerates adoption. For example, the head of the area agency on aging here really pushes our engagement efforts and other programs, and she's really credible. For some people, they need to observe the changes that the Chronic Disease Self-Management Program can make at an emotional level before they really understand it.

We converted a lot of people when we did the Microsoft project. The aim there was to bring older people into the digital age. But we learned so much more—that fun is more inviting than acting healthy. Fun and connectedness are important pathways to reaching people who will benefit from these interventions. Leadership is essential—lay people, health professionals, and community agencies—these partnerships are poised to thrive in the new health reform.

You have to have a champion who basically says, "I'm going to get this done." I'm a champion, but there are lots of us; you never know where you'll find them, but they are crucial—they make the all the difference. If you can't find them, don't bother.

Q8. [not asked]

LINDA SMITH-WHEELOCK, MSW, MBA AND ARTHUR FRANKE, PHD

Linda Smith-Wheelock, MSW, MBA, is the chief operating officer of the National Kidney Foundation of Michigan (NKFM) and has been at NKFM for the past 20 years. She has a master's in social work, as well as a master's in business administration, along with 30 years of experience in the development and implementation of health programs. Smith-Wheelock has presented nationally and statewide on NKFM programs and their outcomes. She led efforts that resulted in a statewide strategic plan on the prevention of chronic kidney disease in conjunction with the Michigan Department of Community Health. Smith-Wheelock has worked to insure the sustainability of the programs at the NKFM. This has occurred through a diversification of the NKFM funding base utilizing state, federal, and private funds in addition to traditional methods of fundraising, such as special events.

Arthur Franke, PhD, brings extensive research, publications, and managerial experience with diabetes expertise at a major pharmaceutical company. Franke has been at the National Kidney Foundation of Michigan (NKFM) for eight years and is currently the chief science officer. He is responsible for the implementation of NKFM programming (with a focus on vulnerable communities and evidence-based interventions that address social determinants of health), in addition to developing and maintaining key partnerships, grant writing, strategic planning, and providing oversight to the ongoing evaluation of NKFM programs. His PhD in microbiology is from the University of Michigan.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

FRANKE: I don't know that our definition would be that different. We feel that activated/engaged patients are going to be more involved in their health care and will be more likely to take action for their own health. We provide the Stanford Chronic Disease Self-Management Program (CDSMP) and other evidence-based programs to help people learn self-management skills. There is a great need for this. Many people think that their health care system and their clinicians will do it for them rather than managing most of it themselves.

In our experience, people are interested in knowing more about the things on the list you provided.

SMITH-WHEELOCK: Knowledge is power. For patients to advocate for themselves—rather than the top-down model—they need to feel like a participant in their care; they need to have the tools and knowledge to do this, whether a person is pre-diabetic or has kidney failure or diabetes.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

SMITH-WHEELOCK: I think it makes a huge difference in the person following their treatment plan if they have input into the plan, plus the knowledge and tools to ask questions like, “Why do I have to take this medication?” If they are engaged, they are more likely to self-manage. But they have to feel trust in the system in order to even have the kinds of conversations with their medical team that will help them care for themselves.

It’s not just the patient who is affected. The people who provide care are also influenced.

In diabetes, 98% of what’s going to happen will be done by the patient. A patient who is more aware and coming up with and buying into the treatment plan will make for a better outcome for providers as well. This will contribute to reducing costs because of prevention of complications.

There is probably a lot of evidence that engagement leads to better outcomes and lower costs. We know this for our population: engaged patients with kidney failure will have fewer hospitalizations and fewer emergency room visits.

Patients’ families also do better when an individual is confident to care for him or herself. Engagement has a broad reach.

Q3. CFAH: As someone who is active in engaging people in communities in their health, are there any types of behavior listed below that you think community-level leaders have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

FRANKE: All of these categories are within the scope of what we do.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

SMITH-WHEELOCK: For pre-diabetes, we began to implement the National Diabetes Prevention Program. We've seen some huge success in this already, although we have taught only four classes. We have a lot more on the horizon.

We offer the CDSMP for diabetes as well as other evidence-based programs for exercise, for example. We use community health workers to lead these programs. We see a lot of potential for their leadership. We focus on low-income minority populations who have the greatest needs, and community health workers are a good match for them. Unfortunately, there are not great incentives, nor is there much infrastructure to fully integrate community health workers. There is a real lack of understanding among clinicians and in the system about how to make use of the skills and talents of community health workers. As health care has become more complex, people are really struggling with even the administrative barriers to getting care. We could do much more if more community health workers had a bigger, more legitimate role.

FRANKE: We've been working on health literacy. One initiative is to piggyback on literacy programs in the community. We designed a program, Read Your Way to Health, so that while working on reading, adult students are learning about health, how to communicate with their clinicians, and about nutrition, self-management, and health care navigation.

Another program is Internet Health Literacy. This program teaches people how to find reliable, accurate information on the Internet. It gives students assignments to go to sites to answer questions. In the process, they learn to use the computer *and* learn about their health. We've implemented it in senior centers, churches and YMCA/YWCAs. We've involved some African American sororities in delivering it and have showcased it at community coalition meetings. There is a lot of interest in this.

SMITH-WHEELOCK: Another promising program is Enhance Fitness. This is an evidence-based physical activity program. We offer it in 20 sites. It's a free group physical activity program that we offer to adults over 18. It's very social and is a useful platform for giving people additional information about their health and the system.

On the kidney failure side, we have a long-standing program in peer mentoring that we hope to evaluate. This is for people who are new to dialysis. The peer mentors are either on dialysis or have had a transplant and are identified by the social workers in the dialysis unit as positive

listeners and advocates. They come to the Kidney Foundation for training. It's kind of like social work 101: how to talk to others, how to coach. The mentors become adjuncts to the social workers in the dialysis unit, but they have more time. This is a very promising program and a great way for someone who has to be hooked up to a machine (no control!) to learn that there *are* ways to find control. We also have trained peer mentors specifically to talk about end-of-life issues with patients.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

FRANKE: Poverty. Literacy. Health literacy. Fear. Mistrust.

The system is becoming more complex, and people's ability to understand their role in it—what they need to do and how they need to act—is low in the populations we are trying to reach.

SMITH-WHEELOCK: Even with the CDSMP, which is so adaptable to the needs of participants, we find that the low level of understanding of health and the health care system is shocking.

And poverty means that some of the simplest things, like transportation, are real barriers. For people who have few resources, getting health care presents many complications. It's no wonder to me that people just wait until a crisis develops and end up in the ER.

Social support is a big barrier as well. If people have social support, this is a huge and important help to them. Programs like Enhanced Fitness give people social support, and it is frequent and ongoing. It doesn't end after six weeks.

We've been impressed by the lack of ability of community groups to work together to truly assist people with chronic diseases. The Chronic Care Model and all these health reform plans mention the critical importance of community groups working together to support individuals really taking care of themselves and their chronic conditions, but we really just don't see that happening.

Q6. [not asked]

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

SMITH-WHEELOCK: We're better off than we were 20 years ago. Some doctors are coming in who are being taught to focus on patients. In the medical system, it's still very top-down. The talk is about how patient engagement will help a bit. How doctors think about patient

engagement is very different from how we do. They think that if they set up a kiosk on the way out of the hospital and asked if you liked your care, then they have engaged you.

I see some movement, but until we see that the clinicians and the system recognize that for chronic disease, people's health care is not just what happens in their doctor's office during that 10-minute consultation. They have to know that people aren't going to be able to change their lifestyle and do what they need to do to prevent complications during that short period. The real action takes place outside of there. What can be done during the 10 minutes to make people's self-care more effective and more possible?

People need many tools because there are so many barriers! People need help where they live, work, and play, not where they go to the doctor, who for many is the sole source of information.

Unfortunately, most of the money and other resources continue to go to [the] medical system. But if patients are thinking about and working on taking care of themselves every day, we have to provide them the tools where they can use them.

FRANKE: I feel like we're running up an escalator that's headed down. Things are happening in health care *so fast*; it's hard to counter that momentum, to help the people we serve to catch up.

SMITH-WHEELOCK: We are convinced that people will get the best support for their engagement is in the community, not in doctors' offices. We really need more involvement of community groups and community resources in this effort.

FRANKE: The system assumes that the public has a certain knowledge threshold. It doesn't recognize that people below the threshold don't know what to do or how to make use of their health care and so can only wait for a crisis. Perhaps we need some patient advocacy effort to mediate this gap and help them to get the care they need. This is becoming ever more critical as the system becomes more complex.

The people we serve need help from those who have time to do this. The health system doesn't know how.

Q8. [not asked]

EMPLOYERS / PURCHASER REPRESENTATIVES

LARRY BORESS AND CHERYL LARSON

Larry Boress is president and CEO of the Midwest Business Group on Health (MBGH). He joined the coalition in 1991 and became its president in 2006. Founded in 1980, the Chicago-based MBGH is composed of over 100 self-funded organizations that provide health benefits to over four million people. Boress oversees MBGH's research, educational, networking, group purchasing, and advocacy activities, speaking out for the "purchaser" perspective on health care. He assists employers in formulating benefits, worksite wellness, and incentive programs as well as measuring the performance of providers and health plans. He leads MBGH's initiatives related to private exchanges, patient safety, and efforts to reduce early elective childbirths and low-value medical services. Boress also serves as executive director of the National Association of Worksite Health Centers, an organization dedicated to expanding the knowledge and capabilities of employer-sponsors of onsite and near-site health, pharmacy, fitness, and wellness centers.

Cheryl Larson is the vice president of the Midwest Business Group on Health (MGBH). Larson leads the coalition's educational and networking activities as well as two major research projects: the National Employer Initiative on Specialty Pharmacy and the Employer Communication Toolkit on Benefits Literacy and Consumerism. She is a national speaker on MBGH research, including employer best practices in value-based benefits, incentives, wellness, consumerism, engagement, communications, and specialty pharmacy benefits. Larson chairs the Worksite Wellness Steering Committee for Building a Healthier Chicago, a community-based initiative of MBGH, Institute of Medicine-Chicago, and Chicago Medical Society, founded and supported by the US Department of Health and Human Services—Region V and Chicago Department of Public Health. She serves on the advisory council for the Center for Employee Health Studies at the University of Illinois, Chicago School of Public Health.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): "Actions people take to support their health and benefit from their health care." What's missing from this definition? What would you add, subtract, or word differently?

BORESS & LARSON: The grounding for many of our responses is from the Midwest Business Group on Health's (MBGH) research. We've surveyed and conducted focus groups with members, their employees, clinicians, and health plans over the years. We also have direct experience working with members and MBGH-led initiatives to support wellness and patient engagement. Also, when we say "consumers" we mean employees, retirees, family members, plan members, and patients.

"Patient engagement" means different things to different people. For employers, sometimes "engagement" means that a worker participates in a wellness program, but participation doesn't usually change behavior. From our research, we know there's a need to help employees with both navigating the health care system and addressing the issue of benefits literacy—not

understanding what benefits are available or how to use them (this includes available wellness and disease management programs). Also, not everyone knows that they can take steps to improve their health. Others do know, but don't care—it's a key challenge in engagement and why the vast majority of people don't engage.

So, in terms of the CFAH definition, we'd expand it to include "benefits literacy": people not understanding what their health benefits are and how to effectively navigate the health care systems. Also, it should convey the need to understand the value of my own health, the value of engagement, and the role I need to play in managing my health. Engagement should lead to positive changes in health behaviors, use of health benefits, and interactions with providers.

Edelman, the public relations firm, has an engagement index. Their research shows that people's willingness to become engaged varies a lot. Some are very willing and others are apathetic about their health.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

BORESS & LARSON: Individuals benefit, because of the impact on their health. They can also save money and have a better quality of life.

Healthy employees tend to be more productive, so employers sponsor health services to have a healthier, productive workforce. Employers are paying for benefit programs and want to see their people using what they pay for, so they offer incentives to participate in these services. Employers also want to recruit and retain a good workforce. Ultimately, employers are looking for an impact beyond health.

Health plans try to engage their members to become healthier and to utilize fewer services. In our focus groups, physicians say that they don't have any control once people leave their offices, so they depend on others, including employers, to help people stay on their medications and participate in preventive care services

Q3. CFAH: As an employer leader, are there any types of behavior listed below that you think employers have more or less credibility to address?

[BORESS & LARSON: *comments are in italics*]

Find good clinicians and facilities. *As a group of employers, MBGH tries to help with this challenge, but a lot falls to health plans' network choices. Quality providers are*

not easy to find, and employers don't necessarily have the expertise to do firsthand assessments.

Communicate with clinicians (doctors, nurses, others). *MBGH has a Choosing Wisely initiative, and our employers also educate their employees about how to communicate better with providers. But this is really an area for patients and clinicians.*

Organize care (appointments, records, referrals). *Patients and clinicians have more responsibility here.*

Pay for health care. *Employers and governments pay for a lot of health care.*

Make treatment decisions. *Again, this is really an area for patients and clinicians. Participate in treatment. In this and the next four behaviors, employers and patients have responsibilities. Employers are offering value-based insurance plans and services, such as health coaching, to help people to engage.*

Make and sustain lifestyle behavior changes. *Employers pay for healthy lifestyle programs and services.*

Get preventive health care. *They pay for preventive services. The Affordable Care Act now assures this.*

Plan for the end of life. *We have a toolkit for employers about helping their populations with caregiver support and end-of-life issues.*

Seek health knowledge. *Employers give employees access to high quality health information.*

(This list is from the [CFAH Engagement Behavior Framework](#))

BORESS & LARSON: With this list, it's hard to generalize for all employers. Each worksite, culture, population, and more is unique. Also, trust and confidentiality issues between workers and employers will affect employer credibility in this list.

There are employers that have the credibility to be involved in all 10 of these challenges and some that have limited standing to act in any of these areas. In between are employers active in some of these challenges. Employers, though, never know about individuals' health care. Instead they contract for these services so employees can access them.

Health systems are more responsible for some of these challenges than employers, or both have responsibilities.

The employer's role in engagement is changing. One trend is that more employers, now nearly one-third, offer onsite primary care services. About 40% of employees who use these services

don't have a regular doctor. Some worksite health care clinics are also providing dental and vision care, plus health coaching. Walgreens has a division that supports 50 employer-based clinics, all of which were recently accredited as patient-centered medical homes by Accreditation Association for Ambulatory Health Care (AAAHC).

Our members are offering a lot of incentives for engagement, increasingly tying rewards to outcomes as a way to propel more people to adopt healthy behaviors and choose high quality providers.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

BORESS & LARSON: One area, as discussed, is incentives for participating in programs, accessing services, and behavioral outcomes. Another is face-to-face coaching and services. Telephone and online coaching is less effective, but some telehealth technology that provides virtual face-to-face is becoming more acceptable and effective.

Our employer members have integrated health management strategies across the whole spectrum, from wellness and prevention to chronic disease management to care for very ill people. Employers are using a sequenced communications strategy for these and are targeting messaging to different groups. They also are trying to reach employees and their families at home with information about benefits and programs. Contracts for health data analytics enable our members to track changes in their population over time. More is being done to encourage physical activity and obesity management. Employers have also been implementing disincentives for tobacco use and treatment noncompliance.

Are these programs providing the positive return on investment that the vendors say they provide? It's an issue that needs more examination. What employers are doing is building accountability into their contracts for wellness and disease management programs. They are holding vendors accountable for getting people to use the services.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

BORESS & LARSON: From employee focus groups and employer benchmarking surveys, we know the greatest barriers are time, access to health services, cost, conflict with lifestyle, and trust and confidence in the people/organizations providing programs. Also, family and loved ones have a huge influence, especially when the employee has a chronic disease and needs to exercise or eat properly. If the meals and opportunities for exercise are supported at home,

there's a greater chance the person will be able to manage their conditions. Convenience is a big driver of why people eat fast food; they feel eating healthy food takes more time than getting takeout and is more expensive. Finally, stress has a huge role. People multi-task all of the time and feel they can't take on anything else.

These are reasons why employers offer a menu of programs and services that are convenient, free or low cost, and readily accessible.

Q6. CFAH: To what extent do you think that efforts by employers can reduce these barriers/increase the capacity of people to engage?

BORESS & LARSON: There are a lot of opportunities to reduce barriers. Employers can motivate employees with incentives, educate them, and offer programs. People spend only seven to 10 minutes with their doctors, but spend over 2,000 hours at work each year, so our members are making their worksite culture and environments healthier. To promote healthy eating, they're updating policies about foods at meetings, in vending machines, and in the cafeteria. Worksites are smoke-free. Wellness programs offer peer support. Employers are creating walking trails and opening stairwells. Beyond that, they're educating employees about available benefits and services.

It makes a difference when senior managers are visibly involved in promoting health and employees see tangible signs of company commitment. Policy change is a big lever.

To be effective, employers must do claims data assessments and surveys to understand their populations and the needs of their workers and families.

No matter what you do, it still can be discouraging for people who are healthy and do the right things to see coworkers who aren't taking care of themselves.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

BORESS & LARSON: Employers spend millions of dollars each year on worksite programs in which only 20% of their population participates. These investments go beyond being nice employers...they're looking for an economic impact from this investment in human capital. Businesses know that when a major system goes down, it cuts into profits. The same goes for the workforce—its well-being is critical for business success.

Each stakeholder has to be accountable for patient engagement. To the extent that they can, employers are putting accountability into their service provider contracts. After all, employers

are not in the business of delivering health care. Clinicians in focus groups tell us that they'd rather work directly with employers than with health plans. Also, health plans only pay attention to large employers, but medium and smaller businesses don't have this market leverage. As a result, most employers are dependent on health plan efforts to engage employees in their health care. In the gap, a massive worksite wellness industry has emerged.

Q8. CFAH: Some employers are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution's behavior to support PE?

BORESS & LARSON: Consumerism or engagement is always in the top three or four priorities that our members have. MBGH emphasizes patient engagement in nearly everything that we do. It's the topic of monthly half-day programs, whether focusing on chronic disease self-management, benefits literacy, or navigating health systems.

Our members really want to help people change their behaviors but also realize not all people are ready and willing to do so. Engagement is increasingly important, especially as public/private/consumer health insurance exchanges become more important and as use of high-deductible health plans increases. The latter has the potential to shift costs to people who aren't engaged. Also, some don't have the knowledge or information to make positive choices. There's also motivation—if people don't care about quality, they won't look for information.

A major problem is that people think they're already doing well at maintaining their health and choosing good doctors. But if you drill into the data, they're basing their decisions on convenience and magazines in the waiting room, not on quality ratings. The American Research Institute has studied how to best convince people to care about quality and have a partnership with their provider. It's interesting that people will be savvy consumers when their car mechanic says they need a new muffler; they challenge the mechanic to show them that's the case. But in health care, people don't do this. Hopefully the Choosing Wisely and similar campaigns will change this.

LAUREL PICKERING, MPH

Laurel Pickering, MPH, is the president and CEO of the Northeast Business Group on Health (NEBGH) and is a nationally recognized authority on trends and innovations in the health benefits marketplace. Since becoming executive director of what was then the New York Business Group on Health in 1996, Pickering has led initiatives in the New York area business community to improve health care access, quality, and value. Under her leadership, the NEBGH launched “One Voice,” the New York Metro Mental Health Collaborative; “HealthPass,” the health insurance exchange which has brought affordable health coverage options to thousands of small businesses in the region; eValue8, which is bringing information and accountability to the marketplace for health plans; and several other initiatives.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

PICKERING: This seems like a good definition to me. One question I would ask is why you chose the word “support” vs. “improve” their health. While it makes sense that health status might not always improve, at first glance “support” seems passive. I am struck by the fact that this definition is from a consumer’s perspective, whereas an employer or provider would be looking to “improve” health.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

PICKERING: Employers are deeply concerned about high health care costs and the impact of poor health on productivity. Members of our employer coalition think that it makes a big difference for people to be engaged in their health and health care. For several years now, in some cases, decades, there has been a focus on offering worksite or employer-sponsored programs to improve the health of employees and their families. We have used health risk appraisals, targeted health interventions, promoted or built fitness centers, and offered incentives to promote health and wellness.

Many employers have hired disease management companies, wellness experts, and required health plans to include health promotion/disease prevention benefits in their health insurance programs. In many cases, employers have been frustrated by low participation rates by employees/families and by the lack of substantial results for their investments. There have also been big commitments from health plans and some providers to tools like online patient/member portals that are designed to support engagement, yet so far there is little to show for these efforts. Engagement still remains low.

The latest efforts are building on new research about behavior theory. Serious attention is being paid to methods that encourage healthy life choices and behaviors. We are optimistic that as more is learned about how to effectively support/encourage behavior change that knowledge will translate into better programs and tools.

Q3. CFAH: As an employer leader, are there any types of behavior listed below that you think employers have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

PICKERING: Of the challenges listed in the Engagement Behavior Framework, there are three that many employers have tried to help their employees with.

- Number one is, of course, meeting the challenge of paying for health care. Tremendous effort from employers has been spent on health benefit design, health plan selection and negotiations, and of course trying to keep up with the cost of health insurance.
- Secondly, many employers are actively involved with trying to support employees as they make and sustain lifestyle behavior changes.
- And lastly, many employers believe that they can play a role in helping employees seek more health knowledge.

These are three areas of engagement challenges that many employers feel they have a responsibility for and the credibility to address.

There have been a few employers and coalitions that have created initiatives and programs to try to steer employees to find good clinicians and facilities. But this is not an area that our coalition and members have focused on, mostly due to the lack of data and transparency.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

PICKERING: Two areas that I have been hearing more about are tools and products that use theories from behavioral science, like gaming and Prochaska's Stages of Change theory, to assess a person's readiness to change. Both of these fields rely on engaging users in very small, doable steps, with little points of progress, and either try to meet the person where they are *or* make the process of change more enjoyable/fun.

Many employers hire health plans and/or disease management organizations to offer chronic care programs. These programs are heavily dependent on using telephonic messages and call centers for outreach. A lot of employees have resisted these efforts, especially when they are viewed as coming from their health insurers.

A higher touch approach that works directly with health care providers and builds on the patient/clinician relationship is needed. People trust health care providers more than health plans. For example, I heard about a company that is actually paying for additional nursing staff in some primary care offices. They are so invested in primary care as the front line of health that they are willing to invest in the extra care.

Some patient-centered medical homes are also going in that direction. More financial incentives for better health outcomes may encourage more providers to become medical homes and provide more care coordination in particular. Hospitals are gearing up to deal with new penalties for readmissions.

A few employers are offering value-based health insurance benefits in some cases, trying to incent smoking cessation and/or weight management by tying premium contribution levels to health status. These penalties may tip employees who are ready to make a change but need a push. Others will just pay the extra cost.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

PICKERING: Most people simply haven't been exposed to what will inspire them *or* will support more active participation in their health and health care. It seems like there are still not big enough incentives to change behaviors and practices.

Q6. CFAH: To what extent do you think that efforts by employers can reduce these barriers/increase the capacity of people to engage?

PICKERING: Members of our employer coalition believe that they have levers that can help reduce barriers to patient engagement. These employers are actively seeking strategies and approaches that maximize their efforts and purchasing dollars. Some employers are finding that they have to figure out their own solutions, that off-the-shelf products are not delivering. In some cases, employers act as change agents. That is one reason why coalitions have been successful in the past; having multiple employers in a community that demands improvement can make a difference.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

PICKERING: All of the employer members of the NEBGH are doing some type of health promotion/wellness program. From their perspective, their key measure is “engagement,” as defined by how many people are participating. How many employees were contacted by a health coach? How many employees picked up the phone or logged into the online program?

But increasingly, employers are curious about the clinical health outcomes of their health promotion programs. Currently, programs are fairly evenly divided between initiatives to try to manage chronic diseases and trying to support healthier lifestyle choices. Some worksite activities have an emphasis on disease prevention too, via promoting health screenings and risk assessments.

Q8. CFAH: Some employers are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

PICKERING: Among our coalition members, patient engagement is a major issue. No one needs convincing. Our annual conference theme this year is about connecting employers with health care delivery systems. Next year, our medical director said we have to focus on engagement!

MICHAEL VITTORIA

Michael Vittoria is vice president of corporate benefits at MaineHealth where he leads employee benefits, integrated disability and absence management, employee health services, and worksite wellness programs for over 18,000 employees at the 10 hospitals and provider groups that comprise one of New England's largest integrated health care delivery systems. Vittoria is a frequent presenter and panelist on health plan design, worksite wellness, and employee engagement at professional conferences and seminars across the US. His article, "A Step-by-Step Approach to Introducing Health Savings Accounts," was published in Benefits and Compensation Digest. Vittoria received a BS in Business Administration from Marquette University, an MBA from Providence College, and a JD from Suffolk University Law School. In addition to being a member of the Society for Human Resources Management and the American Society for Healthcare Human Resources Administration, he is the vice president of the Greater Boston Chapter of the Disability Management Employer Coalition.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): "Actions people take to support their health and benefit from their health care." What's missing from this definition? What would you add, subtract, or word differently?

VITTORIA: The definition seems somewhat passive; it should be more active. People can do things to support their health and benefit from their health care that don't require much active engagement. For example, they can make a doctor's appointment, but not actually be engaged during and after the appointment or follow through on their doctor's advice. So, they may be passively present and go through the motions, but not be actively participating, such as thinking critically about the doctor's recommendation, asking about alternatives, and working with their care team to make the best decisions and get the best outcomes.

Many of our employee initiatives aim to get them actively involved in making better treatment decisions and in managing their health and health risks. When people are engaged, they feel in control even if they're relying on health care providers for technical expertise. They understand what is happening in their situation, understand their risks, and can participate in making decisions and managing their care. This is a different picture than what's in the CFAH definition.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

VITTORIA: Our data indicate that employee participation in our worksite wellness programs is a proxy for engagement in their health and health care outside the workplace. We analyzed claims data to compare active worksite wellness participants with nonparticipants. The two groups have very similar health risk profiles and receive similar treatments. Their utilization and

costs, though, are quite different because worksite wellness program participants are healthier and cost less. Compared to nonparticipants, participants cost us 13.5% less (\$1,200 per year) in health claims utilization costs. Their prescription costs are lower, but participants do use more preventive care services—a 17% higher frequency. The frequency of disability claims is lower for program participants, and when they do have a claim, the duration of their disability is shorter.

Q3. CFAH: As an employer leader, are there any types of behavior listed below that you think employers have more or less credibility to address?

[VITTORIA: comments are in italics]

Find good clinicians and facilities. *Employers can design plans with tiered provider networks, give employees information about providers, and help employees with navigating these systems.*

Communicate with clinicians (doctors, nurses, others). *This is a touchy area because we can't directly communicate with clinicians or get in the middle of discussions between employees and their providers. What we can do is educate employees about questions to ask their providers and similar actions.*

Organize care (appointments, records, referrals). *Like the one above, this can also get too personal.*

Pay for health care. *Employers pay a lot for health care, and we can give employees health savings accounts and other tools that help them to better manage their costs. This is especially important with high deductible and consumer-directed health plans.*

Make treatment decisions. *Employers can provide tools that are easy to use and to understand. This is a productive intervention for us in that employees who make smarter treatment choices usually spend less and get better care.*

Participate in treatment. See "Make treatment decisions."

Make and sustain lifestyle behavior changes. *Corporate-based wellness programs are a key way for employers to have an impact. We spend about \$2 million each year on financial incentives (such as wellness incentive payments for things like having a healthy blood pressure or rebates to employees for gym memberships) to alter health behaviors. We have many different types of worksite wellness programs, everything from farmers' markets to walking circles and more. Employees like these offerings and tend to respond favorably, in part because of the financial incentives.*

Get preventive health care. *For years prior to the Affordable Care Act (ACA), we covered preventive services as part of our health plan. Now ACA requires coverage,*

and employers can incent the use of preventive care through the health plan design. For example, this year we will make preventive medications (such as statins) available to employees enrolled in our consumer-directed health plan option with only a co-payment before their annual deductible is met. So even with ACA, employers can still do more to encourage prevention.

Plan for the end of life. *Employers can offer access to good quality information and other resources without intruding on employees' decision-making. We provide access to an employee assistance program as well as WebMD, which delivers information to employees through their e-mail.*

Seek health knowledge. *See "Plan for the end of life."*

(This list is from the [CFAH Engagement Behavior Framework](#))

VITTORIA: Employers have a stake in all 10 areas, and there's some value for employers to be involved in engaging employees and their families in each of these. Yet, there are some touchy areas for employers to be cautious about. If we become too involved, employees might think that we are doing so because there is a direct financial benefit to us. Also, we can't get too directly involved in health care because of HIPAA and employee's general concerns about privacy (i.e., why is my employer nosing around in my health care decisions?). That's why we tend to use third party vendors and tools with more sensitive areas of engagement.

In short, employers have credibility in all of these areas. But employers need to proceed carefully in those areas where employees might perceive that the primary motive behind a program is to achieve cost savings for the employer rather than acting out of concern for the employee's well-being.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

VITTORIA: Health coaching and disease management programs work well if done in person. I don't know of any employers that are truly happy with engagement results and participation rates from telephonic support. In-person support lets coaches discuss changes in diet and other areas needed. Face-to-face seems to have the greatest impact in terms of health outcomes and costs.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

VITTORIA: The biggest ones are time and resources. People are too busy, so they put off doing the things they know they should do. In health care, part of the problem is that it's hard to get quality information about treatment options, costs, and quality—hard even for doctors and well-educated people. Cost-quality-outcomes transparency is an ongoing challenge for all of us. But technology, such as smartphone applications, has great promise to help us get better information and be more engaged. If your doctor says you need a lab test, people can punch up on their phone which labs do high quality work and cost less. The key is to help people with the time crunch.

Q6. CFAH: To what extent do you think that efforts by employers can reduce these barriers/increase the capacity of people to engage?

VITTORIA: Employers have an opportunity to reduce barriers and support engagement because they sponsor health plans and can provide access to information, tools, technologies, incentives, and more. Employers have more ability to influence engagement than they often believe they have. Or they just rely on negative ways to shape people's behavior, such as creating financial barriers to discourage unnecessary or low-value care, such as excessive emergency department visits. Instead, employers need to develop better strategies to encourage engagement, especially in creating incentives and offering tools to help people navigate health care systems. Technology is now creating new opportunities for employers to get involved in positive ways.

When employees make good decisions, both employees and employers benefit from better outcomes. Employers have to do more to engage their employees in their health and health care, especially by aligning incentives to create these win-win situations.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

VITTORIA: A growing number of employers realize that engagement is critical and have been doing things for years to promote it. They tend to be larger employers that are self-insured and see the potential to manage costs.

For many small and medium-sized employers, no one has clearly shown them how engagement can impact their costs. These smaller employers are fully insured and often feel they're at the mercy of insurers. They've been dealing for years with increased costs. Some might see patient engagement as nice to-do but unrelated to their health care costs. So, employers' views about engagement are often shaped by how they pay for health care.

Q8. CFAH: Some employers are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

VITTORIA: Both self- and fully insured employers are moving to consumer-driven health plans, and there’s an increased need to offer employees tools and technologies to participate in their care.

Disability is a byproduct of poor health, and it’s costly to employers in terms of lost productivity and absenteeism. Small and medium-sized employers don’t fully appreciate that an unhealthy workforce is less productive and less profitable. They need to be thinking more about reducing health risks to improve workforce productivity instead of focusing solely on health care claims reduction.

Overall, in part due to ACA, the health care marketplace has more upheaval than I’ve seen in past years. Employers are searching for solutions but feel the ground is shifting under their feet. Among all the unknowns, they’re still trying to steer a course that will lead to better outcomes for themselves and their employees.

GOVERNMENT ORGANIZATIONS

CINDY BRACH

Cindy Brach is a senior health policy researcher at the Agency for Healthcare Research and Quality's (AHRQ) Center for Delivery, Organization, and Markets (CDOM). She leads AHRQ's health literacy activities and is the point person for cultural competence and oversees projects to improve both health literacy and cultural competence in hospitals and primary care practices. CDOM's ultimate goal is to help improve the quality and efficiency of health care by providing evidence on organization, payment, delivery, and markets. Brach also serves on the Institute of Medicine's Health Literacy Roundtable. Her health literacy projects have included the development of the new Re-engineered Discharge (RED) Toolkit, Health Literacy Universal Precautions Toolkit, CAHPS® Item Set for Addressing Health Literacy, and the AHRQ Informed Consent and Authorization Toolkit for Minimal Risk Research.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

BRACH: Although in an article I recently co-authored we cited the CFAH definition for patient engagement, I have to confess that when I hear the term “patient engagement,” I think differently about it. At AHRQ the chief locus of improving health care is in health care settings. I think of patient engagement as things that clinicians and staff of health care organizations *do to engage* patients—reaching out, shared decision-making, bringing patients into the process of care. Much of my work is aimed at promoting patient engagement by reducing the complexity of health information and other barriers (including cultural and language barriers) patients face in understanding how to be healthy, access health care, and navigate the system.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

BRACH: First, it makes a difference to the person and their family. Just because you are engaged doesn't mean that you will do the things that will maximize your health. It means being a critical consumer and that you are empowered to make decisions. It means being informed and being able to assess trade-offs. It's the opposite of being passive and having things done to you. A recent encounter with the health care system has caused me to recall a phrase I first learned from Don Berwick, “Nothing about me without me.” That is the essence of patient engagement—being an active participant.

Second, it matters a lot to those who interact with the engaged patient as well. How clinicians and other professionals feel about engaged patients varies a lot. Some feel it makes their job harder: They have to negotiate and recognize different preferences. This makes it more

complex to deliver care. On the other hand, clinicians *want* patients to engage because they understand that nothing will happen if they don't. They know the statistics about adherence and health behavior. The understanding is growing that you need to partner with patients to get better outcomes.

Q3. CFAH: As leader on patient engagement in the government, are there any types of behavior listed below that you think governments have more or less credibility to address?

[BRACH: *comments are in italics*]

Find good clinicians and facilities. *We produce quality measures to help in decision-making and inform public reporting efforts.*

Communicate with clinicians (doctors, nurses, others). *This is obviously huge. We provide tools for clinicians to improve all forms of patient-provider communication: verbal, written, patient portals. For example, AHRQ's Health Literacy Universal Precautions Toolkit includes tools on clear verbal communication, designing easy-to-read materials (including forms), and encouraging questions.*

Organize care (appointments, records, referrals). *AHRQ works on organizing care in a number of ways. These include health information technology projects on personal health records, compiling an inventory of care coordination measures, and promoting collaboration within a medical neighborhood. Improving care transitions is a particular area of emphasis for the US Department of Health and Human Services (HHS). For example, AHRQ published a toolkit on how to re-engineer the discharge process that includes the hospital making appointments for follow-up care and a phone call after discharge to make sure you are OK and know what to do when you get home.*

Pay for health care. *AHRQ is not the part of HHS that assists in paying for care, but our work on value-based purchasing and efficiency are aimed at both keeping health care costs down and ensuring that quality is part of the purchasing decision.*

Make treatment decisions. *There are a number of ways AHRQ tries to increase and disseminate evidence about treatment options. AHRQ produces evidence reports, synthesizing the state of knowledge about treatment options. Under AHRQ's [Effective Health Care Program](#), we create both clinician and consumer guides to translate that evidence for patients and providers.*

Participate in treatment. *Patient and family participation in treatment is an essential ingredient in patient-centered care. AHRQ has commissioned [briefs and white papers](#) on engaging patients in their treatment and disseminated information*

about sites that have transformed primary care practices into patient-centered medical homes.

Make and sustain lifestyle behavior changes. *This constitutes the community linkages piece. We try to create links between the health care sector and smoking cessation, exercise, and obesity resources in the community. People spend a few minutes in the doctor's office but what supports are there in the community that can support and sustain changes recommended there? We track the provision of anticipatory guidance, i.e., when doctors communicate with patients about risky behavior and lifestyle changes. Although the percentage of people who actually make those changes upon the advice of their clinician is small, it is a contribution to a bigger issue. AHRQ's Health Care Innovations Exchange features successful clinical-community collaborations.*

Get preventive health care. *AHRQ provides scientific and technical support to the US Preventive Services Task Force, which makes recommendations on clinical preventive services, weighing the evidence on the potential harms and benefits. Decision aids are available on myhealthfinder.gov, AHRQ's Effective Health Care site, and on AHRQ's Health Care Innovations Exchange.*

Plan for the end of life. *This is currently not an active area at AHRQ, but we have a number of grants that explore advance directives and palliative care.*

Seek health knowledge. *To help consumers seek health knowledge, AHRQ has campaigns in English and Spanish to encourage consumers to ask questions.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

BRACH: Promoting patient engagement is difficult, no question about it. We can, however, think about a logic model for patient engagement. One of the prerequisites clearly is that patients have to be able to understand health information. That means we have to follow health literacy principles and communicate in languages that people understand.

I think that there have been some interventions that show promise in hospitals, like including patients and families in the process of hospital rounds. In some hospitals, rapid response teams have been implemented that allow patients and families to call the team in and say: "There is something going on here!" Empowerment strategies like this seem promising.

At an organizational level, including patients and families on committees and teams that are making decisions about how care is delivered can be helpful. AHRQ has published the [Guide to Patient and Family Engagement in Hospital Quality and Safety](#), an evidence-based resource that helps hospitals develop effective partnerships with patients and family members, with the ultimate goal of improving hospital quality and safety. AHRQ has also published a white paper, [Engaging Patients and Families in the Medical Home](#), which addresses opportunities and strategies for patient engagement in primary care settings.

Getting patient feedback (such as [CAHPS®](#) patient experience of care surveys) where we learn how patients are experiencing a specific health care encounter is critical.

Decision aids, if they are not done at too sophisticated a level, have the potential to give patients understandable information and help them realize that there is not only one way of doing things. Realizing that you have a choice is the first step.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

BRACH: One is the structure of the 10-minute visit with the doctor. It's difficult to have the time to process information and feel you can ask questions when the clock is ticking. The structure of hospital care is equally problematic, where you capture a glimpse of the attending physician in lightning-speed rounds.

We seem to be moving toward a team-care system where the patient has multiple individuals they can interact with. This has the potential to break either way. It can be empowering in that it gives patients more attention and time. If done poorly, however, it will result in fragmented, confusing care. We need to be mindful about how team-based care gets implemented.

The culture of medicine is also a big barrier. Most doctors are trained to obtain histories, diagnose, and prescribe treatment—they don't even recognize that there are decisions to be made. They need to recognize that patient preferences vary and to create a space in which to talk about options with their patients.

But there are also barriers on the patient side. Being an engaged patient takes a lot of time. A lot of people don't feel they have that luxury. It's not until they are really sick that it is worth investing the time to be an educated health care consumer.

Q6. [not asked]

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

BRACH: AHRQ sees patient engagement as critical to achieving patient-centered care and better outcomes.

Q8. CFAH: Some public officials are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

BRACH: For us, implementing change is mission-critical. Just coming out with the science doesn’t cut it anymore. When I came to AHRQ, success was measured in how many articles were published in top-tier journals. Later, Representative John Porter told AHRQ’s late director John Eisenberg, “Don’t tell me about the reports you’ve published. Tell me how you’ve changed Americans’ lives.”

This was a huge shift: that we don’t only have to produce the evidence but we also have to speed up the translation. Now we do a lot more work providing tools and aids that can help move patient engagement forward. We are still a small agency with no regulatory authority. Having to think about the behavior change of the entire health care system means working, trying to identify places where things are working well, testing interventions, and trying to spread them by providing tools to help people do this work.

CANDACE GOEHRING

Candace Goehring, MN, RN, works for the Aging and Disability Services Administration in Olympia, Washington, on its [Evidence-Based Disease and Disability Prevention Program](#), an extension of the Administration on Aging's 2010 Recovery Act Chronic Disease Self-Management Program. The programs offered seek to increase older adults' access to effective interventions that help to reduce their risk of disease, injury and disability. Goehring also helps maintain Washington State's patient web portal, [Living Well with Chronic Conditions](#), and is a clinical faculty member at the University of Washington School of Nursing. She has clinical and organizational experience in both public and private health care environments, including regulatory expertise and clinical care.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): "Actions people take to support their health and benefit from their health care." What's missing from this definition? What would you add, subtract, or word differently?

GOEHRING: I don't think our overall definition is much different. We believe people should live as independently as possible in their own communities, and we support and encourage people to maintain healthy lifestyles so they can remain in charge of their lives for as long as possible.

Washington's Chronic Care Management Program (CCMP) used the Patient Activation Measure® (PAM®) after reaching out to eligible clients who had health care issues that could interfere with a more independent and healthier lifestyle. We let them know that there are services we could offer to support them in health improvement. We obtained their permission to meet with a nurse to gain a better understanding of what was needed to engage the person in health care management programs.

This required skills, persistence, and patience. We have to be in the right place, at the right time, and people must be ready to engage in healthy management programs.

The outreach was sometimes done by someone who was known and familiar to the person needing health care assistance. Other times a sense of urgency was the motivation for engagement, such as a sudden or significant decline in a chronic health condition.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

GOEHRING: It makes a huge difference for people who change their behavior and improve their health. It also makes a profound difference to the team working with an engaged individual. Medical professionals also see improved outcomes with people engaged in healthy activities.

In our scope of practice, caregivers are also affected by engagement. They need to know how to contribute to engagement and that those actions can make a positive difference in a person's health.

It reaches beyond the person with the chronic condition. All people with the Aging and Long-Term Support Administration's CCMP had paid caregivers who became involved in engagement work, to the extent the client felt comfortable.

Q3. CFAH: As leader on patient engagement in the government, are there any types of behavior listed below that you think governments have more or less credibility to address?

[GOEHRING: *comments are in italics*]

Find good clinicians and facilities. *We help people find specialists, follow up on referrals, and change doctors if they have an ineffective relationship and express a desire to change doctors. We never tell them they should get a different clinician, but we will support them to make a change if that is their preference.*

Communicate with clinicians (doctors, nurses, others). *Yes.*

Organize care (appointments, records, referrals). *We worked with individuals to make appointments. Our registered nurses helped individuals identify people willing to help them with health care issues. We suggested that people make calls to seek help when we were with them in their home.*

Pay for health care. *No.*

Make treatment decisions. *We looked at the responses on the PAM® and the level of engagement and coached individuals if they were struggling with decisions.*

Participate in treatment. *Yes, if individuals aren't making it to appointments or are using the emergency room, we coach and discuss over- and under-participation.*

Make and sustain lifestyle behavior changes. *Yes.*

Get preventive health care. *Yes.*

Plan for the end of life. *Many individuals already have a plan for the end of life and we address that to the extent necessary.*

Seek health knowledge. *Yes.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

GOEHRING: The nurse care managers providing Chronic Care Management (CCM) were employed by an area agency on aging and had small caseloads of about 50 to one. We had information about people from the long-term care assessment and predictive risk modeling data. The CCM nurse made an initial home visit and completed the PAM®, or the Caregiver Activation Measure, and scored it to make a level determination. The client's level of confidence helped define the nurse's approach. CCM nurses would follow up with individual questions and use the responses to direct the care plan.

We used motivational interviewing skills and found using a coaching approach was a more effective engagement strategy.

CCM nurses had the luxury of no enrollment deadlines, which allowed people time to make health changes. Our work was not necessarily finished at six or nine months; as long as a client was engaged and trying, we stuck with them. The CCMP covered geographically about 50% of the state.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

GOEHRING: We must always listen to what the patient has to say and what their health needs are. Some people aren't ready to engage in health care. Some people are involved in complex personal issues, such as eviction and abusive relationships. They can focus only on those issues, and health becomes secondary.

Q6. CFAH: To what extent do you think that efforts by your agency can reduce these barriers/increase the capacity of people to engage?

GOEHRING: I was a visiting nurse for 25 years before working for Washington State, and I was guilty of many of the things we now try *not* to do. I would come in with my list of what the patient had to do and *little about their behavior/health* would change—or it would change for a little while and then slide back.

What is good about engagement is that we ask, “What do *you* want to do? What do *you* think *you* can do?”

For the clinician, it puts the focus on the client. How do *you* communicate? What do *you* need? How did *you* acquire this behavior?

It's another way to get to know someone and to deliver health care through the lens of activation.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

GOERHRING: We are in the early stage of understanding the importance of engagement. For example, health homes in Washington State are using the PAM[®] and the Caregiver Activation Measure. Shared decision-making isn't fully incorporated in all health care settings, and there is limited understanding of the variables necessary for successful engagement.

Q8. [not asked]

JEAN MOODY-WILLIAMS, RN, MPP

Jean D. Moody-Williams, RN, MPP, is the group director for the Centers for Medicare and Medicaid Services (CMS) Quality Improvement Group (QIG), a part of the Center for Clinical Standards and Quality. The group works to accomplish three aims, including improving the overall quality of health care, improving the health of populations and communities, and lowering costs through improvement for patients and families. Moody-Williams is responsible for the operation of the Quality Improvement Organization Program and the End-Stage Renal Disease Networks. She also leads many of CMS's value-based purchasing programs in hospitals and End-Stage Renal Disease facilities. Prior to joining CMS, Moody-Williams served as the division chief for facility quality and performance at the Maryland Health Care Commission.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

MOODY-WILLIAMS: The one thing I like about the definition is that it concentrates on the *actions of patients*, that it is action-oriented. Many of the definitions start out with a focus on what the provider of care must do to achieve engagement.

While we might start with the patient taking action, we would add “with the support of providers”—to give people the message that they aren’t in this alone—those who provide the care are also part of their effort. This is how we look at engagement.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

MOODY-WILLIAMS: I think it makes a difference to the patient and the clinicians providing the care but also to the family and the community at large. Everyone on the care team is impacted when the patient is engaged. The most significant benefit is to the patient because what they value is considered. Being able to talk about what’s important and having that become a part of a care plan is critical. Being able to receive information they didn’t know about in a manner they can understand and use is also important.

Providers benefit because as they begin to think about treatment and wellness options, they think how those options will fit with the patient’s needs and lifestyle. This will influence how they complete their treatment plan and how they measure the outcomes.

Families and caregivers are important because they often have to facilitate, remind, and support decisions made in care planning. If they understand and know that their loved one is on

board with the plan, it makes it easier. Understanding the plan also helps families know what questions to ask when there is deviation from the plan.

Since patients don't live in a vacuum, we must also involve the community in which patients live, work, and play. Community resources must be readily available to meet the needs of the population they serve. Also, as we begin to have patients and families engaged in their care and talk to peers and extended family members, they begin to model engagement to others. We are looking for "engaged communities."

Q3. CFAH: As leader on patient engagement in the government, are there any types of behavior listed below that you think governments have more or less credibility to address?

[MOODY-WILLIAMS: *comments are in italics*]

Find good clinicians and facilities. *We have a number of websites and tools available on [Medicare.gov](http://www.Medicare.gov) to inform families about health care across the country.*

Communicate with clinicians (doctors, nurses, others). *Our role is to support and encourage open and honest communication.*

Organize care (appointments, records, referrals). *We are working aggressively to encourage the implementation and use of electronic health records (EHRs), integrated care arrangements, and population health management.*

Pay for health care. *This is an obvious role for CMS. However, we don't just want to pay for care or for volume; we want to pay for high quality care, provided in the most appropriate and economical setting that meets the needs of the patient.*

Make treatment decisions. *We believe that decisions about treatment are best addressed between the provider and the patients and family. We may influence some decisions because of what is or is not covered or by providing information about choices and performance metrics, but we do not make treatment decisions.*

Participate in treatment. *We do not provide treatment, but we can support those that do by offering quality improvement and technical assistance on practice flow to facilitate a more effective treatment outcome. We have some projects in quality improvement working with patients who have diabetes, for example, to give them tools to use in decision-making.*

Make and sustain lifestyle behavior changes. *We work to influence healthy behaviors through initiatives such as the Million Hearts® initiative—this initiative promotes awareness first, then we urge people to adopt healthy behaviors that will reduce acute myocardial infarctions and strokes.*

Get preventive health care. *We cover several clinical preventive services and have a number of quality improvement projects aimed at increasing the rate of preventive health services.*

Plan for the end of life. *We encourage discussions about advanced planning.*

Seek health knowledge. *We work with our partners throughout Health and Human Services HHS to spread knowledge to patients and families that can be used in decision-making.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

MOODY-WILLIAMS: We are in the process of launching several Quality Improvement Organization (QIO) innovation projects in which we have provided support to communities to work with patients and families. We also include patients and families in many of our program development efforts.

Our Partnership for Patients Program also involves patients, and it is going well. We think it's making a difference in patient safety. Many people are working together who didn't necessarily do so in the past.

In our End-Stage Renal Disease (ESRD) program, we have also included engagement. We have charged our networks with reaching out to patients to understand their needs and the barriers they experience in becoming engaged.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

MOODY-WILLIAMS: We are learning through our ESRD initiative that people need to know that it's okay to ask questions. We have also encouraged them to invite patients to have a voice at a policy level.

Patients don't always know where to start to look for the information they need. We are trying to learn from them the best way to support engagement.

Q6. CFAH: To what extent do you think that efforts by your agency can reduce these barriers/increase the capacity of people to engage?

MOODY-WILLIAMS: CMS can have a great impact because of the commitment to working with partners in transforming the health care system. From what we're already hearing from patients and families, great strides are taking place, but this is not a job that CMS can do alone. It will take a commitment from everyone to see real action in patient engagement.

Q7. [not asked]

Q8. CFAH: Some public officials are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution's behavior to support PE?

MOODY-WILLIAMS: I've worked on quality for most of my career. I am excited and passionate now because never before have I seen so much interest and discussion on the topic. We obviously need to do things to help people understand how to make this actionable instead of theoretical. There is a real desire to have these discussions.

A number of things are having an impact on attitudes; value-based purchasing and patient experience being tied to payment drives interest. But I think it is bigger. Providers genuinely want to engage patients and families to provide better care and to achieve success in this fiscal environment.

There will be multiple factors coming together to drive this change. There is a genuine desire to become learning systems and get patients involved in the transformation. The change won't take place because of any single thing. Different things move different people. The important thing is that we all move toward a system more inclusive of the consideration of patients and families.

LYGEIA RICCIARDI, EDM

Lygeia Ricciardi, EdM, has served as the first director of the Office of Consumer eHealth within the Office of the National Coordinator for Health Information Technology (ONC) since 2012. There, she is responsible for developing and managing ONC's national Consumer eHealth Program, which aims to enable consumers to be partners in their health and health care through the use of health information technology. The collective aims of this eHealth program are best summarized by the objectives known within ONC as the Three A's: Access, Action, and Attitudes. Before joining the ONC, Ricciardi was a consultant on consumer e-health through her own company, Clear Voice Consulting.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

RICCIARDI: I generally like it. I've been at ONC for two years and have actually used it on my slides.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

RICCIARDI: It makes a great difference to individuals in terms of efficacy and not feeling powerless. It can also make a difference in outcomes and thus affects one's self, family, and the system. It may also have a financial influence and the impact may reach to employers.

Q3. CFAH: As leader on patient engagement in the government, are there any types of behavior listed below that you think governments have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

RICCIARDI: We are supportive of all of these. Our role is as a catalyst and convener that encourages these changes to occur. We can't single-handedly address any of these, but we are working on building—in partnership with others—a policy and technical infrastructure that makes it easier for consumers and patients to succeed in all of these activities.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

RICCIARDI: There are many examples. One is *Open Notes*, a research initiative that studied the impact of giving people access not only to their medical records, but also to the notes providers make about them. It's a fabulous project because it puts to rest a lot of the fears that providers and patients have about engagement and sharing information. I'm interested in the "notes" part, but more interested in the "sharing" part.

Also, I am interested in examples of systems that have financial rewards that are aligned to encourage positive health outcomes. In those environments we see high levels of engagement because it pays off. In a more fragmented system, we don't necessarily see the same commitment to engagement yet. Hopefully with health reform and ACOs, providers (and perhaps even patients) will feel rewarded for outcomes rather than volume of health care services.

Another interesting development is self-organizing patient communities enabled by the Internet—Diabetes Mine, Patients Like Me, Association of Cancer Online Resources. These consist of people who come together and become sophisticated about sharing clinical information as well as how they manage life with their conditions and advocate for research.

I'm also excited about the general ubiquity of technology and how the growth of mobile phones and people's access to the Internet puts their health in their hands. People use the Internet differently when they use their phones. They feel liberated to ask real-time questions and personal, sometimes even embarrassing, questions on the personal device.

The democratization of information outside of health care will result in greater engagement outside the health care context.

I love the growth in consumer-oriented tools, whether they are tools that measure and monitor clinical signs or lifestyle things, such as the increased use of sensors. This is challenging from a privacy perspective, but the growth in information about ourselves—the "Quantified Self" movement—enables people to use data to learn about themselves and apply their knowledge in useful ways.

I'm also interested in seeing health services migrate out of the traditional health system into retail clinics at Walmart and CVS, for example. I think it's healthy to have some competition in the system and more convenience for customers. There are a lot of companies and organizations not traditionally in the health care sphere—including phone companies, for example—that are getting into the health care act. The boundaries between health and other services are beginning to blur.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

RICCIARDI: Access to information. It's very difficult to get access to your medical information, difficult to get data out of devices, and even when you can, hard to access data in a usable format.

One of our goals is to make the information actionable. You can get your information but what can you do with it? I'd love to see more tools that help people make smart decisions. That is, take information from your health record and show where you fit in a demographic group and how to take steps to change it if you want, particularly on a real-time basis.

Attitude is another barrier. A lot of people don't necessarily understand how they are empowered to make changes in their health, and how their behavior will affect them. Ours is in many ways still a paternalistic system. We are still struggling to find a model in which patients dictate the direction. People aren't used to questioning the medical establishment, and they need to be encouraged to push back in a constructive way, to tell about personal goals as well as provide information about their bodies and their behaviors. At the same time we all need to take greater ownership of our own behaviors on a daily basis—they impact our health more than anything else.

Q6. CFAH: To what extent do you think that efforts by your agency can reduce these barriers/increase the capacity of people to engage?

RICCARDI: I refer readers to our paper in *Health Affairs*, [A National Action Plan to Support Consumer Engagement via E-Health](#), for a good description of our plan to do exactly this.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

RICCIARDI: The whole effort at ONC to implement health information technology and electronic health records in particular—and what we have done through Meaningful Use Stage 2—sets up new standards, expectations, and incentives for implementers to walk the walk of patient

engagement. There is an explicit requirement that patients or consumers have to be able to view and download their own data, which means they will begin to have the capacity to use it in a way that is meaningful to them.

Q8. CFAH: Some public officials are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

RICCIARDI: I believe that once providers start sharing data with patients more widely and see the response from patients and the effects on other aspects of performance, they will be convinced.

HEALTH PLANS

SUSAN BLACK, RN, BSN, TAMIKA N. RICHARDSON, RN, RAMONA ANGELO, RN, MHP, AND JANE VAUGHAN, MS

Susan Black, RN, BSN, is the senior director of population health at BlueCross BlueShield of South Carolina. She has worked in the managed care industry for over 19 years. She has a BS in nursing.

Tamika N. Richardson, RN, is the disease management supervisor for BlueChoice HealthPlan. She has worked in the managed care industry for 11 years in utilization management and disease management. Richardson has a BS in biology from the University of South Carolina and an associate degree in nursing from Midlands Technical College.

Ramona Angelo, RN, MHP, is the managing director of Disease Management for Population Health at BlueCross BlueShield of South Carolina. Angelo has been a registered nurse for 24 years, working in various areas of nursing care. She has worked in the managed care industry for the last 16 years. Angelo graduated from the University of South Carolina's College of Nursing with a BS in nursing in 1989. She served in the US Air Force Nurse Corps for seven years. Angelo obtained her Managed Healthcare Professional Certification through the Health Insurance Association of America in 2002.

Jane Vaughan, MS, is the disease management supervisor for BlueCross BlueShield of South Carolina. She has worked in the managed care industry for more than six years in disease management and wellness. Vaughn has a BS in psychology from Tulane University and an MS in physical therapy from the Medical University of South Carolina.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

BLUECROSS BLUESHIELD OF SOUTH CAROLINA (BCBSSC): Physicians, employers, and health plans are missing. Patient engagement takes a combined effort. As a result, we’d insert these stakeholders into the definition so that it becomes: “Actions people, their physicians, employers, and health plans take to support their health and benefit from their health care.” This conveys the collaboration that is needed.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

BCBSSC: It makes a difference to the person in terms of both decreased personal health care costs for complications related to poorly managed chronic disease and improved quality of life. Employers realize decreased loss of productivity and reduced health care costs; health systems would have improved provider/practice quality outcomes and reduced emergency room (ER) and inpatient utilization and costs. For health plans, patient engagement improves quality

outcomes, reduces ER and inpatient utilization and costs, and improves the return on investment (ROI).

Patient engagement also makes a difference for the person's family, especially if people take better care of themselves, then caregivers have a lighter burden. Poor self-management can really affect the family.

Q3. CFAH: As a health plan leader, are there any types of behavior listed below that you think health plans have more or less credibility to address?

BCBSSC: We have multichannel communication with our members. We communicate information to our members through mailings, newsletters, Facebook health tips, and Web and telephonic outreach. We also collect members' preferences and communicate through their preferred methods. In our member surveys, over 75% responded that mailings are their preferred method for receiving BCBSSC communications that have educational materials.

[BCBSSC: comments are in italics]

Find good clinicians and facilities. *We have a Web resource for members to find providers in our networks, and we assist members in identifying primary care professionals (PCPs) or specialists in their area or near their residence. If members do not have PCPs, our health coaches may steer them to identified patient-centered medical homes (PCMH).*

Communicate with clinicians (doctors, nurses, others).

Organize care (appointments, records, referrals). *We have the ability to partner with providers who would like to provide our clinicians with access to their electronic medical records to support continuity of care. We have a secure, Web-based, integrated platform that supports wellness, disease management, and critical health management programs for unique members who may be in multiple programs simultaneously. The platform allows staff in different programs to support one another. The platform allows integrated member claims history, lab, pharmacy, and biometric data imports; it also tracks assessment data, data contacts, internal referrals, and tasks that are documented.*

Pay for health care. *We support this in two ways. BCBSSC has previously implemented pay-for-performance incentives for providers and continues to expand initiatives to improve quality. Also, more employer groups are implementing value-based incentives for employees (and dependents) to encourage participation in*

wellness and/or disease management programs. For example, the incentives may lower or eliminate co-payments for office visits or prescriptions.

Make treatment decisions. *We have clinical practice guidelines posted on the Web, which are reviewed annually. We make recommendations based on national evidenced-based guidelines and recommendations. We have a team of medical directors who review and make recommendations to medical policies and procedures annually. Our case managers have team meetings to review the highest risk members' care plans.*

Participate in treatment. *[See "Make treatment decisions."] In addition, our wellness and disease management programs offer educational resources and information on preventive and chronic disease care. Disease management provides health coaching to members who are identified as not managing well; the coaching helps members set and work on personal health goals. We have inpatient nurses who call members after hospitalization as part of the Care Calls program to help identify gaps in care and advise members on appropriate follow-up to avoid ER and hospital readmissions. We also offer value-based rewards to encourage self-management.*

Make and sustain lifestyle behavior changes. *We have a team of clinically experienced professionals who provide health coaching to members who both are enrolled in wellness and disease management programs and have identified risk factors indicating they are not managing well or may suffer serious complications if management is not improved. We make multiple initial outbound telephonic attempts to engage members. Once engaged, we set personal health goals with them that they agree to and set up a schedule to contact them to follow up and support them as they work toward their goals.*

Get preventive health care. *We have several wellness and lifestyle management programs that members can self-refer to or be referred to by other disease and critical health programs within the plan. As part of the assessment and health coaching process, our staff discusses preventive care reminders based on current, national, evidence-based guidelines and recommendations. Our plan also mails preventive-care reminders from our wellness programs for children, men, and women.*

Plan for the end of life. *Our disease and case management programs ask members whom they work with about having wills and power-of-attorney documents. Our staff has resources to provide members with information for completing such documents in their state of residence. Our health plan has RN case managers who work with the most critically ill members and can assist with facilitating hospice for members.*

Seek health knowledge. *Our health plan provides all new members in health programs with information about communicating with their physicians; this supports a current Agency for Healthcare Research and Quality (AHRQ) initiative. Health coaches and clinicians encourage members to ask questions at appointments, in hospitals, etc. Members who receive health coaching are assessed with health literacy screening questions to identify that type of barrier.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

BCBSSC: Most of the CFAH list is addressed through our continuum of care that spans wellness programs through case management and into disease management. We assist members through this spectrum and use motivational interviewing and goal setting as key strategies to increase engagement.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

BCBSSC:

- Engaging providers that are patient-centered medical homes (PCMHs) and encouraging others to become PCMHs, because this practice model delivers collaborative care.
- Periodic health newsletters.
- Social media, such as Facebook and health texts, has a lot of promise, especially for reaching different populations. We haven't done much yet in this channel but hope to because of the potential to reach younger generations. So many people have smart phones now.
- For disease management and health coaching interventions, motivational interviewing helps our members stay engaged and make healthy lifestyle changes. It works because you're leveraging people's motivations.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

BCBSSC: For our health plan, the biggest challenge is not having members' telephone numbers and e-mail addresses, which we use to supplement telephonic services. We use this contact information for outreach and to engage members in health coaching programs. Without telephone numbers and e-mail, we have to depend on the regular mail, especially in rural areas.

Some members are not savvy about social media and other sources of online information and support. We have to rely a lot on traditional mail to engage members.

Another barrier is personal cost burdens, such as co-payments for primary care and specialist appointments and for medications. Also, the total cost of multiple medications—especially if they’re branded or higher co-pay tier or specialty drugs—can be a barrier. Sometimes people choose only to fill some medications because they can’t afford all of them.

Q6. CFAH: To what extent do you think that efforts by health plans can reduce these barriers/increase the capacity of people to engage?

BCBSSC: Currently, it is not mandatory to provide telephone numbers and e-mail for each covered member on the plan as part of enrollment, so making that a mandatory requirement would significantly help us be able to reach out and engage members in health coaching programs. Regardless, we have to find the right communication styles to connect with people and reach them in a way that makes them want to be engaged in their health. Some of our lines of business have offered key free services for members that remove personal cost barriers, such as a free annual physician exam for members with diabetes.

As mentioned earlier, patient engagement requires a group effort that includes health plans, providers, and employers. We also get outside our walls and go where people are and where they work. That is the way we also do community-based education, such as with the American Heart Association.

Also, we partner with employer groups who offer value-based incentives for specific care, such as reduced or no co-payments for some doctor visits or pharmacy medications, if members participate in specific programs, such as for managing diabetes, heart disease, etc. People respond to financial incentives. Employers can also have us send clinicians to conduct lunch-and-learn workshops at their company worksites. These worksite services give our health plan a face, and members may be more likely to call us when needed.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

BCBSSC: Most are convinced patient engagement matters a lot. Health plans are operating in a highly competitive market, so they need to keep costs down and get good population health outcomes.

We continually strive for excellence and participate in the National Committee for Quality Assurance’s Healthcare Effectiveness Data and Information Set (HEDIS) and URAC’s health plan quality accreditation programs for our commercial populations, as do several of our health plan competitors. And within the last few years, federal entities like the Centers for Medicare and

Medicaid Services are requiring participation in the Five-Star Quality Rating System for Medicare Advantage plans. More health plans are creating pay-for-performance initiatives that impact providers.

Overall, society has seen the tremendous cost impact of neglecting engagement, so it truly should be everyone's concern. Health care cost increases result in health plan premium increases, then employers' cost increases, as do employees' health insurance premiums (or their cost sharing and out-of-pocket expenses). Everyone is gradually getting the idea that engagement makes a difference.

Q8. CFAH: Some health plans are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution's behavior to support PE?

BCBSSC: The market is demanding patient engagement. More employer groups are implementing incentives for employees/dependents to participate in wellness and/or disease management programs, and some are requiring performance guarantees from health plans.

CMS is looking at quality, which depends on patient engagement. We have positive outcomes with our commercial book of business overall return on investment (ROI) for:

- Disease management 2.5:1
- Case management 3.2:1

Also, this excerpt from a recent [Care Continuum Alliance press release](#) on February 3, 2014, describes results of a recent study on the effectiveness of population health management:

“The recent study confirms that implementing comprehensive, well operated population health programs that incorporate wellness and disease management is an effective strategy to reduce overall costs and risks in a population,” said Fred Goldstein, CCA interim executive director. “Further research is warranted to look at the effects of other components, program models and the use of incentives to identify meaningful ways to improve the health of our workforce while controlling our growing health care spending.”

The study found that the overall return on investment of the program is about 1:1.5, so the program saved \$3.78 in health care costs for every \$1 invested in the program. Furthermore, the employees who participated in both the chronic disease

and the lifestyle management components had the highest savings, according to researchers.

If health plans or employers aren't yet convinced about the value of patient engagement, then the strong evidence base and bottom-line impact could persuade them. Also, we have many personal stories from our members that are powerful.

TOM EWING, MD

Tom Ewing, MD, is the executive vice president and chief medical officer for PacificSource Health Plans. Prior to joining PacificSource, Ewing was the chief medical officer for PeaceHealth. The PacificSource family of companies serves more than 300,000 individuals and 5,700 employer clients throughout the Northwest. Ewing has a wide breadth of experience in the areas of clinical management, health care delivery system improvement and transformation, quality management, clinical informatics, and patient-centered medical home initiatives.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

EWING: This seems like an inclusive definition to me. However, before an action takes place, there are a series of dominos that have to fall. So while actions are the results, there have been precursors, such as understanding/knowledge and the level of someone’s activation that are preludes to behaviors. Unfortunately, many health care institutions/providers just think of engagement as a synonym for adherence.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

EWING: When I wear my hat as a health care clinician, patients who are engaged in their health and health care are much more gratifying for me to work with. Engaged people tend to show up and be informed, and they actively participate in care. When patients are not engaged, I can sometimes feel inadequately prepared to help them. I wonder how I can best support them so they can take steps that will lead them to action and to benefit more from their care.

As the medical director for a health plan, we face real challenges everyday to get people to engage more effectively with self-management of their chronic conditions. We live by quality metrics and health outcomes. And the increasing cost of designing programs for people with multiple conditions and the cost of their care is a serious challenge.

From a patient’s perspective, there is a huge amount of frustration both from patients and toward them. Why do so many of us give up in the face of what appear to be insurmountable challenges of dealing with chronic conditions like diabetes, obesity, low rates of exercise, and physical activity? How do we get on a more “virtuous” cycle of health behaviors? What can be done to reduce no-shows and non-adherence to the recommendations of our health care providers and public health experts?

Q3. CFAH: As a health plan leader, are there any types of behavior listed below that you think health plans have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

EWING: To a certain degree, with the exception of planning for the end of life, our health plan has activities designed to promote all the rest of these engagement behaviors. Of course, we have the most chips in the pay-for-care category. After all, that is our core business.

We do have a patient portal (with low rates of participation) that was introduced to help patients and families with making treatment decisions and participating in treatment. Other models like the patient-centered medical home and the Shared Care Plan developed at PeaceHealth are informing our practices/policies.

In customer service ratings, PacificSource always comes out first in our area of the country. We work hard at helping our customers understand their health bills, insurance claims, and the everyday logistics of using their plan benefits. So we have made efforts to assist with some of the record-keeping and tracking or organizing their care.

PacificSource has high visibility in community service activities, and our interventions in preventive health care and wellness initiatives are well respected.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

EWING: At PacificSource we view the Patient Activation Measure® (PAM®) as the most concrete resource for assessing and promoting patient activation. When I was at PeaceHealth, we incorporated the PAM®. Now we are starting to use it at PacificSource in our patient-centered

medical homes. Health care teams are being trained on the PAM® background and provided with related materials.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

EWING: Gaps in people’s health literacy and numeracy skills are great barriers to effective engagement. For some people there are cultural barriers that stymie engagement.

In addition, there is generally a lack of solid clinical insights into what it takes for clinicians to share information in a way that patients can really understand and use. There is a lack of training to help patients and clinicians have more effective connections and conversations.

Q6. CFAH: To what extent do you think that efforts by health plans can reduce these barriers/increase the capacity of people to engage?

EWING: I do believe that health plans can help reduce barriers. There is some interesting work in Oregon with Medicaid coordinated care plans. The plans have very specific quality metrics that are designed to track improved care, especially for vulnerable populations. The plans there have focused on reducing disparities in care by addressing language needs, developing cultural competency of providers, and using a variety of tools to engage patients. New payment models that support these types of programs will make a difference too.

At PeaceHealth we had remarkable success with a nurse/midwife program for members from Central America and Mexico. More initiatives to address specific populations with culturally sensitive care will help.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

EWING: In my circles, my peers are convinced about the importance of patient engagement. At this point there is enough solid evidence that it can help improve health outcomes. At face value it just seems obvious, but I have often been warned about over-trusting/-relying on a “blinding glimpse of the obvious.” So best to move ahead but be cautious and not overpromise. We may not know enough yet. Some of what we think we know may not be right.

Q8. CFAH: Some health plans are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

EWING: For anyone on the fence about the importance of patient engagement, it will take more quality metrics linked to engagement and, of course, new payment models to persuade some. There is always a lag/gap between research and the translational work of putting science into practice. A continual education and dialogue on effective interventions will be critical. And we need more research on behavior to come from social scientists and to inform practice. There are many tools of other disciplines that can help improve clinical care. At the end of the day, citizen education is key. To transform to a healthier society overall is the real goal.

THOMAS L. SIMMER, MD

Thomas L. Simmer, MD, oversees Blue Cross Blue Shield of Michigan medical policy, professional payment policies, and national programs to improve quality, cost, and access to medical services. He is responsible for reimbursement to more than 25,000 physicians throughout Michigan. Under his leadership, BCBSM introduced physician incentive programs to promote cost-effective ways to prescribe drugs and to provide consistent care for people with chronic illness. Simmer also provides leadership to the Michigan Quality Improvement Consortium. Prior to joining the Blues, Simmer served as vice president of health and medical affairs for Health Alliance Plan. He also served as associate program director for the Internal Medicine Residency Program at Henry Ford Hospital and was the recipient of several distinguished service awards. He graduated from the Wayne State University School of Medicine and earned his bachelor's degree from the University of Michigan. Simmer is a member of the American Medical Association and Michigan State Medical Society and a Fellow of the American College of Physicians.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

SIMMER: Yes, there’s a need to focus on actions. This definition has two goals: prompting patients to not only take ownership of their health but also to better manage their health care. I wouldn’t necessarily put the second, consumerism, into the definition. The priority should be having people become better stewards of their health, with becoming better consumers of health care as secondary. People have limited bandwidth and interest to do the first, let alone the second. The definition mixes a low priority with a high priority.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

SIMMER: Patient engagement requires a major transformation to reverse the current relationship between patients and providers. Currently, patients go to their providers and help them figure out what is wrong and expect the provider to fix it. Patients are in a passive role. What we need is the reverse, with providers helping patients become better stewards of their health and better managers of their health care. We want patients to say their doctors helped them understand their health and guided them in making changes to improve health. This is revolutionary: each of us is the most important contributor to our health, and health systems work to support us in maximizing our health. It requires an adjustment for all.

Q3. CFAH: As a health plan leader, are there any types of behavior listed below that you think health plans have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

SIMMER: This isn't a list that I'd create because it over-emphasizes the role of health systems and health plans.

All primary care providers need to have robust patient portals, which would be worksheets for patients and their doctors to use together to help patients take a more active, engaged role in their health. When you come for a visit, providers should first make sure you receive any preventive services that are due. Then providers should do a health risk appraisal to focus on your own health status and goals. The provider helps you weigh options and develop a plan. This process should include assessing your motivation to change and your interest and confidence in changing behaviors; then it should skillfully move you toward self-actualization over time. Reviewing your clinical test results should be part of this process. Then you, the patient, directly use the portal to set your own goals, such as writing in a quit day for smoking. The portal should let you set alerts or reminders for tasks, such as medication refills, that will help you move toward your goal. It's important that each individual chooses which alerts to receive and how, such as through their smartphone or automated calls. Otherwise, if the provider does it, the alerts won't be welcome but will be like spam e-mail, a nuisance. Case managers should walk you through the menu of reminders so they are tailored to your preferences. Besides integration with phones, the portal should also help you connect with your provider.

Patient-centered medical homes (PCMHs) support the use of patient portals, but frankly, providers aren't taking advantage of portals because all of their bandwidth is being taken up

trying to meet meaningful use standards for health information technologies. Just a few PCMHs are moving forward with using patient portals in this way.

In CFAH's list, only the first—find good clinicians and facilities—has less connection with a patient portal. This is something that people can do in person with their providers, and primary care providers could do a better job supporting their patients in this area. For example, there is no such thing as a “good facility” or a “bad facility.” Rather, all have strengths and weaknesses, and one set of qualities may better match a patient's preferences than another. Patients often care a lot about location. The provider may be able to tell the patient that some hospitals are better at communication with him/her than others in the area.

If health systems make better use of patient portals, we have to keep in mind that patients may not want to use more than one portal, such as one for their primary care provider, hospital, health plan, regional health information exchange, and specialist. If people have to remember passwords for each one, they are unlikely to use them. It's not realistic, and I've seen it among my own family members, even when I ask them to share their lab results with me so I can help. They don't want to go online and figure out their usernames and passwords.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

SIMMER: Beyond what I've talked about, some of the best interventions are those that help people set goals for themselves and then let them get prompts for things that they may forget to do, such as get information, return to the portal to see their lab tests, or schedule appointments. Providers need synchronous prompts so they can, for example, call the patient on their quit date and offer encouragement.

In five years, all this may seem quirky because we've already achieved it.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

SIMMER: Habit. Behaviors we do now are habitual, and our habits contribute to our lifestyle health conditions. The key is to create new habits to help us succeed as stewards of our health. We all need to prioritize what behaviors to change, to consider which ones are important to do for health and which ones we're willing to do and feel confident that we can succeed.

One particular opportunity is changing the adult periodic health exam. About 18 studies have shown it doesn't achieve patient activation or patient engagement, but it persists because doctors and patients like it. Doctors say it helps them build relationships with their patients, but

health plans can't be paying for this just to create good doctor-patient relationships. Further, the periodic health exam reinforces a sense that the doctor is in control of your health. Patients go in and see all of the instruments. Being unclothed makes them feel subordinate to the provider.

The focus of what is now the periodic health exam should be helping and encouraging patients to become better stewards of their health, with a patient portal component. A skilled provider would help patients move along the stages of change, similar to the expertise that health trainers at gyms have. Health systems don't have enough providers with these skills, and the focus might be on developing these skills among the incoming generation.

Q6. CFAH: To what extent do you think that efforts by health plans can reduce these barriers/increase the capacity of people to engage?

SIMMER: We can start by making patient portals a payable event for doctors. Currently, health plans pay a vendor to get new enrollees to sign up for patient portals, and there's some evidence that this practice is good. (But the favorable results may actually be just a lack of better options to be compared to.) We'd see better results if providers owned this process, instead of health plans, and I'd like to see research studies comparing these.

We do pay providers to set up patient portals, but meeting other meaningful use standards overwhelms them. In general, health plans must change what we pay for, especially investing in efforts that build activation and engagement.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

SIMMER: Health plans look at patient engagement as a way to have a competitive advantage. So they offer enrollees incentives, such as skipping co-payments or vanishing deductibles. People see health plans as offering juicy rewards and sign up. Health plans are also paying vendors to activate enrollees. It's good business for the payers and bad business for providers because they can't compete as a cottage industry. It's a suboptimal situation because the ultimate goal—getting people to be better stewards of health—gets lost.

There might be a bridging strategy to bring together health plans and providers around a common goal and then identifying effective strategies to change outcomes. The health system needs to address health more broadly, not retrofitting narrow solutions to improve performance metrics. Admittedly, even these narrow efforts can be better than not doing

anything. Health care is still very fragmented, and we need more than just making tweaks to achieve our goal.

Q8. CFAH: Some health plans are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

SIMMER: I see a lot of zeal among health plans, perhaps akin to a Tower of Babel. The focus should be on connecting patients to primary care providers for support, not creating a lot of information silos with each part of the health system having its own patient portal. Ultimately, it’s about building the capacity of PCMHs in ways that change providers’ behaviors so they really help people be engaged and informed.

ARTHUR SOUTHAM, MD

Arthur Southam, MD, is executive vice president of health plan operations for Kaiser Foundation Health Plan (KFHP). He is responsible for leadership of the health plan's marketing, sales, service, and administration functions. KFHP provides health benefits coverage and care to over 9.3 million members covered by over 100,000 employer groups, Medicare, Medicaid, and other government programs. Prior to joining KFHP in 2001, Southam had been CEO of two other health plans, chairman of the California Association of Health Plans, and a member of the Institute of Medicine Committee on the Quality of Health Care in America. He received his undergraduate and graduate degrees from Amherst College, UCLA, and Pepperdine University.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

SOUTHAM: The choice of “patient” for the definition may be off. It is too *medical care* centric. “Consumer” or “individual” might be better term.

A possible alternative could be: “Consumer health engagement is actions people take to improve their health and realize the greatest benefit from their health care.”

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

SOUTHAM: If a person is engaged in their health and health care, it helps them to maintain health, may reduce the need for medical care, and may improve the efficiency and effectiveness of the medical care they receive. Providing skills and tools that allow people to engage in their health and health care provides them with a greater sense of participation and control, which can improve satisfaction and how people feel. Good health benefits the individual, the parties that pay for their medical care, and society, because they can be more productive and don't consume as many health care resources. Consumer and patient engagement can also improve the efficiency, outcomes, and satisfaction experienced by care providers.

Q3. CFAH: As a health plan leader, are there any types of behavior listed below that you think health plans have more or less credibility to address?

SOUTHAM: Health plans I have worked with in the past have worked to support consumer engagement in their health and health care. The ability of a health plan to effectively support consumer engagement in these areas depends on the interest of the consumer, the capabilities

of the health plan, the capabilities of providers, and the relationship the health plan has with care providers.

Kaiser includes two entities with a close relationship: the insurance/health plan and the medical delivery system. My comments will be from the perspective of the combined health plan and medical delivery system unless otherwise noted.

[SOUTHAM: *comments are in italics*]

Find good clinicians and facilities. *Yes, this is an important role of any health plan that requires or encourages patients to establish a relationship with a physician. We help people online, through our call center, and in our medical facilities. We provide information about medical credentials, as well as other characteristics that consumers want to know about to make choices in line with their needs and preferences.*

Communicate with clinicians (doctors, nurses, others). *Yes, health plans can provide consumers with information and tools that help them effectively communicate with providers, either electronically or in person. We provide support to help people use providers whom they choose, like, and trust. We offer communication tools and tips, such as bringing written questions to appointments. We offer personal health records and a way to securely view medical and personal health records. Consumers can send secure messages to their providers and usually get responses within 24 hours. This platform lets them engage with their caregivers without making an appointment and coming to a medical facility. Insurers that are not closely affiliated with providers don't have as many opportunities to facilitate communication.*

Organize care (appointments, records, referrals). *Yes, as an integrated plan and delivery system we support all of these actions.*

Pay for health care. *Yes, the health plan arm of Kaiser exists to pay for health care, and on top of that, each year we help people with about \$500 million in out-of-pocket costs.*

Make treatment decisions. *Yes, as a medical delivery system, we support this type of engagement. Our doctors give options, discuss trade-offs, and can indicate which course of treatment may be best in a way that encourages patients to make their decisions.*

Participate in treatment. *Yes, as a medical delivery system, we encourage our providers to empower people to be participants in their treatment and treatment*

decisions. We provide educational information and tools that support patients' understanding and ability to engage in treatment.

Make and sustain lifestyle behavior changes. *Yes, we offer online programs and information, classes, worksite programs, etc., to support healthy behaviors and engagement in medical care. It is very difficult for humans to make significant behavior changes and difficult for health plans to determine how to effectively or efficiently support such changes.*

Get preventive health care. *Yes, we do this from both the health plan and the medical delivery system sides. The insurance side pays for preventive services, and the medical delivery side reminds people when they're due for preventive care.*

Plan for the end of life. *We support end-of-life planning, but as an integrated health system we have to be careful because some people are suspicious that we're trying to save money. Of course, end-of-life planning is something that everyone needs to do. We offer tools, such as a template for durable power-of-attorney for health care. Other stakeholders need to offer support for this important activity.*

Seek health knowledge. *Yes, we provide a vast array of online and printed health information in multiple languages. We send people information tailored to their clinical and personal characteristics and preferences.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

SOUTHAM: Several phenomena show a lot of promise for supporting engagement in health and health care:

- Health assessments/health risk appraisals that are easy to do, relevant to the particular patient, provide engaging feedback, and are linked to resources for follow up and to support behavior change, such as health coaching.
- Social technology, including but going beyond social media, enables people to get information and come together around health conditions or shared interests. They can share relevant information with each other, get social support, learn from the experiences of people like them, and help others.
- Broad-based access to online information lets people get as much, or as little, information as they want in their preferred language.

- Personal health records, including open charts, encourage people to participate at the level they want. The best types summarize or translate what's in the native medical records for non-clinicians and yet enable users to drill down into their full records if they want. This technology has a lot of promise for supporting patient-provider communications and people's understanding of their situation and choices.
- Online public evaluation and feedback about providers (such as Yelp) provide information that can help improve communication and facilitate selection of providers with desired characteristics.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

SOUTHAM: People are really busy with their lives (the time barrier). Also, they have different personal interests and seek different levels of engagement. A third barrier is having different priorities. People are “solving to” and focusing on their priorities in life at any point in time, whether it's feeding their families, going to school, a relationship, or improving a health behavior. They solve to what's needed to survive and/or maximize their utility. A fourth is the obtuse language of the medical profession, which is difficult for non-clinicians to understand and isn't meaningful to them. Medical terminology helps the profession to communicate efficiently, but it also can limit consumer understanding and communication. A final factor is that some providers are not interested or skillful in enhancing patient engagement.

Q6. CFAH: To what extent do you think that efforts by health plans can reduce these barriers/increase the capacity of people to engage?

SOUTHAM: Health plans can help by efficiently providing easy-to-access and useful information, including general health information or information/reminders relevant to the particular consumer (e.g. preventive services, prescription refills). They can provide various forms of health coaching or care management support for some or all beneficiaries.

However, the limited relationship between most health plans and their beneficiaries makes it difficult for most plans to support or maintain significant behavioral change. For example, plans can remind people that smoking is dangerous and provide information about ways to change. However, the superficiality of the relationship between a health plan and a beneficiary makes it difficult to significantly affect behavior.

Meaningful change usually requires the influence of a social circle that is meaningful to the individual. What works for middle age men is when their 10-year-old says, “Daddy, please stop smoking. I don't want you to die.” The overall environment and social relationships matter a lot.

The limited relationship between most plans and most of their affiliated health providers also limits the role health plans can play in influencing provider behaviors that affect consumer engagement.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

SOUTHAM: Most health plans view engagement as important and want to support it. But they recognize that they are only one (relatively weak) factor in supporting patient/consumer engagement. Some see their obligation as providing information, but not too much. Their customers want their insurance premiums going to medical care, not a bunch of mailings about things they already know they should do, like eating well. Information must be tailored to the individual. Providers can reinforce and encourage behavior change.

Q8. CFAH: Some health plans are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior and work to change their institution’s behavior to support PE?

SOUTHAM: Most/all health plans are already persuaded that engagement is good thing, but that doesn’t mean they can or should provide resources to support every potential idea or a vendor that thinks they can influence consumer/patient engagement. They have to consider the cost effectiveness of what they do. What interventions will be effective? Do customers want their health plans spending money on changing public policy about food and nutrition?

Because of Kaiser’s integrated system, we have more opportunities to enhance patient engagement than a traditional insurer. Not every organization has both the payer and medical delivery system components, nor should they. Each player in this arena has appropriate things they can do.

PATIENTS

“E-PATIENT DAVE” deBRONKART

Dave deBronkart, also known as “e-Patient Dave,” was diagnosed in January 2007 with stage IV, grade four kidney cancer. Despite his grim prognosis, after treatment involving surgery and a clinical trial of a powerful high-dosage drug, deBronkart’s cancer went into remission and his remaining lesions have continued to shrink. Today, deBronkart is an advocate for patient engagement, activist, speaker, and writer. His mission is to evangelize the “e-patient” movement—empowered, engaged, equipped, enabled—and includes opening health care information directly to patients, creating a new dynamic in how information is delivered, accessed, and used by patients. He works to advance a new world of participatory medicine—one in which patients become effective agents in creating and managing their own health in partnership with physicians. You can read deBronkart’s blogs on epatientdave.com, *Forbes*, and e-patients.net.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

deBRONKART: I love it, but there’s a trap. How widely do you define “support,” “benefit from,” and “their health care”? On the surface it sounds like the usual meaning—health things we see in magazines all the time, and doctor visits, plus all the activities in the CFAH model. But increasingly I see activated patients taking “to benefit from their health care” to a much deeper level, becoming full partners in practice management, health policy, and even in medical research. And not just in the conduct of the research—patients with appropriate skills want to participate in defining the *goals and design* of research.

Engagement goes hand in hand with empowerment. A disempowered person shrugs hopelessly and says, “There’s nothin’ I can do about it.” That’s powerless, and somebody with no power sees no reason to be engaged, so they treat health care like a car in a car wash: they roll up the windows and get things done to them. In contrast, an empowered, engaged person says, “There are things I can do,” and they get a move on.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

deBRONKART: The personal level is simple: health and care are about your body and mind, and you’re the only one who’s there all the time. Nothing any professional does can have maximum impact without the help of the person who’s always there.

At the organizational level, if you're not speaking up to your clinicians and hospitals about what's important to you, there's little chance you'll get it. The practice needs to *listen*; it benefits the provider to draw out patient preferences. Otherwise, whether or not their services are optimally targeted is left to chance.

And at the system level—state, national, and global policy—if we're not acting to say what's important to us, we're leaving it to chance.

Patient activists need to speak for themselves. Disability activist Ed Roberts said, “When someone else speaks for you, you lose” (see my [blog posting](#)). Just ask the early suffragettes—they learned the hard way that having men speak for them in Congress didn't produce results.

Engaged patients can also be effective partners in coping with clinicians' information overload. In my case, my drug's side effects can be fatal, so I wanted to learn how to cope with them. The literature had *nothing* about it, but my online patient peers gave me 17 firsthand accounts, which were a real help in my worst times. Today, my oncologist, Dr. David McDermott, says he's not sure I could have survived if I hadn't been so engaged. How's that for value?

Q3. CFAH: As a leader in the patient community, which of these engagement challenges do you address, or are there any types of behavior listed below that you think patient leaders have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

deBRONKART: They're all good. I'd add an eleventh: “Design and create a safe, effective, and caring system.”

To me, empowerment is knowing what you want and speaking up, and engagement is being in action about it. And to me that includes more than the clinical encounter. Is the whole system what I want it to be, what I know it could be? A growing number of practices are listening to what patients want, and not just in the visit.

In some cases, patients contribute their career experiences to help a practice solve difficult problems. Five years ago, Kingston General Hospital in Ontario was a mess. Then their new CEO, Leslee Thompson, led a culture change that weaves patients into every committee in the hospital—even hiring. One patient suggestion brought hand hygiene achievement from an intractable 30-60% to 92% in less than a year. If a clinician had solved that, they'd have a blue-ribbon paper in *Health Affairs*.

Meanwhile, an in vitro fertilization (IVF) clinic in Nijmegen, Netherlands, gave their patient community a Wiki and six months to discuss this topic: “If we could do anything for you, what would your top 10 choices be?” Of course, tops was for insurance to cover more fertilization attempts. But next—if they could have *anything*—was “empathy, not just information” from their doctors. After that was separate waiting rooms for couples who had conceived, so the ones who haven't wouldn't have to confront it.

As we confront our skyrocketing spending, think, how much do empathy and a waiting room cost? Yet those are what the patients said was most valuable them. They have nothing to do with medicine and everything to do with *caring*.

Think about it. The rock-bottom, core economic question about the industry is, “Who gets to say what's valuable?” In every other industry it's the customer. In medicine, if people want more *caring* and less treatment, I think we should do it...otherwise we'd be spending more, for something people want less! It's not complicated.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

deBRONKART: On the activation front, I like what I've heard about Judy Hibbard's Patient Activation Measure® (PAM®). On the information technology (IT) and medical records front, I like the Office of the National Coordinator of Health Information Technology's one-minute video telling the public the value of electronic health records.

The low-hanging fruit for engagement with a patient's chart is to ask people to proofread their records. In my speeches, I sometimes ask how many in the audience (always less than 10%) have examined their own records to see if they're correct. Consistently, two thirds of those

who've checked have found mistakes: missing allergies, conditions they never had, important typos. My own mom's hyperthyroid showed up as hypo—a mistake that could have been deadly! Asking people to check their chart *before* any crisis hits can get people familiar with the content in a low-pressure setting.

By the way, this isn't just a patient rights or patient safety issue. It's a disservice to a *clinician* if they're handed wrong information.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

deBRONKART: The first barrier I've seen over and over is people not realizing it's valid to think for themselves. The second barrier is that patients don't want to come across as rude, so they hesitate to ask questions. A third is not knowing where to start. In all three cases it's immensely valuable for the provider to invite engagement and offer suggestions—because as Susannah Fox's research shows, clinicians are still the trusted authority, even among engaged patients. (My doctors sure are *my* chosen experts!)

Q6. [not asked]

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

deBRONKART: If you mean clinicians not being persuaded, what I make of it is that they were trained to think that nobody can do anything useful if they don't have medical training. That's archaic now—misinformed.

If you mean patients not being persuaded, my response is what I said above. People need to realize that in today's world, clinicians can't know everything and can't do everything. We need to get activated, get off our butts, and do what we're capable of. My mantra is, "Let patients help"; the flip side is, "C'mon, patients—help!"

Q8. CFAH: Some people are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

deBRONKART: I would really, really like to see some sociologists study what happened in the women's movement in the 20th century in the western world. When I was born in 1950, women pretty much didn't see their lower status as a problem—most were comfortable in their

role or at least accepted it as the way things are. What was the progression of events and ideas that really altered that? The change took a generation or two but it was profound—and I mean, deep.

Today, many of us don't remember what it was like in those days, but last year some perfect evidence went around: [45 vintage sexist ads that wouldn't go down well today](#). Anyone who thinks you can't change culture should look at it—today we find that *previous* world unimaginable. How did that happen? What parts of it can be replicated today?

Note that, as I said in my book, information alone doesn't change behavior. In feminism, a pivotal moment was the movie *9 to 5*, which popularized the issues and made the whole subject so entertaining that ordinary people at the grocery store told their friends about it. That's when it really took root in the general public. Can we do that for patient activation and engagement? I'd love to find out.

EVE HARRIS

Eve Harris uses social media, including a blog begun in 2007, and group presentations to advocate for health care consumer empowerment. Her work demonstrates her passion for patient engagement and health care reform with areas of special interest that include shared decision-making, safer care transitions, health literacy, and aiding the newly diagnosed. After many years in health and human services public relations, she recently launched an encore career as a patient navigator, earning a certificate in patient navigation from California State University in 2012. Currently, Harris works with young female cancer patients to help them understand—and access, if that’s their choice—medical options for preserving their fertility. She graduated from the University of Arizona with a degree in communications. After treatment for her own “mild case of cancer,” she has been NED (no evidence of disease) since 2004.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

HARRIS: It’s a good definition and is comprehensive. Actions are measureable. But engagement is a state of mind, a shift in the relationship between docs and patients, with the goal to support patients’ health. As a patient navigator, how to benefit from provider encounters is where I spend time. I see an opportunity there. Although most of “health behavior” takes place elsewhere, I’m interested in the interaction, in the patient-provider relationship, setting that up for success.

For example, in the current system, patients spend a lot of prep time figuring out how their insurance works and then they sit anxiously in front of a provider, feeling like less than a full partner—this is not the way to get value.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

HARRIS: It made a difference to me. I was an employee at a major academic cancer center about one day prior to my initial diagnosis. By the time I came into the system I was already my surgeon’s press agent; she was one of my higher profile internal clients. I had great treatment from my providers. They expected that I would want to see and would understand data; I saw the benefit of increasing my level of being engaged. I was in a medical situation with lots of shades of gray; I had ductal carcinoma in situ, sometimes called “stage zero” cancer. My provider was involved in developing decision support tools. The argument is still going on about how much treatment it requires, but being engaged helped me feel comfortable about my course of treatment.

I didn't make any treatment decisions quickly. I tend to make decisions out of my head versus out of my gut. But engagement doesn't always take the same form. By contrast, I advocated for a friend after his cancer diagnosis who had sought me out specifically because he knew he tends to make emotional decisions.

My father is 87 and certainly remembers a time when medicine was practiced differently. But he likes receiving an after-visit summary; he files them for future reference. And he recognizes that maintaining his quality of life depends in large part on maintaining his mobility. He goes to the gym three times a week!

Q3. CFAH: As a leader in the patient community, which of these engagement challenges do you address, or are there any types of behavior listed below that you think patient leaders have more or less credibility to address?

- Find good clinicians and facilities**
- Communicate with clinicians (doctors, nurses, others)**
- Organize care (appointments, records, referrals)**
- Pay for health care**
- Make treatment decisions**
- Participate in treatment**
- Make and sustain lifestyle behavior changes**
- Get preventive health care**
- Plan for the end of life**
- Seek health knowledge**

(This list is from the [CFAH Engagement Behavior Framework](#).)

HARRIS: We are the experts on our own experience, which includes everything that happens outside the encounter, including quality of life and observations of daily living. Personal health records and electronic health records (EHRs) are an example of where we deserve credibility. They provide value when they're well executed and danger when they're not, and patients can help. For example, it's a good thing my provider was compliant when I told her to remove the lung cancer diagnosis that had been mistakenly recorded in my EHR!

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

HARRIS: I advocate for the use of a navigation model and other support tools—high touch interventions, as well as software. I don't advocate for any particular apps, but I think some of them will become very useful.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

HARRIS: The biggest barriers are our pay-per-procedure model, adverse financial incentives, and health disparities across the population.

People who are in crisis who have never been asked to do anything like this are really challenged by the idea of getting engaged. And how providers communicate is often a barrier. Without basic numeracy and literacy you can get lost easily, even if English is your first language. But it can be subtler, too. A patient recently told me she consulted an oncologist who gave her “all the statistics” but no information that she felt was meaningful. Doctors often focus on the wrong thing and don't address the patient and her family as a whole.

Q6. CFAH: To what extent do you think that efforts by patients can reduce these barriers/increase the capacity of people to engage?

HARRIS: I focus on the outpatient encounter, especially communications aspects. I advocate for individual engagement and empowerment—having access to information about one's illness and one's self. Patients often say they feel the pressure of time. There are ways that having a navigator—and/or preparing well for a provider encounter—can start to alleviate that pressure.

Q7. [not asked]

Q8. CFAH: Some people are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

HARRIS: As a navigator, I'm pretty reflective, not persuasive. “I'm here if you want to call; if you change your mind,” for example.

CAROLYN THOMAS

Carolyn Thomas has over 30 years of experience in journalism, marketing, and public relations (PR), including corporate, government, and nonprofit PR. In May 2008, while working as the communications coordinator for Canada's Victoria Hospice Society, Thomas was hospitalized for a myocardial infarction caused by a 99% blocked coronary artery. But two weeks earlier, she had been sent home from the same hospital's emergency department with a misdiagnosis of acid reflux—despite presenting with textbook heart attack symptoms. Disturbed by her experience and hoping to share what she'd learned with other women, Thomas used her PR experience to launch her first blog, [Heart Sisters](#), in April 2009 and has gone on to write a second, [The Ethical Nag: Marketing Ethics for the Easily Swayed](#).

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

THOMAS: This is the definition that I use, too. In fact, I have quoted you in my blog articles about patient engagement. But I think that sometimes the notion of “actions” assumes that you are not sick.

I attended the 2012 Stanford University Medicine X conference on an ePatient Scholarship. This annual conference is billed as “the intersection of health care and technology” and thus attracts a cross-section of health care providers, tech-savvy patients, and the “worried well” hypsters of the Quantified Self movement. As a person living with ongoing chronic illness issues, I felt so out of place, because so much of what I was hearing simply does not apply to me or to the patients I talk to on social media or in my women’s heart health presentations. It struck me that many of the Silicon Valley people I met there just don’t get it—they don’t get me. They seem to be living with the luxury of what Dr. Ann Becker Shute calls “healthy privilege.” It’s sometimes tough to be in a crowd like that—they are so busy high-fiving each other over their shared conviction that technology is the savior of health care as we know it.

I would probably rate low on the Patient Activation Measure® even though I am curious, involved, knowledgeable, and as active as I’m able to be as a patient.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

THOMAS: It makes a difference to the patient themselves, of course, and to those who care about them. I’m absolutely gobsmacked sometimes by the kinds of questions my audience

members ask during my heart health talks. For example, an elegantly dressed older woman once raised her beautifully manicured hand during the Q&A portion of my presentation and asked, “Carolyn, my doctor says I have a ‘heart rhythm problem.’ What does that mean?” How are patients like this leaving their doctors’ appointments without understanding even the basics of their diagnoses? And why is she asking *me* when she won’t ask her own doctor? If she’s like my late mother, it’s probably a combination of embarrassment at appearing stupid and also not wanting to take up too much of the doctor’s valuable time. And doctors wonder why patients like this end up being “*non-compliant*”—patronizing terminology, by the way, that many of us just can’t stand!

Patient engagement can’t help but have an effect on clinicians—both positive and negative. We know that not every physician welcomes what must seem a profound change in the doctor-patient hierarchy. That’s why some docs prefer the less-threatening word “engagement” to “empowered.” One of my blog readers, for example, described this visit to her new cardiologist:

“When I first began discussing my condition with him, he said he hadn’t realized I was a doctor. I told him I’m not a doctor, but I am a very good researcher. He gave that small, insulting half-laugh that doctors reserve for this response and said that he wasn’t sure he approved of patients doing research. I told him I had no inclination to apologize for it. I said that I knew he was interested in my health, but not nearly as interested as I am. It’s his job, but it’s my life.”

When I now bring information or questions to my doctors, I expect that they will help me make decisions about my care and also let me help them understand the specific perspective. I’m thinking that it was far easier in the old days when our health care providers could just say: “Here’s the diagnosis; here’s the treatment plan. See you in two weeks.”

Q3. CFAH: As a leader in the patient community, which of these engagement challenges do you address, or are there any types of behavior listed below that you think patient leaders have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

THOMAS: The first thing I remind my “constituents” (whether they’re the women in my heart health presentation audiences or the readers of my blogs) is “I am *not* a health care professional—merely a dull-witted heart attack survivor—and nothing I say should ever replace sound medical advice from your own care providers.” But, having said that, I do proactively try to help patients to help themselves by offering general information about engagement challenges.

Q4. CFAH: What are some interventions that you’ve heard of that show promise in helping people to engage in their health and health care?

THOMAS: There has already been significant success with smoking cessation. We are now moving toward an all-out smoking ban in public places here in Canada, and smoking rates are down significantly. And current quit-smoking programs seem to be shame-based. My theory is that people don’t quit because docs are telling them not to smoke, but rather because of social ostracism. It sounds odd, but that now appears to be working.

When you’re talking about chronically ill patients, however, you often run into this reality: patients want to *stop* needing to think every moment about their bodies/health. We just don’t want to deprive ourselves every minute of every day to accommodate this relentless disease of ours! As oncologist Dr. James Salwitz, in his blog, described one of his cancer patients, “He just wants to be a person, and not a patient anymore.”

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

THOMAS: Here’s a good example: the American Heart Association tweeted recently about the “10 benefits of walking to prevent disease.” That’s what sociologists call an avoidance goal. I tweeted back—“Why not say: ‘Walk so you’ll feel good!’?” That’s called an approach goal—found to be more attainable than avoidance goals. These issues are framed wrong; the last thing most of us want is to think that we *have to* take this action to avoid disease, but we all want to have more fun and feel better.

Also, look at Dr. Victor Montori’s work at Mayo Clinic on what he calls “the burden of treatment,” a key concept in the field of [minimally disruptive medicine](#). This is an alternative to

the current approach of evidence-based medicine (like relentless treating to numbers) that is pervasive in medicine. Treating to numbers isn't always evidence-based, however. It may seem counterintuitive, but intermediate endpoints (targeting lower numbers) are not necessarily connected to better health outcomes, as December's [2013] controversial new cholesterol guidelines revealed. Maybe we will be more engaged in our health care when our symptoms are addressed and when our actions mean that burdensome symptoms become less overwhelming and that burden of treatment is eased.

Q6. CFAH: To what extent do you think that efforts by patients can reduce these barriers/increase the capacity of people to engage?

THOMAS: A 2012 study out of the Palo Alto Medical Foundation and published in the journal *Health Affairs* about the issue of "[difficult patients](#)" really resonated with me.

Until a whole lot of patients are willing to be seen as "difficult," it's unrealistic to think that we will rise up as one homogenized voting bloc. That's not going to happen. Right now, for some patients, even reading stories about this is too threatening.

I would like to say that patients do hold a key role in increasing capacity to engage, but realistically, the people I see and hear from (those living with chronic illness) are often too overwhelmed or too exhausted—just from putting one hospital-booted foot in front of the other—to lead this charge. Maybe it's generational. Maybe our kids will spearhead the change. Maybe others in the world who are like Dr. Victor Montori will lead us by example. And I have more hope for current medical students reducing barriers to our participation than I do for many current doctors.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

THOMAS: I think it's hard to tell because the inspirational patient voices you most often hear from at conferences—like e-Patient Dave—make it tempting for non-patients to assume that all of us *are or could* be like him if only we had the gumption to do so. This just isn't true. I happen to have a public platform from which I can speak up as a patient as my health allows, but that hardly makes me a poster child for engagement, and I'm careful to point out that I don't and won't position myself as speaking for other patients. Others may be just as interested in the concept of patient engagement, but are only able to function as their limitations allow day by day. So even the smallest nudge toward increased patient participation is to be celebrated, no matter how small it may seem compared to those who are doing more out there in bigger ways.

Q8. CFAH: Some people are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

THOMAS: A couple of small but significant ideas. In the Canadian province of Saskatchewan, doctors are prescribing exercise to their patients on prescription pads. This constitutes a free pass to the YMCA/YWCA with doctor's orders. Another program is "Walk with a Doc," an international community walking program launched in 2005 by Ohio cardiologist Dr. David Sabgir. Docs register online and then show up at a park on Saturday morning; they give a five-minute health talk and then go for a 45-minute walk with whoever arrives that day. This beautifully broadens the concept of patient engagement to physician engagement.

In both cases, the doctor legitimizes the patients' actions—and in the latter, even participates!

People already *know* the evidence. Very few people don't know that you should exercise and eat healthily. As cardiologist Dr. John Mandrola likes to say, "You only have to exercise on the days you plan to eat!"

It's not always money that's keeping people from engaging in their own health. Information is part of what we need, but our doctors' endorsement of our participation is key. Consider, for example, that only one third of all eligible heart patients are referred by their doctors to cardiac rehabilitation programs despite the well-known long-term effects on improved patient outcomes that such rehab provides. This failure to refer is inexcusable.

KELLY YOUNG

Kelly Young is a patient advocate, speaker, and writer who has lived for almost seven years with rheumatoid disease, also known as rheumatoid arthritis (RA). In 2009, Kelly created Rheumatoid Arthritis Warrior (rawarrior.com), a comprehensive website about RA that battles misconceptions and works to help patients be better informed and have a greater voice in their health care. Her goal is to foster a more accurate awareness of rheumatoid disease and improve diagnosis and treatment. Young is also the president of the Rheumatoid Patient Foundation and serves on the Mayo Clinic Center for Social Media Advisory Board.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

YOUNG: I think this is good—obviously I could break it down further. I’d want to be sure that “actions” include decisions.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

YOUNG: Our engagement in our care doesn’t always make a difference in the outcome. I work from the patients’ side and say, “These are ways that you can help improve your care...” but sometimes it doesn’t make a difference. For example, discussing with your doctor how much you should pay for care or what your burden of treatment should be based on your illness—lots of times the end result of that kind of engagement isn’t marked by a clear line.

To the patients themselves, engagement or participation might mean that they had some measure of control regarding the choices available to them. To the extent that our engagement improves health, everyone—other stakeholders included—hopes that will lead to improved outcomes and lower cost. But I’m skeptical. There isn’t a linear relationship between engagement and outcomes.

As long as I’m doing well, and I have a plan for a condition, and I know what to do, it’s fine. But with some of my other conditions it’s not that simple. My doctors don’t know the answer; they don’t have a treatment; there’s no cure yet.

Q3. CFAH: As a leader in the patient community, which of these engagement challenges do you address, or are there any types of behavior listed below that you think patient leaders have more or less credibility to address?

[YOUNG: *comments are in italics*]

Find good clinicians and facilities. *No*

Communicate with clinicians (doctors, nurses, others). *Yes*

Organize care (appointments, records, referrals). *No*

Pay for health care. *No*

Make treatment decisions. *Yes, but only on the side of being informed. Specific to rheumatology, for example, knowing their individual characteristics and encouraging them to see themselves as individuals.*

Participate in treatment. *Definitely. For every prescription, ask what it's for, know what it will do, what can I expect, how long until it works, how will I know if it's working, side effects to look for, etc.*

Make and sustain lifestyle behavior changes. *No. This is so strongly emphasized already and still not shown to be effective for RA patients, so I don't talk much about it.*

Get preventive health care. *There is no preventive care for RA. For other patients, I talk about it in terms of immunization, reporting side effects, and infections. In my writing, I call it "comprehensive care" for RA. Addressing issues other than joints is important.*

Plan for the end of life. *No*

Seek health knowledge. *No*

(This list is from the [CFAH Engagement Behavior Framework](#).)

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

YOUNG: There are a ton of apps for RA, and I haven't seen any one of them take off. I've worked on some of them myself. The challenge is going to be finding something that works, that patients will do, and that doctors will look at. The intervention has to reflect meaningful disease activity on our part that is of interest to our doctors.

There is great potential in social media, I think. Our patient community is pretty active—inter-patient activities focus on whether and how physical therapy, medications, etc., are working for them. I get letters from people who have been reading on our site for two years but stay in the background. They are absorbing [information] but are not really involved publicly for a while.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

YOUNG: Access to information, access to their data. There's a prevailing attitude on the side of clinicians that looking for and using this information is not good behavior on our parts. I think that attitude is a big barrier; people don't want to be seen as troublemakers for asking too many questions, disagreeing with a clinician, or bringing information to the table.

Q6. CFAH: To what extent do you think that efforts by patients can reduce these barriers/increase the capacity of people to engage?

YOUNG: Individual patients? To only a small extent. We can try to move around to more patient-centered providers so we can participate more. My group champions the good doctors. We encourage people to seek a second opinion and advise people to avoid/leave crazy ones.

Patients can't change the culture of our engagement alone. That's why we created an organization: to have an impact. We have to create alliances and participate in professional scientific meetings and organizations that set standards for our care.

We have slowly built our participation in the American College of Rheumatology. They have to trust that we are not wild and crazy and difficult patients. But to get real change, we have to attack the problem from the opposite side—medical school, continuing medical education—with clear messages that patients need to be heard.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

YOUNG: I think a lot of patients are like me—or at least they are moving in this direction as they find things not working. They become engaged in communities and see the success of others and that encourages them to keep trying. With RA, this whole thing is a process. When you are diagnosed, you aren't told what the disease is. As you begin to figure it out, you first think you are the only one with these problems and that the failure of the medicine is your fault. Then when you talk with other patients, you realize you aren't alone: this is the situation of the majority of people with RA.

Q8. CFAH: Some people are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

YOUNG: I wish I knew. I do know that it's not *one* thing. RA has gotten short shrift from the media and the government. We are trying to put together information and find ways to get it into the hands of the newly diagnosed.

We aspire to be like [patient communities for] diabetes. They are a couple decades ahead of us in some things. There is insulin; it works for many. Diabetes education is legitimate. It is institutionalized.

There are similarities between conditions. We hope that eventually everyone with RA will have access to these kinds of resources. As it is, we start from a position of ignorance, and when treatment doesn't work, it's our fault. No one tells us we need to see an eye doctor or consult a cardiologist to see if we need to have an ultrasound of a carotid artery.

VENDORS / HEALTH CARE CONTRACTORS / CONSULTANTS

ALEXANDRA DRANE

Alexandra Drane is the founder, chief visionary officer and chair of the board at Eliza Corporation. Eliza aims to make people happier, healthier, and more productive via health engagement management. Drawing from 10 years of surveys with people about their health, Eliza blends business intelligence, technology, and communication expertise to improve care experiences, reduce costs, and advance population health. Prior to Eliza, Drane co-founded Seduce Health, a nonprofit focused on reframing how to engage people in conversations about their health. She also co-founded Engage with Grace, a movement focused on making sure individuals' end-of-life wishes are understood, communicated, and honored. She holds a BA in economics from Tufts University.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

DRANE: The responsibility of/opportunity for the health care system to inspire people to *want* to take these actions [is missing].

I would consider taking out the word “patients” from the title. Instead, consider something like “The end result of a collaborative effort whereby the health system makes healthy behavior feel desirable and attainable, and as a result, individuals get fired up about their health.”

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

DRANE: Health engagement supports people in taking care of themselves, whether that’s getting a flu shot, having their screenings, filling their prescriptions, etc. These health behaviors have proven to dramatically reduce long-term care costs. Ultimately, better health feels good, costs less, and increases productivity—a win for all. For example:

- Patients who receive Eliza follow-up outreach after a hospital stay are 25% less likely to be readmitted to the hospital within 30 days of being discharged.
- Eliza outreach led to a 76% increase in the number of patients who get their recommended diabetes screening.
- Eliza outreach more than doubled rates of prescription refill over a six-month period.
- Eliza outreach led to a four-fold increase in participation in online smoking cessation programs.
- Eliza outreach led to a 137% increase in colon cancer screening rates in a Medicare population.

- Eliza outreach increased engagement among young, generally healthy individuals—boosting their perceptions of their health plans’ brands far beyond what more expensive, traditional advertising campaigns could deliver.

Beyond these outcomes, when done well, the person benefits from feeling like they have a partner they trust (driving retention and stickiness); communities also benefit from having models of better health (this matters in online environments too...social support networks help everyone in them feel better).

Q3. CFAH: As a health care contractor/consultant, are there any types of behavior listed below that you think health care contractors/consultants have more or less credibility to address?

[DRANE: *comments are in italics*]

Find good clinicians and facilities. *Yes—by understanding what people value in a doctor relationship, we facilitate an MD Harmony-type situation.*

Communicate with clinicians (doctors, nurses, others). *Yes—both by giving people specific wordstrings to bring to their doctor (i.e., asking about generic meds) as well as sending along alerts regarding patient needs/desires.*

Organize care (appointments, records, referrals). *Yes—on a spectrum that includes timely reminders for upcoming appointments all the way to addressing barriers to best care practices.*

Pay for health care. *Yes—by matching individuals to the health care resources best suited for their individual profile.*

Make treatment decisions. *Yes—our products both integrate with and further facilitate treatment decision support.*

Participate in treatment. *Yes—our philosophy starts with engaging people in their health but doesn’t stop until their particular health situation is resolved.*

Make and sustain lifestyle behavior changes. *Yes—in areas from diabetes care to stress management to smoking cessation.*

Get preventive health care. *Yes—helping people get these important screenings through proactive reminders as well as understanding and addressing the barriers and motivations that people have around getting these screenings.*

Plan for the end of life. *Yes—and while this hasn’t historically been a place where the health care system has a lot of credibility, this is starting to change as the health system realizes the hunger people have for better understanding their end-of-life*

options, having them openly communicated, and most of all...honored by the health care system.

Seek health knowledge. *Yes—as part of the backbone of all we do.*

(This list is from the [CFAH Engagement Behavior Framework](#).)

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

DRANE: Gaming methodologies that make the pursuit of health more entertaining, persuasive profiles that understand and leverage what really makes a person tick, the effective use of storytelling and other ways of forging personal connections that make it easier for a person to start a tough health behavior, and online social support networks that let people with similar health concerns connect with, learn from, and support each other.

But most importantly, we see value in outreach that recognizes that health is life and addresses the individual holistically. For example, our research and experience indicates the need to talk about the “life context” issues that impact health. Eliza calls them “the unmentionables,” and we’ve been able to quantify the impact of these issues on health, well-being, and productivity. We’ve found that up to 94% of people report dealing with at least one of the following such issues: financial problems, relationship troubles, job stress, a bad sex life, and caregiving needs. Also, 40% of survey participants said they were simultaneously dealing with four to six of these issues. Beyond that, people who report dealing with four or five unmentionable issues are five times more likely to report bad health, while people who say they have no unmentionables are three times more likely to report excellent health.

We predict that health plans and employers will start paying greater attention to how they proactively assess and address these unmentionable issues—not only because they impact quality and cost, but also because acknowledging these challenges shows a concern for people’s well-being (which health plans will need to do if they truly want to be the consumer-focused organizations that we hope they want to be). Actual support for the hidden drivers of health—breaking away from the traditional definition of health care into areas like the unmentionables, which typically have been avoided by the health care industry—are proving to be worthy trends to watch.

Q5. CFAH: What do you see as the greatest barriers to patients being more and more effectively engaged in their health?

DRANE: A presumption that most individuals have the same level of interest in (even obsession with) their health as those of us who have dedicated our lives to the health of the nation. Couple

that with the condescending approach that the health care system often takes in its messaging; real-life factors like caregiving and financial stress that suck time and energy, which the system often ignores; and finally, the competition that healthy behaviors get from the food and beverage industry. It's no wonder we're still struggling, no matter our great passion and best intent.

Q6. CFAH: To what extent do you think that efforts by health care contractors/consultants can reduce these barriers/increase the capacity of people to engage?

DRANE: There is a huge opportunity for the system to better address both of the above barriers—changing approach and tone (making the pursuit of health feel sexy and desirable) and assessing for and addressing those life context issues. After all, we need to not only appear relevant, but also attractive compared to our competition (that is, promoting things most people want to do anyway, like sit on the couch eating junk food), which of course has an advertising budget that far outpaces what we in health care have to work with.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

DRANE: All of our customers are working hard to foundationally change their approach to achieving healthier outcomes. The Affordable Care Act (ACA), the coming of the [health insurance] exchanges, and the shift from wholesale to retail—all of these changes are driving an urgent focus on becoming genuinely consumer-centric.

The health care system is taking on more risk and is forced to play by different, increasingly transparent rules (like [Medicare's Five-] Star metrics). To that end we've seen many players in the space taking a more consumerist approach—understanding and messaging to the things that really matter to people—to help drive engagement and healthy behavior change.

The tide is shifting—we now have large health plan and employer customers who are asking to assess for and address unmentionable issues in their populations, which they didn't have the appetite to do in the past.

In addition, the health 2.0 movement in particular is hard at work developing tools and technologies that help integrate health engagement into daily life—for many people, recording eating habits or tracking prescriptions has become as routine as checking e-mail. This movement has drawn people from all ends of the health care space: doctors, health plans, technologists, and most of all entrepreneurs who understand the huge opportunity there is in health engagement.

Q8. CFAH: Some health care contractors/consultants are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e.,

evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

DRANE: Most health care executives are thinking about how they can spend their dollars in a way that creates more value for a population while reducing all of our costs. Engagement is the key to making that happen. Whether we are talking about taking better care of chronic conditions or preventing them in the first place, the role that each of us plays in our relationship with the health care system is only increasing. We will each be navigating our own paths toward our optimal health and that will require an industry that considers us holistically and provides the tools and communications to let us take the reins, in partnership with our providers, without breaking the personal or collective bank. So, technology products and solutions that engage individuals in a mind-share-grabbing and inspiring way are and will continue to be attractive investments.

Also, given the changing health care conversation, it pays to be intriguing. While there still is uncertainty about how the ACA will play out, it's pretty clear that there will be a long and bumpy road to a more consumer-friendly health care system. The specter of health exchanges already has encouraged more health care organizations to take a page from consumer retail gurus' playbook. Here's an example: Since, for the most part, consumers prefer to be beguiled rather than lectured to prevent illness and disease, an engaging approach is significantly more successful in a noisy and busy world where taking care of health is often the last on the list of daily to-do's. Women will and should expect, for example, to not only chuckle when they get a "flirty" mammogram reminder but be more likely to say they'll schedule their screening based on the more engaging approach. In fact, we've found that when women receive a flirty mammogram reminder, they are 26% more likely to schedule their mammogram than women who hear the "same-old, same-old" type of reminder messages of yesterday's health care system.

That same-old, same-old perspective is worth considering when it comes to engagement overall—if we keep trying the same approaches with people who aren't budging in their behavior, we're all wasting our time, energy, and money. To help address that kind of insanity, we've developed the Eliza Engagement Index™ (EEI) that serves as one of the cornerstones of our behavioral intelligence deliverables. The EEI is a scoring algorithm based on predictive attributes of engagement, such as how likely a person is to have a recommended screening or to register on a website. It creates an instant picture of how available, receptive, and responsive members are to your brand and how that stacks up against other organizations in their space. The EEI—which is unique in the field—lets you evaluate a population as a distribution of not just cost or risk but also engagement. Approaches like this drive better targeting and messaging strategies—and deliver the health outcomes that the industry needs.

MARY MINNITI

Mary Minniti is a program and resource specialist for the Institute for Patient- and Family-Centered Care. The Institute for Patient- and Family-Centered Care works to advance the understanding and practice of patient- and family-centered care. The Institute accomplishes its mission through education, consultation, and technical assistance; materials development and information dissemination; and strategic partnerships. Prior to joining the Institute, Minniti spent more than 25 years in quality improvement, community organizing, implementation of patient-centered medical homes, and the enhancement of the patient experience of care. She has worked for PeaceHealth, an integrated health care system serving communities in Oregon, Washington, and Alaska, as the pursuing perfection project manager in Whatcom County, WA, and as the quality improvement director for PeaceHealth Medical Group in Eugene, OR.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

MINNITI: The definition is a behavioral description that does not account for the richness of a person’s life. People act within a context of relationships with others. So I view engagement as something that happens within collaborative encounters. Engagement happens with and among family, health care clinicians, and community. There are interactions and tools that can increase the engagement of another in a health care setting and ones that may disengage an individual. As I think about health goals and action, it involves how I might gather information, then how I act on the information with the support of others, not in isolation. Because we act or engage in health activities based on available resources in our neighborhoods and communities, continued engagement to solve health concerns I have may be impacted by a variety of factors.

The work of Kate Lorig at Stanford in the development of the program, Living Well with Chronic Illness, is important. This is a peer-led program to help those living with chronic conditions learn more about self-management and its impact on overall health. This program has helped many become more engaged in their choices, such as symptom management, food choices, and exercises. Programs like this are not available in all communities. Isolation can impact one’s ability to be engaged effectively. Individuals’ failure or inability to take actions on their own behalf has a ripple effect back to the community. Non-engagement impacts society, interactions with others, and overall community health. However, authentic engagement is not just about doing what the doctor tells you to do. It is about making choices based on values and preferences and relationships beyond the clinical encounter.

The recent [February 2013] issue of *Health Affairs* that focused on patient engagement spotlighted attention on this topic and its many facets—primarily from the perspective of the health care system. For many professionals inside health care environments, patient engagement is still defined as adherence to medical advice. As a result, there are judgments being made on how well people are doing with compliance to those standards. I believe most people are doing the best they can and do not consciously have an intention of compromising their health today. Most of us are simply making the best choices we can within the context of our lives and communities. We need to do a better job of understanding where people are. We need to partner with respect.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

MINNITI: Certainly it impacts an individual's life but also the lives of their friends, co-workers, and loved ones. Our behavior and health status also influences the environments that others live in. For example, when I was growing up, my mother smoked, and her addiction to cigarettes impacted the whole family. When she developed emphysema later in life, that impacted us all too. Until then, she thought of herself as healthy. When it had a direct impact on her daily life, she quit using tobacco. She was engaged in her health in a new and different way.

Engagement in health and health care has the potential to affect the length and quality of our lives. A lack of or inability to engage in changing health behaviors can also impact the cost of health care/illness for individuals and for society. For those inside health care who are focused on Triple Aim activities (optimizing health, care, and cost), the level of engagement of individuals should be a concern.

Q3. CFAH: As a health care contractor/consultant, are there any types of behavior listed below that you think health care contractors/consultants have more or less credibility to address?

- Find good clinicians and facilities**
- Communicate with clinicians (doctors, nurses, others)**
- Organize care (appointments, records, referrals)**
- Pay for health care**
- Make treatment decisions**
- Participate in treatment**
- Make and sustain lifestyle behavior changes**

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

MINNITI: Through the Institute, we offer resources that assist providers, patients, and other health care professionals to collaborate on quality improvement and safety efforts in authentic and meaningful ways. This includes creating mutually beneficial opportunities to improve the way care is provided. This includes listening to and understanding perspectives of patients and families and believing their perspectives have value and can contribute to creating a better health care experience for all.

The Institute's overarching work is about creating partnerships with health care staff, clinicians, patients, and families at four levels: the clinical encounter, at an organizational level in quality improvement and safety, in the community, and at a policy level. At the clinical level, we encourage creating systems that provide information in unbiased and affirming ways, respect the individual's values, and encourage the individual to participate in decision-making to the degree they wish. In this way, an individual is more likely to participate in treatment decisions and participate proactively in treatment. When patient and family advisors participate in quality improvement and safety, they collaborate on ways to reduce costs and learn more about communicating with providers to make more informed decisions, including decisions at the end of life.

The way the current system is organized is difficult for most of us to navigate. It is complex and care experiences do not necessarily provide cost-effective ways to meet population health needs. We promote patient- and family-centered care as an essential way to build partnerships that seek to improve the care together. Our work tries to facilitate these partnerships where problems can be addressed by both those receiving care and those giving care. Valuing different perspectives is important, but it's especially important to invite patient and family advisors to be part of the solution. Encouraging and promoting patient and family advisory councils is one strategy; inviting seasoned advisors to participate on quality improvement and safety teams is another way to engage patients and families.

The health care system loses credibility when we fail to authentically connect with patients and families. When I was at PeaceHealth, we worked with patients who had diabetes and congestive heart failure. They participated in designing ways to improve care across the community. One of their suggestions was to develop a role for a registered nurse who would work across organizations to work with those people whose complex conditions were unstable.

As these nurses began their work, they were astounded by how little the patients knew and understood about their condition. Over the years, for these most vulnerable patients and their families, the health care system had failed to explain information in ways that were useful to them and helped them understand the vital role they played in their own health outcomes.

So, it is critical that health care providers learn to connect in ways that meet the patients and families on their own terms, using language that creates understanding. Too often providers use jargon and lingo that may communicate their expertise but the meaning and relevance to patients' lives is missed. I remember one patient, a mechanic who became an advisor to our program. He had diabetes and in looking back realized that he didn't really understand what the doctor had been trying to say over the years. He said he wished the doctor had explained to him that his body was like a car, needed regular tune-ups, and would last longer if he used better fuel (food). Too much of the time health care staff and providers fail to share information in such a familiar context. Those are missed opportunities for patient engagement.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

MINNITI: When I worked at PeaceHealth Medical Group, we developed a pilot program to create a patient-centered medical home. Patients and families were considered part of the health care team; patient and family advisors participated in the design of the clinic programs. Everyone had a role on the team and worked to the top of their license. Rather than just being a roomer or task completer, medical assistants functioned as health coaches and helped maximize the effectiveness of the team; by working together, everyone learned more about the patient/family. Everyone also understood the importance of their relationship and interactions with each other and the patient and their families. Even the front desk person functioned as a care facilitator. Everyone contributed. This shifted us from having the doctor direct all of the care and task assignments; the health care team changed how they approached routine work and maximized the interactions they had with the patient and family. Outreach, calls, and follow-up care for the patient and family increased. Care was no longer oriented just to the exam room. Care was timely information provided on the phone, care was in the relationships developed with all members of the team, and care was coordinated and built on referrals to community resources.

In my current position with the Institute for Patient- and Family-Centered Care, I see organizations that have become more patient- and family-centered in their care and how they approach all the work. They welcome patients and families as advisors in many roles. This new way of collaborating and building authentic partnerships within a health care organization can

be transformational and increases the engagement of advisors in their own care and beyond to improving the health care system for all. Inviting patients and families back into the process changes the expectations of everyone and creates an appreciation for everyone on the health care team. The health care professional is an essential member of the team, as are a person's family members, who most often support a patient in achieving their health goals. But ultimately, the patient is the most important member of the team and is in charge of his/her health.

This is a very different role for both patient and doctor. Doctors become coaches and advisors. In this example, doctors' clinical judgment and diagnostic skills are better utilized. At the same time, doctors are trained in health coaching and motivational interviewing. They learn to collaboratively develop health goals with patients and listen to what matters most to the patients: what they want to achieve. Traditional health care has asked the patient to be the passive recipient of services to and for them. In a new patient- and family-centered model, patients and their family are invited to become more active. For someone who has always been told to do what the doctor says, without opportunity for input, this can be startling. When all of a sudden your doctor starts to ask you what actions you'd like to pursue to solve your health care problem, you may respond, "That's what I pay you to do!" Explaining why their involvement is essential and setting the context for this change in relationships helps invite more participation. To build confidence with new roles, patients and families need encouragement and support for these expectations and new behaviors.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

MINNITI: Most patients and families don't have a lot of experience and/or confidence in partnering as part of a health care team. This is where the beginning of an office visit or health care encounter or conversation can really set the tone. It is important to show that you believe patients and families have the ability to participate *and* you are inviting them to engage and will support them as they develop the skills to do so.

It is hard to challenge the perspectives and authority of health care professionals. But the professionals inside health care need to hear more from patients and families about their preferences and values too. Health care is not just about fixing a problem—sometimes it is about healing, which is different. People want a voice in the decisions about their lives. We need practice on the small things so when a big situation comes up, we have experience voicing our choices and observations to people who traditionally have not listened to or considered this perspective in the decision-making process.

I am convinced that everyone inside health care comes to work to do a good job, to help people live long and well. But unfortunately much of the health care system and the way care is organized are saddled by traditions, hampered by the way we've always done things. Everyone (especially specialists) comes in with all sorts of rules in their head. They are trained to find out what is wrong and then do something about it. The traditional role for nurses has been as an advocate for the patients—speaking for them. In a newly redesigned system, we want to create opportunities to hear from the patients directly. The patient should be invited in so they can find their own voice.

It is time to make changes. Working in partnerships with patients and families and health care teams reenergizes everyone. Meaningful work is better for all. It is worrisome that so little time is available for getting to know patients, especially in primary care. Office visits where doctors interact with patients in increments of three to seven minutes are practical barriers to building relationships. And for the clinicians, it is isolating to spend all day just popping in and out of exam rooms. Without a team, they feel burdened by needing to do it all in a pressurized production setting. They do not experience the joy of medicine within those confines.

Q6. CFAH: To what extent do you think that efforts by health care contractors/consultants can reduce these barriers/increase the capacity of people to engage?

MINNITI: As time goes on, I think we will start to get a more realistic view of engagement. Right now, I believe there is a lot of misunderstanding about the intention of each player. We judge each other harshly—patients aren't compliant; doctors don't listen. When we understand and honor the importance of healing relationships between members of the health care team, I become hopeful. When a partnership is established, and everyone is engaged in working with patients and families, I see wonderful outcomes and am hopeful we can all have a different experience.

Payment reform can help. If we focus more on outcomes and less on charging for procedures or requiring office visits that may not be necessary, then it is inevitable that health care will become more team-based, outcomes-focused, and the definition of quality will include both technical, clinical quality and the patient experience of care equally. The attention to results will reinforce the need to pay for and deliver care differently.

At the same time, people who have had the experience of a culture shift to patient- and family-centered care share their stories of healing experiences, improved outcomes, and reduced costs. Documenting the changes that have occurred as a result of patient and family advisors working in health care settings on improvement and safety inspires others to remove

attitudinal and other barriers to their participation. Sharing success stories of team-based care and programs that increased patient and family engagement will help. Patients and families have the capacity to participate effectively, but in many instances they haven't been invited to get involved, supported in this new way of working together, or acknowledged for the value that their experience brings to discussions on change and improvement.

The paternalistic attitude of health care providers—"I know best"—comes from their clinical training and a desire to make people better. In an acute situation, like a trauma, I want my doctors to apply their clinical training so they save my life. However, once that's been done, I have to live that new life if my health has been impacted long-term. To navigate toward health requires that providers work with me, listen, and communicate respectfully with me. Building those collaborative communication skills among health care professionals needs to happen.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

MINNITI: I suppose there are different attitudes about patient engagement in different parts of the country and even within various health care organizations. But I am often surprised at the degree of variation in how health care acknowledges and values the presence of family in helping in the healing process. For example, when my son-in-law had recent back surgery, he wanted to have his wife and daughter present as he woke up in the recovery room. The center said his daughter wasn't allowed to come in or even be in the facility. So much of health care is set up for the convenience of the staff and doesn't consider patient and family needs. For my son-in-law, seeing his daughter's face was a big motivation for undergoing surgery and the rigorous recovery process that was ahead. We can do a better job of matching goals and motives between health care providers and patients and families. It's hard to stay engaged with people who don't respect and value the choices and perspectives we bring to the relationship.

In the case I just described, perhaps the providers and staff believed that more patient engagement and choice would be "dangerous," because they could think it might compromise safety or the rules of their organizations with which they found comfort. Emerging evidence of family presence in these circumstances shows it doesn't require more time or impact safety. However, resistance to changing the way we've always done it is a natural human reaction. For that reason, there is an inclination to wait to see all the outcomes, and many will not make these changes quickly.

It helps to work in or with a system that has people on board who have experienced more inclusive and open policies and perspectives, where there have been innovators and early

adopters of more patient-/family-centered care. Others are stuck in the traditional practices that don't work anymore. In some cases, individuals will retire before they will change or until the expectations change, and they no longer have incentives that reward the status quo.

Q8. CFAH: Some health care contractors/consultants are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

MINNITI: Stories of success and progress are important tools to convince people that patient engagement is important. Seeing and learning about short-term gains, sharing data, and researching the impact of engagement is helpful. Having a positive experience will make a difference. Training of clinicians needs to emphasize more experiences providing patient-/family-centered care as well as valuing emotional intelligence as a clinical skill. And health care providers need more understanding about how difficult it is for people to make changes in health behaviors. They need a greater appreciation for the context of people's lives and the challenges they face.

In public and secondary schools, we need more education and conversations about health and wellness and health care. Each of us needs to understand that we are accountable for our own health and that the health care system is our partner, but we are responsible to participate actively.

Health behaviors do change, but significant changes may take a generation. Health education in schools can raise awareness for our children around health risks of certain behaviors. This can impact their families, who can change from the pressure of our children. We saw such astonishing change in smoking behaviors when there was growing unity around changing attitudes and knowledge about the dangers from tobacco. It took a multi-pronged approach, but things have really shifted. It makes me so happy to see fewer smokers and know that has contributed to people's overall longevity. My father and mother were not so lucky in their generation. We need to seek approaches to expand health knowledge, health literacy, and the value of healthy lifestyle choices, at all ages and in many settings of life. People are making choices every day. We all stand to gain or lose from these behaviors and choices.

GORDON K. NORMAN, MD, MBA

Gordon K. Norman, MD, MBA, serves as chief medical officer for xG Health Solutions, following prior executive leadership roles in the provider, hospital, health plan, and supplier sectors of health care, with a focus on quality improvement and population health improvement. Previously, Norman served as chief innovation officer for Alere, Inc., where he was responsible for product discovery, development, and management for the Alere Health Division. Prior to joining Alere, Norman served as executive director of PacifiCare’s dedicated disease management unit, providing disease management programs for the company’s health plans and Medicare demonstration programs. He also served as PacifiCare’s vice president of Health Care Quality, accountable for health and disease management, quality improvement, and medical informatics. Norman received undergraduate, medical, and MBA degrees from Stanford University. Following family medicine training in Maine and New York, he practiced in rural upstate New York and later, southern New Hampshire. He remains a board-certified family physician.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

NORMAN: The overall CFAH framework for patient engagement is very comprehensive, but it weights all 42 behaviors equally. A few actions in this set are probably more important markers of engagement than others.

The short definition in this first question is perhaps too short. Behavior is central to patient engagement, but there are some missing elements. An amplified or mid-level definition would add three other components to the CFAH short definition.

- Attitudinal or emotional commitment.
- Sustainment of engagement behaviors over time.
- Collaboration, that is, working with the health care team, caregivers, and community resources to improve health, support engagement.

These additional layers are associated with successful patient engagement. The last item requires that physicians change how they engage patients—this doesn’t receive as much attention as it needs.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

NORMAN: The long-term outcomes would achieve the Triple Aim of improved health outcomes, efficient care (including the patient being actively involved and/or adhering), and better patient

experience (including shared decision-making). Decisions are stickier behaviorally when people actively participate in making them with their care team.

Q3. CFAH: As a health care contractor/consultant, are there any types of behavior listed below that you think health care contractors/consultants have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

NORMAN: As previously mentioned, this definition is very comprehensive. Some clinicians might question the relevance of some of the actions, but the list overall captures engagement. Still, few people can get their heads around 42 behaviors.

For my group of stakeholders—health care consultants/contractors—it's helpful to distinguish between:

- Disease management contractors for health systems or employers that directly engage enrollees/employees, often outside the physician-patient relationship (although some strive to keep the primary care provider informed). The main barrier for these contractors is that they aren't individuals' clinicians, so they lack that leverage in getting and keeping people engaged.
- Care delivery contractors, like xG Health, that work directly with the health care delivery system to strengthen how it engages patients. We help physician organizations and delivery systems design and implement patient engagement solutions (as well as other care design and delivery issues). In this capacity, we have expertise and services to offer in all 10 of CFAH's engagement challenges.

Increasingly, insurers are changing how they pay for health care, with more incentives and risk being placed on providers. Especially for health care providers that have downside risk in contracts, they must master patient engagement in all 10 areas of CFAH's framework or else pay a price.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

NORMAN: I've extensively reviewed behavior change research and patient engagement models in the literature. The [Information-Motivation-Behavioral Skills \(IMB\) skills model](#), sometimes called "Fisher and Fisher" for the researchers who developed it, is one that I hold in positive regard. This fairly simple model—straightforward to apply in care delivery—says relevant information coupled with motivation leads to behavior changes. Fisher and Fisher demonstrated its effectiveness in changing two behaviors that can be intractable: substance abuse and sexual behaviors among people infected with HIV.

People have to be trained how to apply information and how to change behavior. Information is necessary but not sufficient to change behavior about 80% of the time. But what do medical schools teach? Give patients information, and if they don't change, give them even more information. Repeat, and repeat again. If patients still aren't adhering, then use some type of "hammer," such as embarrassing or scolding them.

Also, motivation by itself isn't sufficient to change behavior. A person in the ICU after a heart attack is extremely motivated to change. But data indicate the changes aren't sustained. After 30 days, about 25-35% have stopped one or more medications. After a year, a majority has stopped one or more medications, and a sizable minority no longer takes any of the medications.

People need to know what to do, how to do it, and be motivated to do it. The IMB model is like a tri-legged stool—you need all three parts. The World Health Organization has recommended IMB as a preferred model for adherence, which is a subset of patient engagement.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

NORMAN: There are multiple barriers: environment, circumstances like health literacy, and more. The human condition is the foremost. We're flawed, irrational creatures. Habits are particularly enduring, and bad habits are the hardest to break. Emotions often overpower intellect as determinants of our behaviors. Long-term, important health goals are easily undermined by short-term gratifications that seem trivial by comparison.

These barriers have been studied, and while some effective approaches to dealing with them have been developed, this is not yet an emphasis in medical education or most clinical training, leaving providers suboptimally prepared to engage patients despite the high credibility and trust which typically accompanies the patient-physician relationship.

Q6. CFAH: To what extent do you think that efforts by health care contractors/consultants can reduce these barriers/increase the capacity of people to engage?

NORMAN: Disease management contractors with health plans or employers can impact engagement among enrollees/employees. They can get better results with the IMB model, use of behavioral economics in insurance benefit design, and changes in the worksite or care environment. For example, Kaiser Permanente is now designing buildings with staircases in the center of hallways and the elevators at the end. The design makes stairs the easier, quicker path to go to a different floor.

External disease management programs, though, cannot get the same engagement outcomes that a delivery system (i.e., providers) can if it fully leverages the patient-physician relationship. This relationship is almost sacred. It's confidential; people are putting their life into the caregivers' hands. They are exposed, vulnerable.

For this reason, delivery systems get the best engagement results if they have systems to support and encourage patient involvement in their care. Clinical systems are needed to support engagement because even "good" physicians inconsistently deliver optimal care unless they have systems to support that process. Unlike humans, systems don't forget, and they aren't pressured to see a lot of patients. Even in health systems with high quality ratings, wide variation exists among clinicians, even for a single diagnosis or procedure.

Electronic health records (EHRs) are part of this evolution toward patient engagement systems. EHRs are used to primarily support documentation. Now they're being used to prompt workflow, provide protocols, and guide both providers and patients in managing care based on evidence-based guidelines. xG Health integrates EHRs in the design of systems to support consistent delivery of evidence-based care.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

NORMAN: Patient engagement gets universal lip service, but some of it's rather glib. If you talk about "patient engagement," heads nod. The field is gradually evolving. "Patient compliance" used to be the going term and now it's "patient adherence." "Compliance" infers hierarchy,

presuming that patients should do what their doctors tell them. Still, contractors' actions can be inconsistent with what's established to be effective in patient engagement.

The CFAH Framework could be used to assess engagement, and such performance measures would prompt changes in the delivery system. Ideally, quality measurement systems will eventually track and report individual clinicians in terms of patient engagement.

Q8. CFAH: Some health care contractors/consultants are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

NORMAN: If there are consultants or contractors that don't believe in patient engagement, I don't hang out with them. To convert them, you'd need to acquaint them with the literature, or perhaps some case studies from the literature, about the degree to which engagement makes a difference in outcomes. You can make a strong evidence-based case. It doesn't have to be taken on faith.

But the converted may not alter how they do things. This goes back to the basic human condition. Just knowing the right thing to do doesn't mean that it will translate into action. Whether for patients or providers, engagement is not a simply rational exercise. The non-rational elements have to be in play.

If we're going to engage patients, we have to change clinicians' behaviors, which is no easier than the general population. We call it "clinical inertia." When Geisinger Health System started tracking the recommended practice of routine annual foot examinations for diabetic patients, they found only a 60% completion rate. The solution was creating a system to embed foot exams into routine care processes when staff would take diabetic patients into the exam room. Along with creating prompts, Geisinger trained nurses to examine feet when they weigh patients, get patients to the exam rooms, and take blood pressure. The delivery rate is now 99%, and even the physicians who resisted the initial change now support it.

Don Berwick, the former head of the Institute for Healthcare Improvement and administrator of the Centers for Medicare and Medicaid Services, once wrote about all-or-none measures for quality. The premise is that patients want the right care 100% of the time, not 50% or 75% of the time. Geisinger applied this principle and picked nine measures that constitute ideal diabetes care based on incontrovertible evidence. They started measuring individual clinician performance in a way that if the physician missed just one of the nine, then s/he scored a zero. When Geisinger started, they found less than 3% of patients received all nine components of ideal care. Now

about 40% of patients with diabetes receive all nine, with the best medical practices achieving 60-70% adherence. Because it's recognized that some diabetic patients will continue to smoke, Geisinger is unlikely to achieve 100% in the near future, but this case shows that dramatic improvements are possible when clinicians are highly motivated to improve quality and rely on team-based care and support systems to create new approaches to care delivery.

Mature delivery systems must find more ways to alter physician behavior, especially because the physician-patient relationship is the most underutilized but powerful engagement leverage point. Geisinger's approach underscores this. Primary care physicians in its system have only two jobs. The first is to work with therapeutically complex patients whose situations require their deep expertise and analytical skills. The second is to enhance their relationship with patients. Non-physician caregivers provide all other patient care, with the primary care physician coming in at the end of the office visit to build that trusting relationship so that it's strong when patients need more intense care or when patients need to make health behavior changes that depend on high patient engagement.

JANICE M. PROCHASKA, PHD

Janice M. Prochaska, PhD, is the president and CEO of Pro-Change Behavior Systems, Inc. Pro-Change is committed to helping its wellness partners enhance the health and well-being of individuals and organizations through developing and disseminating behavior change management programs. Prochaska, a highly published author in the field of social work, leads a team of Pro-Change experts in health behavior and organizational change. Her research on change using the Transtheoretical Model led to a contract with Electronic Data Systems and the formation of Pro-Change in 1997.

Q1. CFAH: Here is the CFAH definition of patient engagement (PE): “Actions people take to support their health and benefit from their health care.” What’s missing from this definition? What would you add, subtract, or word differently?

PROCHASKA: At Pro-Change, we consider patient engagement on several levels. One way we support engagement in health is by reaching out to people to engage them in behavior change and health programs, by recruiting participants, by working on retaining their participation, by connecting with them regularly in order to help their progress, and by celebrating when they are having success. So in general we view engagement as more of a continuum:

Reach → Recruit → Retain → Progress → Success → Sustain.

While we are seeking to engage people in healthier living, we also want to engage people to see the benefits of participating in the change process. So even if the pressure to change is coming from an external source like an employer, we ideally want people to have ownership of their change process.

We also regard an engaged patient as someone who is a proactive health consumer. To that end, we have designed programs to help people get ready to make informed health care choices, share decisions with their providers, engage in healthy practices, and be responsible about health care costs. So this is more along the lines of how people can engage with their health care.

All of these activities cost money and time. So we believe it is important to assess a person’s readiness to engage. Once we get a sense of where they are at—not ready, getting ready, ready—then we help individuals progress so they can be more proactive with health care choices and behaviors.

Q2. CFAH: If a person is engaged in their health and health care, what difference does that make? To whom?

PROCHASKA: Being more engaged in health and health care has the potential to save money for individuals, their families, and communities. Engagement improves well-being. Productivity and presenteeism in the workplace is improved. And society benefits. Engagement offers many levels of benefits.

Q3. CFAH: As a health care contractor/consultant, are there any types of behavior listed below that you think health care contractors/consultants have more or less credibility to address?

Find good clinicians and facilities

Communicate with clinicians (doctors, nurses, others)

Organize care (appointments, records, referrals)

Pay for health care

Make treatment decisions

Participate in treatment

Make and sustain lifestyle behavior changes

Get preventive health care

Plan for the end of life

Seek health knowledge

(This list is from the [CFAH Engagement Behavior Framework](#).)

PROCHASKA: Right now, we are working on the engagement challenges listed in the Engagement Behavior Framework in some way. In fact, our Proactive Health Consumer program addresses all of the challenges listed. We do ongoing research about how to support lifestyle and health behavior change. Funding from the National Institutes of Health and others like the Centers for Disease Control and Prevention support both our behavior change and our proactive health consumer studies and initiatives. Then Pro-Change works through a variety of wellness partners that license and distribute our work through health plans, employers, providers, and the government.

Community health centers are one of the users of our programs. Some self-insured employers have also adopted our programs to use with their employees and their families. Primary care practices and accountable care organizations are interested as well.

Q4. CFAH: What are some interventions that you've heard of that show promise in helping people to engage in their health and health care?

PROCHASKA: Lately we have been developing our proactive health consumer area. We also keep developing more lifestyle management programs. These all show promise. We have ongoing interest from partners like the YMCAs, the American Association of Family Practitioners, and new clients like Healthstat, Paradigm, and Breakthrough.

Our programs are designed to speak to people where they are at, to respect where they are at: not ready, getting ready, ready. People need to be listened to and to feel like they are understood.

By basing our work on a self-assessment of someone's readiness to do a healthy behavior, we can then tailor change strategies right for them. This assessment of readiness goes beyond the assessing stage and helps someone explore the pros and cons of making a change, the processes they are using now to see what is and is not effective, and the confidence to do so. Our assessments aim to be specific with regard to behavior and situations.

Q5. CFAH: What do you see as the greatest barriers to patients being more effectively engaged in their health?

PROCHASKA: Some people just don't know how to change their behavior, or they may be demoralized. Or they think this business of health care is the doctor's job—that they already have enough to worry about.

At the same time we do recognize that some providers don't want more involvement from patients; instead, some clinicians just want patients to follow directions. And many clinicians are simply used to being in charge. Values and preferences of patients are often not on the table for discussion. For example, when I had recent foot surgery, after four weeks my doctor wanted to know if I was happy. I said it was hard to be happy because there were still some things I couldn't do yet like play tennis or go for a walk. But my doctor just wanted me to acknowledge that I was happy with his surgery and care. So he was worried about measuring his skills, and I was measuring my life. We had different criteria for quality.

Q6. CFAH: To what extent do you think that efforts by health care contractors/consultants can reduce these barriers/increase the capacity of people to engage?

PROCHASKA: We have been so impressed with some of the work at community health centers. For example, change activities within some [centers] are designed to support healthy pregnancies and work on healthy lifestyles. The direct feedback about these programs is very positive. We have created programs that patients like using and appreciate.

When Pro-Change started its research on how people change behaviors and began to define the stages of change, we started with smoking because it was the easiest to study and measure. Either you are smoking or not.

We wanted to learn how people changed on their own. We learned that how they change depends on many factors; people did different things at different times (or stages). Then we began to apply what we had learned about stages of change for smoking cessation to other areas, like exercise, weight management, medication adherence, depression prevention, and stress management.

Q7. CFAH: How would you characterize the general attitude of your colleagues/constituents toward patient engagement—its importance, the extent to which it is their concern, etc.?

PROCHASKA: We hear the most challenges of engagement around getting people to use behavior change programs. This is the problem that many health care stakeholders want to solve. So employers or health providers are trying incentives and penalties, or sticks, to motivate adoption. We hear that some health insurance premiums are being tied to health status. Some are trying to find ways to inspire change by making it more fun with games or competitions between teams.

At the end of the day, there is a growing recognition that we need people to take better care of themselves. Too much money is being spent on the consequences of unhealthy choices and on health care. We don't think that patient engagement is just the flavor of the week. The concept of how we can take more responsibility for our health and health care is not going away.

Q8. CFAH: Some health care contractors/consultants are still not persuaded that engagement is important in achieving better outcomes. What would convince them PE is important—i.e., evidence, examples, regulation, programs—or would persuade them to pay attention to/change their own behavior to become more involved?

PROCHASKA: I heard an interesting statement last week that the Affordable Care Act is going to make physicians sit down and start to listen to their patients more. That since they will be serving more patients and more diverse patients (some who may not have had health insurance before), that the understanding and knowledge base of both individual and population health management will be impacted. I thought that was fascinating. I hope it is true.

The new health insurance exchanges in particular will bring new people into the picture too. They could also bring challenges and new attention to how to best engage patients in their health and health care, how to best support behavior change. These new policies and more

access to care will put great pressure on clinicians. They will need help with matching interventions with the readiness of patients.

We see that there is a need for something like a clinician dashboard—and we have developed one. It lists patients' lifestyle health risks, shows their stage of change, and recommends evidence-based, stage-matched strategies to support change. The recommendations to clinicians are based on individual patient assessments. It seems like movements to improve health care quality are going to blend together in the future with activities to support people's engagement in their health and health care. These will be interesting times ahead.



Engagement Behavior Framework*

What is the full range of actions individuals are now expected to do if they are to optimally benefit from their health care? The CFAH Engagement Behavior Framework assembles a comprehensive list of measurable behaviors that individuals and/or their caregivers must perform in order to maximally benefit from health care.

Identifying and then measuring specific behaviors is the most effective way to drive quality improvement efforts. To borrow a phrase from that movement, “what gets measured gets done.”

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)

Engagement Behavior Framework

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
- 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 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

* 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)

Here to Stay

What Health Care Leaders Say About Patient Engagement