What Do Patients + Families Want From Patient Engagement?

A brief written for attendees of the Gordon and Betty Moore Foundation Convening on Patient and Family Engagement

February 2014
Thomas A. Workman, Ph.D.

Co-edited by:
Dave deBronkart
Casey Quinlan
Jeanne Pinder
# Contents

**Executive Summary** ................................................................. 3
Purpose ........................................................................................... 3
Methods ....................................................................................... 3
Findings ....................................................................................... 3
Themes .......................................................................................... 3

**What Do Patients and Families Want From Patient Engagement?** ........ 4
Purpose .......................................................................................... 4
Method .......................................................................................... 5
What We Learned ........................................................................ 7
Major Themes From the Responses ................................................ 8
Health Care Organization Design and Operations .............................. 12
Conclusion and Implications for the Convening ................................. 16

**Feedback From Convening Participants** ........................................ 19

**Commentary From the Patient Co-Editors** ..................................... 20

**Appendix. Questions for the Open Inquiry of Patients and Family Caregivers** ................................................................. 24
Executive Summary

Purpose
This brief provides background information for those convening to develop a roadmap and set of strategies that advance the research and practice of patient and family engagement (PFE). In doing so, the group will be working toward a vision of PFE as developed by the broad range of participants. The purpose of this brief is to help inform the vision with the patient and family perspective, to ensure that it remains at the center of the discussions.

Methods
Patients and family caregivers from a variety of organizations and online networks responded to five open-ended questions about their health care experiences. The purpose of these questions, which were informed by the Patient and Family Engagement Framework (Carman et al., 2013) and extant literature, was to identify the core outcomes of patient engagement efforts that matter most to patients and families. The inquiry was not intended to be a representative sample. Seventy-nine unique responses were collected. The co-authors analyzed the responses to determine emerging themes related to patient and family needs and desires.

Findings
As a whole, responses were varied in their focus and emphasis, yet were consistent with the Framework and other existing expressions of patients and family members in blogs, online discussions, conference presentations, and published literature. Regarding PFE in direct care, the majority of respondents expressed that an active, collaborative role is essential to produce safe and appropriate care that accomplishes the outcomes that matter most to them, such as returning to work/family activities or enjoying a good quality of life.

Respondents also expressed the need for patient and family involvement in health care delivery governance, and health system policy making. However, respondents indicated concern that clinician and medical staff attitudes and organizational barriers limit the degree of patient and family participation needed for successful engagement.

Themes
Four themes emerged as essential elements to patient and family engagement in direct care:

1. Mutual Respect: Patients and families want the respect they have for clinicians reciprocated; they want clinicians to value their input and, where feasible, honor their expressed desires.

2. Education: Patients and families want to be fully informed of all aspects of their condition and care and wish to share information.

3. Relationship: Patients and families want a personal relationship with clinicians; they want to be known by their clinicians as unique individuals.

4. Equal Responsibility: Patients and families recognize their own responsibility in being active participants in their health and health care.
Three themes emerged as essential elements to patient and family participation in health care organization design and policy:

1. **Input**: Patients and families provide suggestions on all aspects of organizational design and policy to create systems that are truly patient-centered.

2. **Feedback**: Patients and families give feedback about their care experiences to correct problems and transform care.

3. **Transparency**: Health care organizations make all aspects of the system transparent for patient and family input and feedback.

A set of implications emerges as a charter for those developing engagement strategies. These include:

- Removing attitudinal and system barriers that limit or deter clinicians or staff from fully engaging patients and family members in direct care or health care organization design and policy.

- Providing incentives to clinicians and staff for engaging patient and family input and feedback.

- Creating uniform open access to medical records for patients and family members and making costs of care transparent.

- Communicating stories of successful engagement resulting in improved care delivery or health outcomes to a wide audience.

**What Do Patients and Families Want From Patient Engagement?**

**Purpose**

The need for a clear expression of the patient and family perspective is crucial to guide the efforts of those gathering to advance research and practice in the field. This brief provides background information for those convening to develop a roadmap and set of strategies that advance the research and practice of patient and family engagement (PFE). In doing so, the group will be working toward a conceptualization of PFE as developed by the broad range of convening participants. The purpose of this brief is to help inform the group of the patient and family perspective, to ensure that it remains at the center of the discussions.

Creating a single representation for the diverse population of patients and family caregivers is obviously challenging. Patients are not a homogeneous group. There are, however, a growing number of clear patient and caregiver voices that, through blogs, published books and articles, conference presentations, and online discussions, express an urgent need for incorporating patients and caregivers more meaningfully into all aspects of health care. Yet, these voices account for only a small fraction of the total population of patients and caregivers. And even these few spokespersons vary in their own vision of what patient and family engagement can and should be.
To expand beyond these few voices, we invited patients and family members who follow or belong to patient associations to share their own answers to several critical questions. This report describes the goals and methodology used to collect the responses, expresses the themes that emerged from the responses, and summarizes our conclusions and implications for the broader collective of stakeholders developing engagement strategies. We also provide a commentary by the patient co-authors and a summation of the discussions concerning these results with convening participants in a series of webinars held in January 2014.

Patient engagement remains a topic that lends itself to the application and expression of various positions and perspectives. We hope that the insights provided through this briefing can be used to inform the generation of a set of strategies that move the field forward—uniting, rather than further dividing, the work in the field. Further, we hope that conveners will find in this briefing a patient- and family-driven charter that helps direct the practice and research ahead as we work toward a truly patient-centered health care system.

**Method**

To obtain patient and family caregiver input, we sent an invitation to respond to five open-ended questions through patient organization e-mail lists and social media. The questions were designed to elicit patient and family experiences, desired changes to health care, and the patient and family role in health care. A complete description of the methods used is available at the convening Web site.

**Question Development**

First, we focused on the Framework for Patient and Family Engagement (Carman, et al., 2013) and its endpoint of partnership as the point of inquiry, asking participants to describe experiences where they did or did not feel like a “partner” with clinicians or health care organizations. Second, we aimed to ensure that the questions inquired about all three levels of engagement, as described in the Framework—from direct care to organizational governance and infrastructure to public policy. Draft questions were reviewed.
by experts, tested with patients/family members, revised, and then approved by the AIR Institutional Review Board.

**Respondent Recruitment**

To elicit responses from the broadest base of patients and family member knowledge and experience, we used a multi-tiered recruitment approach:

1. AIR staff members who were not connected to the project were asked to send invitations to friends and family members.

2. Organizers from several patient organizations—The Society for Participatory Medicine, the National Health Council, the Genetic Alliance Registry and Biobank, and Consumers United for Evidence-Based Medicine—sent invitations with links to their memberships.

3. Invitations were spread across social media with the assistance of patient co-authors and others. The link to collect responses was open from November 19 to December 20, 2013.

We captured a total of 79 unique responses. The vast majority of participants answered all five questions.

**Response Analysis**

We began by using qualitative analysis software to search responses for commonly used words and phrases. The most common words or concepts expressed across responses are identified in Figure 1, which represents the frequency of the use of each word.¹

**Figure 1. Most commonly used words/concepts across responses**

We next developed a coding scheme to reduce the data into categories based on frequently mentioned concepts. We then began an iterative process to refine the themes and determine implications for the convening.

**Feedback From Convening Participants**

An important part of the process was obtaining preliminary feedback from convening participants through a series of webinars conducted on January 15, 22, and 23, 2014. Feedback from the participants as well as the Moore Foundation and convening steering committee are incorporated into these findings and detailed later in this paper.

¹ The larger words appeared more than 90 times across responses, while the smallest word appeared 10–15 times. In many cases, words of similar nature were condensed to a single word for the purposes of counting (e.g., the word “heard” representing words related to the behavior of listening to a patient or caregiver needs or suggestions).
What We Learned

Patients and families see their active participation as essential to receiving safe, affordable, high-quality health care. The majority of the responses indicated that active participation by patients and family members was essential to improving the safety, affordability, and quality of health care. Their participation was identified in two broad categories:

1. **Participation in direct care:** Partnership between patients and clinicians where both parties exchange information and work collaboratively to make care decisions and improve health outcomes.

2. **Participation in health care organization design and governance:** Patients and family as key advisors to health care organizations to improve care delivery and create patient-centered processes and policies.

Participants were most able to articulate the specific elements of partnership with clinicians in the direct care setting. A slightly smaller number of responses identified elements to participation in health care organization design and policy. Participants were far less articulate on the specific partnership with public policy makers, although they identified a number of areas where policy change was needed to advance improvements in health care.

Respondents expressed a need for specific changes to health care delivery, but were less able to articulate the mechanisms for these changes. A number of responses offered very specific changes to the health care system, such as open access to medical records and costs or notification systems when physician appointments are running behind to avoid time lost waiting.

However, respondents were less able to articulate the means or mechanisms that could produce these changes. Several participants identified broader structural or attitudinal barriers that kept the system from being more aligned with their own wishes, yet did not include in their response how patient and family participation could overcome those barriers.

Patient and family experiences with health care delivery is a significant contributor to improving health care. Respondents shared a large number of stories, many of which illustrated positive and negative experiences that illuminate key aspects of health care system design or policy that produce unsafe, inefficient, or unproductive care. Patients and families see these experiences as essential opportunities to guide improvement.

Patient and family partnership with clinicians and health care organizations is a means to the larger end of achieving desired health outcomes. The responses consistently expressed engagement in direct care and governance or infrastructure as necessary to achieve care that meets the needs and wishes of patients and family caregivers and the outcomes that are most important to patients/families.

Several responses were adamant that engagement or partnership for its own sake was both unwanted and unnecessary, but was critical in order to ensure that the outcomes of care were aligned with, and driven by, patient and family desires.
What Do Patients and Families Want From Patient Engagement?

Major Themes From the Responses

Several themes emerged from the responses that lend more clarity to what patients and family want from engagement efforts. Since most of the responses surrounded patient and family engagement on the direct care and organizational design and governance levels, we have organized themes for each of these levels.

Direct Care

The majority of responses focused on the direct care setting and specific elements that patients and families saw as critical to successful care and treatment. However, while these themes are placed in the direct care context, it is important to acknowledge that patients and family expressed a clear understanding that larger organizational policies and infrastructure enable or disable many of these elements. These themes are represented in Figure 2 by the frequency and emphasis of each theme.

Patients and caregivers desire a mutually respectful relationship with clinicians, providers, and staff where patients and caregivers are fully informed and share equal responsibility for the accomplishment of outcomes. While respondents fully articulated likes and dislikes about their direct care relationship, fewer responses provided suggestions about how to create desired experiences, although we note several in each theme. These themes are fully outlined with example responses below in the order of their frequency and emphasis.

Figure 2. Response themes concerning participation in direct care

Mutual Respect

Respect is a two-way street. While patient respect for clinicians and other health care professionals is essential to a successful partnership, respondents also expressed that respect of clinicians and staff for patients and family is equally critical. Said one respondent,

“I want the doctor and his staff to set a tone of mutuality and respect, starting with ease of communication as to understanding the doctor’s special skill sets, the setting of appointments, and the personal connection the moment the patient enters the system or facility.”
Specifically, respondents wanted respect from clinicians, administrators, and staff for their own knowledge, experience, and input. Stated one respondent,

“In any partnership, respect is the key to success. I respect my doctors’ expertise, and they respect my input as the patient.”

Respondents provided a broad range of examples of respect or disrespect including:

- Clinicians who did (or did not) solicit or acknowledge an opinion or information shared by the patient or caregiver
- Care delivery organizations that did (or did not) consider the patient and caregiver’s schedule and needs when making appointments
- Clinic or hospital staff who respected (or did not respect) a patient or caregiver’s need for information, explanation, or conversation regarding a treatment, test, or procedure
- Clinicians who respected (or did not respect) a patient or caregiver who disagreed with or chose not to follow a recommendation

Education

Like respect, education was seen as a two-way street. A number of responses identified ways in which the patient or caregiver could educate the clinician and staff about what they’ve learned works best, or the information about their condition or a treatment that they discovered through their own research. Respondents indicated that their providing information was also crucial to achieving the outcomes that mattered most to them. One parent gave an example of the kind of input solicited by hospital staff:

“We were asked what had worked for our son in the past in things such as pain control, sleeping positions to facilitate breathing, and what our goals were for this hospitalization.”

“I wrote a letter to my health care team before I went into the hospital. It was my attempt to personalize my care and introduce myself to my caregivers. I also made requests and expressed my expectations for safety measures. I knew it would either be ignored or embraced, and, amazingly, it was embraced by my health care team. It had exactly the impact I imagined, and all of my expectations were met . . . including them welcoming and accommodating my husband to stay overnight and be my advocate, removing my urinary catheter in recovery before I even woke up, meeting my pain management needs, and so many more things.”
Patients and family need a variety of information from clinicians and staff. Their stated needs included:

- Their condition and its implications and prognosis
- The care they were receiving
- The treatment or testing options that were available to them
- The outcomes they could expect, both benefits and potential risks
- What role they could play in accomplishing those outcomes, including managing their care
- Information about the costs of care

One respondent stated:

“Educate to engage; patients want to know. Teach them so that they can be effective in their care management.”

And another respondent got right to the point:

“Prices for standard procedures and treatments posted on the friggin’ wall.”

Information and education should be provided in a way that is literacy appropriate and easily understood by the patient or caregiver, free of technical jargon. Said one respondent:

“I would like to see greater sharing of info without using technical jargon. I realize it’s easier for a doctor to use technical terms ‘cause that’s how he sees it, but the patient and caregiver don’t always understand—and need it all in simple terms.”

A number of respondents identified their access to their medical records as a specific example of the kind of information they needed.

One respondent wrote:

“Transparency—access to my own records over time, so I can map my own process.”

Another stated,

“A clinic would share all information about a patient with the patient. No information asymmetry in this partnership.”

The ability to share medical records with other clinicians for the purpose of coordinated care. Several referred to this directly as “blue button,” a technology that enables patients to download their personal health records so that they can be shared with other providers. Stated one respondent:

“I would like to see the ability for the various medical professionals involved in care to be able to immediately see what other professionals have in their records about an individual (me).”

Respondents also expressed a need to be better educated about the broader health care system, including how to navigate the many complexities surrounding access to care. Respondents shared stories of long waits to get appointments or having to work around a system to get the care they needed through trial and error, rather than through knowledge.
Several respondents offered suggestions on how information and education could be provided in the direct care experience.

- Clinicians and staff explaining and informing patients and caregivers as a common practice at all visits
- The use of patient advocates and navigators
- The transformation of waiting areas into learning and information centers

“...I did not go to medical or nursing school. I am not a trained health care provider. Unless someone encourages me, educates me, demonstrates for me, I will not know how best to be engaged.”

**Relationship**

Patients and family caregivers clearly expressed that the direct care experience is centered in a relationship between patients/family and care providers.

**A number of participants framed their responses around the concept of relationship,** starting with sentences like, “I have a great relationship with my gastroenterologist” before describing the care experience.

**Patients and caregivers are known by their clinicians and health care organization.**

One respondent stated,

“All of my doctors know me. They know my name, that I have two children, and that my husband likes to fish.”

Another respondent stated the importance of being known by the clinician as far more than a “feel good” experience:

“Developing a relationship with a primary care provider has been shown to lead to better health outcomes because the provider is able to learn more about the patient as an individual and can spot things that are abnormal for that patient specifically.”

**Use of common conventions or courtesies.**

Respondents often cited common conventions that developed or maintained a personal relationship, such as the clinician and staff greeting the patient in a friendly manner, asking questions, and listening to responses without interruption.

“We especially value the time, attention to detail, and personal relationships we have developed. Being known, remembered, and recognized as engaged patients are critically important to us.”

**More time.** Responses emphasized having sufficient time to discuss issues during the visit without feeling rushed. Several participants commented they often felt the clinician was working to end the interaction and move to the next patient, making them appear uninterested.

Empathy. Respondents also noted the role of clinician empathy and understanding for the fear, frustration, and other negative emotions of the patient and caregiver. Stated one respondent,

“Be kind . . . . I am not at my best when I come to you.”
Participants were less articulate about ways in which this relationship could be fostered, though many offered theories on why it did or did not exist in their own experience. Some respondents blamed the larger health care system, citing the tight schedules and heavy patient loads that clinicians face. Others said the issue was attitudinal, noting that clinicians who valued the relationship with their patients and families found a way to foster it.

Equal Responsibility

Patients and family caregivers consistently expressed their own responsibility for becoming an active participant in direct care. Responsibility was defined in the responses in a number of ways:

- Preparing for clinical appointments by having information and questions ready
- Seeking additional information from a variety of sources
- Taking an active role in their self-management

“...just as my doctors do. I bring my knowledge, research, experience, and questions.”

Passive patients are a problem. A number of respondents identified “passive” patients as detrimental to direct care. Passive patients were often described as those who were not working to improve their own health, were not sharing information with their providers, and were not taking an active role in making decisions. There was also a sense that passive patients did not communicate with their providers.

Some expressed frustration that organizational policies and procedures or individual clinicians, administrators, and staff did not always encourage or embrace patients and caregivers who took this responsibility.

Others expressed delight in feeling that their attempts at taking responsibility had aided them significantly in their partnership with clinicians and organizations, which ultimately resulted in achieving their desired health outcomes.

Health Care Organization Design and Operations

Patients and caregivers also expressed a strong desire to help shape the health care delivery organization on a broader level by engaging with health care organizations. The goal of such involvement is to enable these systems to operate in ways that improve the care experience for a broader group of patients and caregivers and/or achieve the outcomes of interest to patients and families. Three themes emerged and are identified by frequency and emphasis in Figure 3.

Responses noted the benefits of active participation in organizational design and policy, and warned of the danger of not involving patients. Several respondents commented that only patients and family caregivers can truly define and operationalize patient-centered care for a care delivery organization, making their involvement essential for organizations trying to accomplish this goal.
Many responses in this area mentioned significant safety concerns, medical errors, and other potentially deadly consequences caused by medical staff at hospitals or clinics who ignored or dismissed the input and feedback from patients and caregivers.

Inclusion of the patient and family “voice” was an essential element in creating a safe and effective care delivery organization and system. The sentiment was expressed consistently and emphatically across the majority of the responses. One respondent stated,

“As someone who worked in hospital administration, we (and I) did not often value the voice of the patient, until I ‘WAS’ that patient (sic).”

Figure 3. Response themes concerning participation in organizational design and policy

| transparency | input | feedback |

Input

Respondents want to help create systems of care that reflect and enable the needs and outcomes of interest to patients and families. One respondent noted,

“Involv[e] patients at the VERY outset—ask patients for input into policies and procedures (sic).”

Several respondents referred to input as giving patients and family “a seat at the table.”

Patients and family members expect to see their input put to action. As one respondent stated,

“Close [the] feedback loop as soon as you can about what you did with our input.”

Another respondent was blunt:

“Until the patients are taken seriously and listened to, nothing is going to change.”

Respondents suggested mechanisms for organizations to receive patient/family input, such as:

- Patient and family advisory boards
- Policy committees
- State insurance boards

One respondent wanted to see a broader range of input mechanisms:

“Multi-modal inputs, from suggestion box via email, to Facebook and Twitter, to committees and workgroups, to blogs and newsletters.”
Patients expressed that patients and families providing input should be paid for their efforts. Said one respondent,

“I think recruiting real patients for these tasks and paying them to do a good job is essential.”

Regardless of mechanism, the overarching belief expressed across the responses was that care delivery organizations (and other health care system organizations) should “continuously invite and encourage patient input.”

**Transparency**

Respondents voiced a clear need for health care organizations to become more transparent. Respondents noted that many operations or policies of the health care system were unknown or unexplained.

Many of the responses related to this theme were short and lacked significant detail. While the respondents see transparency as an essential part of input, they are less able to articulate what it is they need to know.

Respondents listed costs for care, procedures and policies, priorities, and goals for projects as non-transparent. Example responses include:

“Operations should be transparent and patient input should be sought after and valued.”

“Transparency in records, costs, adverse events.”

“Process improvement should be transparent, easy to initiate by patients, and have transparent feedback and results.”

Transparency was connected to issues of safety, implying that medical errors were hidden rather than communicated to patients and family. Several long stories were submitted by patients/family caregivers about medical errors not being reported or addressed. One respondent wrote:

“There would be total transparency and accountability for health care harm and communications and conversations would not be shut down if there is harm.”

Patients engaged in organizational projects need goals and organizational infrastructure explained before meaningful input can be provided.

**Feedback**

Responses suggested that the experience of patients and family caregivers served as an important tool for health care organizations to identify areas for improvement. One respondent stated,

“I would like to see patients and families being able to openly and freely give feedback and share their stories of when it was done right, how it felt, and when it was done wrong, how it felt.”
Another said,

“What Do Patients and Families Want From Patient Engagement?

Do not quote, cite, or distribute

In the minds of the respondents, feedback serves two important purposes:

1. It enables health care organizations to learn, in real time, how patients and family caregivers are experiencing the results of their quality improvement efforts. Feedback becomes, in essence, a measurement for an organization to assess the practical implementation of its policies and procedures and to identify critical gaps.

2. The collection and processing of regular feedback from patients and caregivers also serves as a form of engagement itself. Patients and family member respondents seemed to suggest that providing feedback was seen as part of their role in helping improve health care, for both the organization and the broader system.

Only a very few participants offered specific suggestions on how patient and family feedback could be solicited (online surveys, written surveys, and in-person conversations). This indicates that most respondents are treated by organizations that do not have mechanisms in place.

A large number of stories shared by participants were feedback about a specific care experience. For example, one respondent provided feedback on hospital billing, based on her own dilemma caused by a bill arriving six months later. Others offered specific situations where clinician or staff recognition of feedback would have avoided negative outcomes, poor care, or a medical error. A number shared stories of feedback that was ignored by clinicians and negatively impacted the accomplishment of their desired outcomes.

Like input, responses echoed the sentiment that soliciting feedback from patients and family was meaningless if it did not lead to changes in the policies, procedures, or operations of the health care organization or broader system. Special emphasis was placed on organizations listening to and acknowledging the feedback they receive. For example, a respondent stated,

“Ask me what I want; make what I think are policies and etc. and actually use my feedback. Let me know how/what changes were made as a result.”

What Patients and Families Contribute

Across the responses, patients and family caregivers expressed what they believed they brought to health care systems. Figure 4 provides a graphic of the most commonly expressed concepts, arranged in size by frequency and emphasis.
Key points from the responses:

**Respondents emphasized strongly that patients bring a clear sense of the outcomes that matter most to them.** A large number of comments suggested that patients and family often come to health care expecting to achieve different outcomes than what the system produces.

**Patients and family offer a perspective on health and health care that offers important guidance to the health care system about priorities and goals.** Respondents suggested that patient and family perspectives about health care differ significantly from that of health care providers. For patients and families, health care is not the central activity of their lives; health care is a means to accomplish more significant life goals. Respondents indicated that this perspective is often lost in daily health care operations.

**Patients make health care humane.** Also interesting were the references across the responses to humanity; a number of respondents indicated the need for health care systems to regain human empathy and compassion, becoming less automated and regimented, treating people rather than diseases, and recognizing the human impact of health and illness on individuals and families. Patients and families believe that they provide that humanity by sharing their desired outcomes and the impact of the condition and treatment on their daily life and priorities.

**Conclusion and Implications for the Convening**

Overall, the responses to the open inquiry—much like the broader sentiments among patients and family caregivers being expressed across social media, conferences, online discussions, and published literature—suggest that patients and family caregivers consider their engagement to be an essential aspect of the health care system.

**They see their role as keeping the system focused on the health outcomes that are most important to patients and families.** They see collaborating with the system as a way to improve the quality and safety (and overall experience) of care. And yet, they say, they are often not treated as an essential part of the system.
The majority of the patients and family caregivers who responded do not wish to see themselves as supplicants to the health care system. They see themselves as partners who have meaningful, insightful, relevant input and feedback that play an important part in direct care, as well as overall health system organization, operations, and policy.

Several respondents felt that their own clinician or health care delivery organization was well on its way to recognizing and utilizing this essential partnership role of the patient and caregiver. Yet, others expressed despair and frustration at a system that seemed to ignore, disrespect, and disenfranchise patients and families. They added that the result of doing so had led to significant harm, discomfort, or inconvenience to the patient and/or family caregiver.

This seems to mark a widening gap, fraught with the risk of missed opportunities for positive change, in engagement between patients and the healthcare system. Clinicians and organizations that fail to close that gap—that fail to recognize the patient/family role—are not simply missing a key ingredient in the success of the health care system; they risk any chance at improving population health and health care. Patients and families see care that is directed “to” them or “for” them, rather than “with” them, as a significant threat to health care reform.

There are obvious limits to this inquiry, which is also why we insist this report cannot be representative of the entire patient and family population; rather, it provides a small piece to the larger puzzle. Most of the respondents appear to be highly activated patients, many of whom were connected to some patient organization as well as to the literature and conversations occurring on those listservs, conferences, and blogs. A more representative survey targeted to patients and family without such connections or personal activation might have yielded different responses.

Most significantly, existing attitudinal and system-based barriers must be explored and removed. Patients and family caregivers acknowledged a number of specific barriers, ranging from profit motives to litigation and poor medical training to pressure from health care systems interested in volume over quality. While respondents rarely presented health care professionals who did not demonstrate partnership as villains, there was a clear sense that some individual clinician, administrator, and staff attitudes and professional practices were problematic.

Most respondents believed that the cause for these attitudes and practices originated in the system itself, through such (suggested) mechanisms of poor training, missing or poorly implemented policies, or a lack of accountability for professionals’ attitudes and practices. One specific implication raised by the respondents was that rewards and incentives were needed to motivate clinicians and other medical professionals to embrace and encourage patients and family contributions.
We developed a set of tentative concrete steps, including these general baskets, for transforming the landscape:

- Address—through education, training, incentives, and organizational policy—the removal of attitudinal barriers on the part of clinicians, administrators, and staff to patient and family engagement.
- Emphasize input and feedback across all care settings.
- Provide patients and family members with information and education, including open access to costs and medical records.
- Focus on outcomes of greatest interest to patients and family.

**Stories of success when the patient and family role is fully utilized must be communicated as evidence that such a role is essential to health care.** Engagement strategies should build opportunities for the dissemination and communication of successful partnerships between patients/family and health care providers so that the patient and family role is valued, utilized, and celebrated.
Feedback From Convening Participants

We presented an earlier version of these findings, our conclusions, and implications to individuals invited to participate in the upcoming convening through a series of webinar conversations held in January. Our intent was to seek feedback from the group about what findings resonated or conflicted with their own vision and understanding.

Discussion in these meetings focused on representation. Did the responses truly reflect the majority of patient and family experiences? Several participants in the discussion stated that the responses resonated with responses they’ve received from patients and family members who are less activated. Others questioned whether the summation spoke only for those patients and family who were more empowered—and vocal—than the average patient.

Several patient and family advocates expressed a sense of disappointment in our summation of the patient and family vision. They argued that our conclusions did not go far enough to state the essential nature of patient involvement. Many of these comments have been addressed in this final version of the paper; we returned to the raw data to ensure that we had relayed responses accurately and emphasized their sentiments appropriately. In many cases, we adjusted our language in our conclusions so that the respondent voices as a whole fully reflected, when indicated, this belief.

The discussions expressed concern over the focus on the direct care setting when addressing patient engagement. Feedback often centered on the issues of the direct care experience. This suggests a need for the convening as a whole to place engagement in its broader context. We believe the responses suggest that while the direct care experience is the way in which most patients and families think about health care, there is a clear indication that those experiences are shaped by organizational and public policies. The patients and family members who responded to our inquiry were vocal about their role in shaping those policies. They suggest that engagement does not live solely in the domain of the patient—provider relationship.

The majority of feedback we received surrounded our conclusions and an early attempt to condense the findings into a single vision statement from patients and family, which we have since removed from this paper. It was evident from the feedback that a single statement could not possibly convey the breadth and variety of responses, or speak for an entire patient and family population. Instead, by providing a sense of what patients and family want from engagement, a broader vision and roadmap can be built upon by other key stakeholders.
Commentary From the Patient Co-Editors

In preparing for this convening, AIR recognized the importance of including the perspective of highly activated patient observers, in addition to the many established industry participants in the event. We’re grateful for AIR’s vision. Because our views are beyond the ordinary, they invited us to prepare this commentary.

AIR’s vision is aligned with the Institute of Medicine’s major 2012 report, Best Care at Lower Cost, which identified patient empowerment as one of the four cornerstones of the future of medicine:

Note the wording: anchored on patient needs and perspectives. Not “takes into account” patient perspectives, and not “must be cross-checked with.” Anchored on.

To us, this says it’s imperative that all players in the continuum of care—including and especially patients—examine what they mean by that, and understand:

- What is the patient’s view of how medicine should improve?
- What is the patient’s view of “patient-clinician partnership”?
- How will we know when we’re achieving it, and when we’re falling short?

We recognize that this is not easy: it is culture change—a substantial shift in authority and autonomy, enabled in part by access to information and driven in part by the need to do right by the ultimate stakeholder, the patient.

A core issue for this convening is that as in other cultural movements—for instance, feminism, or the civil rights struggle—the future cannot be envisioned solely by canvassing the dominant group; we must ask the “lesser” class, who await emancipation.

We found ourselves focusing on how levels of activation vary greatly. Some patients—people who’ve found themselves with a medical need—want simply to be well taken care of, without engaging in deep research and decision making. Others are like this respondent:

Can I just say I hate when healthcare providers use words like “patient engagement” and “patient empowerment”? It creates an us vs. them type dichotomy, and also implies that healthcare providers are 1) responsible for patient’s level of “engagement” and “empowerment,” 2) that patients aren’t “engaged” or “empowered” on their own, 3) that only health care providers can activate patients in that way. It is not something you do TO patients, it’s something you do WITH them. “Engage with” them—talk with them—it’s a two-way street. You can’t expect someone to be engaged if you’re not engaged with them. I get the feeling that health care providers think that patients are a problem they need to fix, but really all we want is to be treated as people. How would you talk to your mother, sister, best friend if they were going through this medical issue? That’s how I want you to “engage with” me.

Patient–Clinician Partnerships

Engaged, Empowered Patients: A learning health care system is anchored on patient needs and perspectives . . .
Engagement levels vary greatly, and it’s important to recognize that while most of the public doesn’t yet think this way, this project confirmed that the already-emancipated provide a useful preliminary view of what the future can be: they exemplify the IOM’s “patient needs and perspectives” as seen by “engaged, empowered patients.”

We talked a great deal about words: person-centered care or patient-centered care? Patients collaborating with providers, or acting in ways complementary to their providers’ actions, or patients directing their providers? “Family caregivers” recurred, even though we all know that not all caregivers are family members.

We also had heated conversations about whether “patient” was really the word we wanted, implying, as some suggest, a recumbent or supplicant position. We decided to keep it because it covers the most territory.

Reviewing the responses to this inquiry, we submit these observations to the convening:

- **Emancipated patients want voices at multiple levels:** direct clinical encounters, organizational policy and infrastructure, and, for some, public policy. This matches AIR’s (and colleagues) multidimensional model.

- **Patients want to be asked and they want to be heard.** The traditional paternalistic approach of “Here’s what you’re going to get” doesn’t work for engaged, empowered patients. “Nothing about me without me” is how activated patients see it. (Note that the phrase arose twenty years ago, in the disability movement!)

- **Patients want to know what’s going on**—even ones who aren’t particularly activated.

- **We want partnership, but it’s merely a means to an end.** It is the pathway to care that meets the needs and wishes of patients and family caregivers, and to care that understands and honors outcomes that patients and families say are important—to them.

There is no single answer or vision for all patients and caregivers. We must not assume that one size fits all; in fact, patient-centered care demands that we listen to each patient’s needs and preferences.

But it is equally important to assess and grapple with the forces that drove this convening—a sense that individual health care, and the marketplace writ large, can each devalue the patient.

In closing, we urge that this convening recognize the following:

- **Many patients are already engaged.** The health care system can learn from meeting them where they are, since that will accelerate system-wide engagement.

- **Already-engaged patients can be a powerful asset for building engagement** throughout the broader patient community—which is “all the people, everywhere.”

- **Patients are the industry’s core; their needs are its purpose.** While some practitioners earnestly view patients as supplicants at the altar of miraculous care, that era has passed.
The science of medicine can never be placed above the human component of care. Nothing about us without us.

Many patients—including some who aren’t very activated—want to partner with their care teams. They want to understand as much as they can, be asked, be heard, be part of the process. If health care facilitates that partnership, making it the bedrock of the care continuum, everybody wins.

Thank you for considering what patient-centered means. Please: Let patients help, in every way possible.

Casey Quinlan
Jeanne Pinder
Dave deBronkart
Bibliography


Appendix
The Open Inquiry of Patients and Family Caregivers

Direct Link from Participant Invitations:
We want to know YOUR vision of ideal engagement!

The AIR Center for Patient and Consumer Engagement is gathering thoughts from patients and caregivers across the country.

We want to know what you think about “patient engagement”—which means efforts by doctors, hospitals, and other health care providers to involve you in health care decisions and policies.

Your thoughts and needs will be used to help a group of engagement specialists who are gathering in February, 2014 to create a plan to involve patients in their health care. We want to hear what you think people working on patient engagement activities should be focusing on. This survey was developed and reviewed by patients like yourself to ensure that it best captured your preferences and insights, and was approved by the Institutional Review Board at the American Institutes for Research.

The link below will take you to a secure Web page where you can record your answers to five questions. The entire process should take you around 10 or 15 minutes. Your relationship with your doctor is not at risk. We may use part of your answers as examples, but will not identify you. You are welcome to get a copy of the paper by clicking this option at the end of the survey. Your name, mailing address, or e-mail will be collected separately from your answers to the questions.

If you have any questions or concerns about this survey, you are welcome to contact the AIR Institutional Review Board at (202) 403-5000 or Tom Workman at (202) 403-6443 or tworkman@air.org.

The survey is for individuals who are 18 years of age or older, and who have received direct health care (or served as a caregiver to a friend/family member who received direct health care) in the past 12 months. If either of these criteria do not apply to you, please do not fill out the survey. We deeply appreciate your willingness to add your voice to the process of creating truly patient-engaged health care for everyone.

I am 18 years of age or older and agree to take the survey
Link to the Survey

Thank you for participating in this brief survey! Please record your answers to the five questions below and hit SUBMIT.

You may write as much or as little as you wish when responding to these questions.
There has been a lot of discussion in health care about patient engagement, which is defined as a partnership between patients and their family members on the one hand and clinicians, health care organizations, and even public policymaking bodies on the other. Many companies and organizations are developing ways to engage patients and families in health care. We want to know what engagement activities you would find most valuable.

1. Please describe a time when you, either as a patient or as a caregiver, had a direct care experience (for example, at a doctor’s office, hospital, clinic, or emergency room)? To what extent did you feel fully engaged (treated like a partner) during this experience? What happened that made you feel this way? Describe the ways in which you felt you were treated like a partner. Describe the ways in which you felt you were not treated like a partner.

2. Imagine that you have the power to change anything you want to about our health care system. What types of things would you like to see happen? What types of things would you do in this improved system? What types of things would clinicians do in this improved system?

3. In this ideal system, what role, if any, would you like patients to have in helping change policies and procedures that improve care for all patients?

4. How do you think health care organizations can work with patients as partners to improve care for all patients? What would a partnership between a patient and a clinic or hospital look like?

5. What suggestions would you give to those who are designing patient engagement strategies and activities that would best meet your needs as the person being engaged?