

# Patient and Family Engagement: A Framework for Developing Interventions and Policies

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We got invited to submit a publication to Health Affairs in 2013 that really asked us to think, “How do we think about patient and family engagement? How can we think about what are the major issues in this area?” We've been thinking about this concept for a long time, and in all of these varying kinds of definitions, and in all the ways in which different kinds of people had been thinking about it. I'm happy to say that we created a framework that has gone viral, and it's been adopted and used by a lot of folks.

A lot of people said to me afterwards, "Gosh, I'd kind of been thinking about that. I wish I had done that." We don't take full credit for it; we built on a huge body of our colleagues' work, creating something that I hope addresses some of the things we've been talking about today.

One of the things we are talking about today is how important a clear conceptualization of patient and family engagement is in order for us to develop and assess the impact of interventions, how to measure the outcomes of those interventions, and to understand the mediating and moderating mechanisms towards some of the outcomes. So, it was really important exercise for us.

## Framing Patient and Family Engagement

- Our definition of patient and family engagement
- Reasons for a framework
- Elements of the framework: continuum, levels, and factors
- Employing the framework to engage patients and families in the uptake, understanding, and use of research evidence



For the purposes of this symposium, I want to spend a little time describing some of the elements of the framework, and then Tom will talk in a lot more depth about some lessons learned in some key areas. I am also going to introduce a roadmap that we created which gets to some of the "how" questions. Tom will also discuss, how this framework and the roadmap can guide specific interventions.

## Our Definition of Patient and Family Engagement

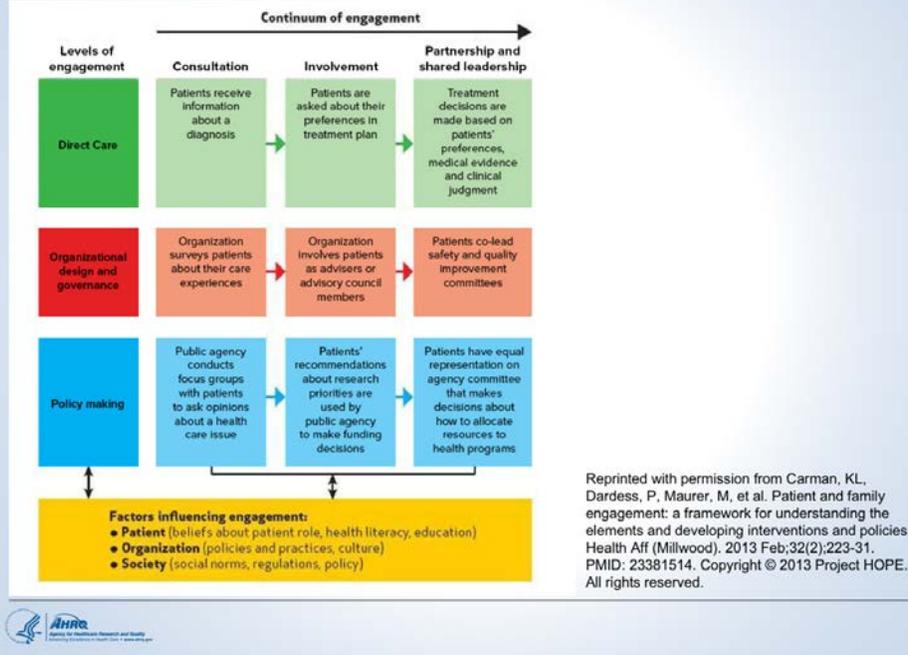
- Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policymaking—to improve health and health care.



Our definition of patient and family engagement is patients, families and their representatives and health professionals working in active partnership at various levels across the healthcare system. That's direct care, organizational design and governance, and policy-making, to improve health and healthcare. We developed this definition drawing on a number of other definitions, but with the aim that the ultimate goal here should be about moving from consultation to partnership. It is also a statement that engagement isn't just about what patients do, it's what systems and organizations do. It's what individuals interacting with patients do. It's not just engagement in direct care, it's engagement in the organizations that are creating the policies in which patient engagement does or does not occur. Finally, it's about improving their outcomes by improving the efficiency and the effectiveness of the healthcare system.

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For some people, patient engagement might be an end in and of itself. From our perspective though, it's important to think about our ultimate outcomes. Let's talk about the multiple levels here because this is a really important issue. Patient interactions don't occur within an organization just at the direct care level, they occur at many points and when accumulated, they can have a huge impact on outcomes. Even the organizational design and governance levels are ultimately shaping the actions and the creating the barriers and the facilitators for engagement, both for individuals within the system and for the patients themselves.

We have not only three levels of engagement but also a continuum of engagement, moving on the top from left to right. For example, testing ideas with people and showing them materials, or asking and getting their input is one form of involvement. But what that's really doing is asking people to give us their input on a host of things that we have decided. If we want to push that further towards involvement, then we start asking patients about their preferences. What are their values in treatment? What are the things that are important to them? We move from just making everything and consulting with them to getting their input into some key issues. But we can push that even further, where we end up moving towards more of that partnership paradigm where patients really have much more of a seat at the table.

As we're moving from direct care, where we're really comfortable with patient involvement to thinking about patients being involved in policy, where they have a say about policy decisions or the structure of the systems in which they're operating in a true partnership way. We think transformation can come, but it's also very challenging for everybody in the system. And of course the base is always that should be doing what they want to do. This is not a question of this being forced on them, because the starting point has to be where they're at. I have to say that my perspective is that we run a much greater risk of making it difficult for patients to engage than we run the risk of coercing them into engagement. I don't think that's what our problem is.

So the other part of this framework to think about is these factors influencing engagement. Again, we've taken the wide-angle lens in this conversation. For example, What are the things that influence what people do? It's not just what individuals do, it's what else is happening. At the individual level, beliefs about the patient's role, health literacy, and education are going to influence a patient's ability to do the things on this continuum, but so is the organization. Because patients are usually interacting with someone who's involved in a system. How that system structures things is going to have an influence on what actually happens. And then finally society-- social norms, regulations and policies are all going to have an influence. Law is trying to say that shared decision-making has to occur, what an influence that has on the actions by doctors, patients and health plans.

So that's the big picture of how we created a framework that we hope allows people to see where they are. Where are they doing work? Where are they focusing on? These things are very interrelated and interactive -- if we engage at one level, what influence does it have on another level, and it can go both ways. We can talk about that a little bit more later.



Carman KL, Dardess P, Maurer ME, et al. A Roadmap for Patient and Family Engagement in Healthcare Practice and Research. (Prepared by the American Institutes for Research under a grant from the Gordon and Betty Moore Foundation.) Palo Alto, CA: Gordon and Betty Moore Foundation; September 2014. <http://www.patientfamilyengagement.org>.



The framework was used by a variety of organizations to think about the work they're doing, about research and development of interventions, about how can they move towards greater partnership.

The framework served as the key undergirding for a convening of a broad range of stakeholders by the Moore Foundation, where the questions asked were: "How do we move from the 'why and should we' to 'how?'" "How do we make engagement happen?" "What are the different ways in which we can make it happen?" We convened about 75 stakeholders -- patients, family members, providers, administrators, payers, foundations, CMS, AHRQ, a variety of leadership. They all agreed that achieving this partnership across these various levels were crucial and important. And the roadmap became a concrete way to talk about how we get patient and family voices into this. If you look at the strategies embodied here, for example, patient and family preparation, and clinician and patient leadership preparation, you can see that it's not just about the patients. It's what clinicians do, it's care and system redesign, and it's organizational partnership. We're moving from the individual level to change within the system.

Regarding measurement and research and transparency and accountability, we can't improve on a system if we don't understand how we're doing. Legislation and regulation and partnership and public policy -- all of these came out of that two-day convening, each with strategies and tactics and are opportunities to drive progress towards patient and family engagement. There are areas where progress will have a significant impact on its achievement and where change is necessary and possible, although not easy. I'm going to give you just a quick overview of lessons learned and then Tom will go into more detail.

## Four Key Discoveries From Applying the Framework

- **Getting beyond engagement as effective patient-provider communication.**
- **Partnership requires infrastructure.**
- **Partnership must involve mutual interests.**
- **Patients are not waiting for providers to engage them.**



What have we learned so far? Most people are thinking about patient engagement at the direct care level but there are a lot of opportunities for much more patient involvement. You are much more likely to have a system accomplishing its goals if patients are giving you input into the structure of that system because the systems now in healthcare is not just about physician work. It's patient work. Even if you're in a hospital environment, when we think about family involvement and outcomes and self-engagement and care, there are a lot of very important insights and input patients can have into how we are designing things. We have to move away from thinking that it is a matter of behavior to thinking of how the system is structuring the context around behavior.

A second lesson is partnership requires infrastructure for everybody in order to do it. You know, in a lot of cases, a lot of research environments aren't used to having patients as partners. This has come up in a lot of the research work. IRBs aren't used to patients as partners as opposed to subjects. It's requiring a lot of change in the infrastructure of how we support it.

The third lesson – for healthcare providers engaged in patient engagement when it feels like it's accomplishing their goals for patient adherence and patient compliance. And not necessarily in the broader set of range of activities where patients' role and patient input would be valuable for them and also valuable for the system. And I think these are really key sticky points that we're going to have to make some real movement on. And so I'm going to leave it at that Tom and let you sort of get into some more of the details of these examples.

## Thinking About Patient and Family Engagement Relative to Research Evidence

1. **Patients and families cannot partner with research evidence.**
2. **Patients and families bring differing interests about the use and application of evidence.**
3. **Patients and families bring different methods and approaches to goals and objectives.**



Sure, thank you. I can't say enough, really, about those last two lessons though about mutual interest as well as patients not waiting for providers. And so I spend an awful lot of time with patients and more importantly patient and family advocacy organizations. And so many of them are not sort of waiting for us to develop the latest decision tool. They're off. They're doing their own thing. They're accomplishing amazing things and sometimes it's our catching up to them. And part of that goes back to that understanding that we step outside of the clinic and meet patients and families where they live particularly. So a few things that we wanted to talk about when we apply all of this to the subject of today's conversation which really is patient engagement in evidence. I'm going back to the very name of our conference today. And I want to start by saying patients and families under this framework cannot partner with evidence. In fact, evidence is a resource just as it is for all of us. However, patients and families do always partner instead with those who supply evidence or those who supply information. But, again, once we step out of the clinic, for a second, we recognize that in our broader culture and why society was one of our factors that, in fact, it might be Dr. Oz that they have a far greater relationship with than they ever have or with their mother-in-law or with someone else. And so one of the issues becomes our trying to think of ways to build a relationship and especially a partnership between a patient and a piece of evidence is really, I think, perhaps a waste of our time. Instead, we should be thinking about our sources because that's who we partner with. And, again, those partnerships when we understand mutual interest make great sense to partner. I partner with my, I don't know pick whoever, my next door neighbor who seems healthy as a horse because I have a mutual interest to do so. I may not have that with my clinician. I may not have that et cetera. And so we have to think about this partnership a little bit differently. The second thing that we've learned and awful lot we did quite a bit of work and we just finished a national survey through PCORI that we hope to be publishing in the next two months. We should have a webinar in October through PCORI and where we actually surveyed patients and families and asked a lot about their relationship with evidence. And one of the things that we saw very clearly is that they had a very different set of interests than we often have about the use and application of evidence. And, again, this goes back a bit to our understanding this larger sense of information. A number of our patients really don't quite understand what evidence is as opposed to what information is. And so certainly our thinking about those terms a little bit differently was important. But much more importantly was the sense ultimately that we heard quite a few times from patients that their interest in evidence wasn't always the same as our interest. And I think Kristin alluded to that but we have to continue sort of that allusion. We come in as researchers and we say, "This is really the important question." And our patient says, "That's not my question at all. My question is, when do I go back to work? That's my question." And everyone here knows there is not a RCT that will answer that question for anyone. And so when we really look at this issue of why aren't we seeing patients taking in evidence, one of the questions becomes how have we worked between patients and families, caregivers and researchers to try to connect what those real questions are, those mutual interests. How could we find some bridge between those two issues ultimately? We've heard very clearly that those interests may be different and so we may have to listen differently. It's interesting. A lot of my work has been around helping bring in patients and consumers into a research interest. And yet, often, very much like what happens with clinicians it becomes a little bit of a one sided street. How do I get the patient to fit into my research agenda? As supposed to our asking an open partnership what is it that we might be able to explore together that can answer the most important questions? And what happens when we say I can't answer that question. I don't have the technology. I don't have the methodology yet to answer that question and how might we work together to find those answers. The third thing that we've come to learn is that patients and families bring different methods and approaches to some of our goals and objectives. In other words, sometimes there are plenty of bridge interests. In fact, one of the most important interests I see often times with comparative effectiveness research is wow, that's great, this really does help me decide between a couple of different things. The evidence is there. Now, how do we get that out? And sometimes our thoughts about the goals of getting that out, what we call dissemination or diffusion don't always work in the same ways, of course, than patients and families may think about that. We, of course, adore academic journals and we use academic journals as an important way in which to get our information out. And we continue sort of in the scientific way several have mentioned throughout our time today about a scientific accuracy and how important it is and sort of the enemy as anyone who knows who has worked with plain language in trying to condense down something accurately while still ultimately communicating it in a way that someone can understand or comprehend. What we heard from patients and families and I think what we find as we build partnership is that our goals may be similar but our methods may be very, very different. So it helps us to start to think about how could we take CER evidence and get it into the grocery line? How could we take CER evidence and make it a part of Thanksgiving dinner conversation? Because what we heard often times from our patients and consumers is that that's when those conversations begin to happen and that's when those considerations may occur.

## Partnerships Toward Evidence-Based Health Care

- Patients and families partner in the study, analysis, and conclusions of research that produces evidence.
- Patients and families partner in the translation of evidence.
- Patients and families partner in the dissemination and diffusion of evidence.
- Patients and families partner in the application of evidence in the decisionmaking process.
- Patients and families partner in the efforts to address knowledge gaps and evidence uncertainty.
- Patients and families partner in the development of new forms of research, evidence generation, and evidence synthesis.
- Patients and families partner to create a culture where evidence-based decisionmaking is the foundation of health care.



And so our thinking about how we might build some of our-- a better understanding about our patients and our families into the way that we accomplish our goals and objectives might create a partnership where we actually accomplish those goals thought they'll feel very odd and different to us. They'll feel very, very different to the scientific community. So I do want to say just a word about how we do this in evidence based healthcare especially how we do this in research. And this means that we actually partner-- let families partner in studies in the analysis, in the conclusion, letting patients partner in the translation of evidence. We can really go through the entire research process itself and ask the important question, how could patients be a part of the inquiry? And how could patients be a part of the discovery, the analysis and finally the communication about that information? Those forms of partnership are things that AHRQ has taken leadership with, PCORI has taken leadership with and yet, we're still learning what the best methods are. It's fruitful and very important, I think, that we continue to look at ways that we can foster those partnerships. And so I think something the Eisenberg Center has taken some great leadership in is how do we do that? How can we connect our patients and families into the process? To show that the result is we have evidence that is meaningful and therefore gets communicated out. I want to then finally sort of connect and leave some time for questions but I want to finally connect that roadmap that Kristin shared with you.

## A Roadmap for Patient and Family Partnerships That Yield Shared Use of Evidence

- Patient preparation
- Care and system redesign
- Organizational partnership
- Transparency and accountability



So those how strategies that she showed you from the roadmap become how strategies as well in engaging patients and families we think in this entire evidence enterprise. And it means, of course, patient preparation but I would like to suggest and I'm actually going to just focus on that one in my remaining time, again we'll be writing about all eight. But I want to suggest in patient preparation one of the things that we've certainly seen clear from a number of our studies with patients and families is this notion of evidence itself. So the questions that we often hear from patients, you say two more women-- two less women will die, I'm going to use an example from this morning, if they do this treatment. And our patient says, "Am one of those women? Is that me?" I don't know. Maybe. Let's hope. And so even our conceptualization about evidence is a dialog that we need to continue to have in our preparing patients. How do we think about risk? What does risk mean? And where ultimately will the decision have to lie with me and will consequences have to lie with me? And so our preparing patients by having this much broader conversation-- it's interesting, we've been having this conversation with one community in the country around end of life issues. And the question was, "How do we get more efficient in having those very difficult end of life issues in the clinic?" Well, it can't happen in ten minutes. Let's have an end of life discussion in ten minutes, right. It needs to happen every week at church. It needs to happen at the bridge club. It needs to happen at a variety of places. So our thinking about patient preparation from a bit broader stance, our patients will show us how to prepare them and so critical that we think in those terms. So, again, just want to start to stay that one of the issues for us, one of the tasks for us and we hope to share it is this task of AHRQ really understanding how we connect in partnership our patients with our research and our evidence enterprise. I think the map can help guide us that way. And I think that there's a variety of things we can do in partnership with patients ultimately to arrive to those very clear pathways.