Quality Field Notes

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Interview

An Integrative Approach to Patient Engagement

Aligning Forces Humboldt, which is located at the California Center for Rural Policy at Humboldt State University, has developed a successful method for assessing and maintaining patient involvement in its work leading the *Aligning Forces for Quality* (AF4Q) initiative in Humboldt County, Calif. AF4Q is the Robert Wood Johnson Foundation's signature effort to lift the overall quality of health care in 16 targeted communities across America.

The alliance created a four-level framework for engaging patients in its different efforts, depending on the patients' knowledge and interests, and the time and skills needed for the projects. The projects include leading workshops to help people with chronic illnesses manage their health and participating on committees to help primary care offices improve the care they provide.

To gain insights into how the framework has helped patients bring value to the alliance's work, we sat down with Jessica Osborne-Stafsnes (pictured left), project co-director, and Melissa Jones (pictured right), project director for Aligning Forces Humboldt.

Aligning Forces for Quality

AF4Q is the Robert Wood Johnson Foundation's signature effort to lift the overall quality of health care in 16 targeted communities across America. These briefs distill some of the key lessons learned by these regional alliances of providers, patients, and payers as they work to transform their local health care and provide models for national reform.

Q

Why did you decide to develop this patient engagement framework for your work in Humboldt? How has the framework evolved over time?

Jessica: We developed the framework because of the experience we had with Our Pathways to Health, a program sponsored by the Robert Wood Johnson Foundation to support patients with chronic illnesses in managing their health. The program was incredibly successful and had a robust implementation. Many patients who graduated from the program were very passionate and became peer leaders. We tried to channel their enthusiasm by plugging them into other AF4Q projects without adequate support and planning, which cultivated a challenging experience for all stakeholders. We realized that we weren't thinking about the skills or training the patients needed to feel successful and empowered in these other programs.

So, the framework came out of the need to support people's interests and skill sets, and to make appropriate placements with the projects we have based on the skills the projects demand. It also helps to give patients clear expectations of the goals and responsibilities they're taking on when getting involved in a new project, which we've found helps to alleviate a lot of frustration. We felt the need to reflect on how we had engaged consumers in our community and our vision for engaging them moving forward.

We treat the framework as a working document, and we continually refine it based on lessons learned. For instance, in the last six months, we added a piece about organizational readiness because we realized patient engagement isn't only about patients' ability to engage in their own health or quality improvement projects. It's also about how ready an organization is to work with patients on these projects.

Q **How did you develop the four levels of the framework?**

Jessica: We started with the level of engaging patients to better manage their own health; we also work with patients to use our public reports about local health care quality, so it was a natural next step. And second level, to engage patients to use health information online and become peer leaders to support others in managing their health.

We developed the third level as a result of our work with the Humboldt-Del Norte Independent Practice Association (IPA) to integrate patients in quality improvement efforts. This is reflected in our Patient Partners project.

Most recently, we've been working on the fourth level, which engages patients as equal committee members working at the policy level. Our community-wide project on surgical rate variation engaged participants at this level of the framework.

Q **The Our Pathways to Health program began in 2008 and has more than 1,000 graduates. How has the program changed over time?**

Melissa: It is a licensed program at Stanford University, so there is an established curriculum to run the workshops. We've developed partnerships with organizations in our community to offer the workshop for their specific populations. For example, we'll have a workshop for our local VA clinic and another for people with poor vision.

Jessica: Our relationship with the IPA through AF4Q has helped us get support from the primary care community for the Pathways program. We saw significant growth by reaching out to primary care providers to ask for referrals to the workshops. Referrals have gone from 23 to 40 percent.

Melissa: Provider referrals are critical to sustaining the program. We give presentations on the program and the referral process to providers' offices and track our top-referring providers.

Jessica: I just interviewed our top 10 referring providers and they said they like knowing that they're referring patients to an evidence-based program. Since it is licensed by Stanford Patient Education Research Center, physicians know it's research-based and consistent, and many of them hear positive reports back from their patients.

Many providers have said, "I will see a patient in a 15-minute window, but I know there are many factors, such as social determinants, which impact their ability to live with their chronic condition." The program's goal is to provide a space for folks to explore those issues and address them, and many providers consider it a help for the patient and the provider. It's a relatively low commitment on their end to refer someone to Pathways. It ends up being a value because the patient has the opportunity to explore issues like symptom management, nutrition, active living, and goal-setting in a very supportive environment.

Q **How do you identify the peer leaders for the Pathways workshops? And then once you do, how do you keep them involved?**

Melissa: After patients graduate from the workshop, in the program evaluation we ask, "Would you be interested in being a peer leader?" If they say yes, we invite them to the annual orientation and leader training. Once they become leaders, we keep them actively involved by holding quarterly leader lunches to update them on workshop schedules, address any issues, and build camaraderie.

Q **Are peer leaders compensated?**

Melissa: They can choose to be compensated or they can be volunteers. We leave that up to them because some may not want the money; they may do it purely because they love the program. Other folks find that having that little bit of income is really helpful.

Q **What are some lessons you’ve learned or changes you’ve made since the beginning of the Pathways program?**

Melissa: Most of the adjustments over the years were not only to be responsive to our community, but also to not ask too much from our leaders. It’s also become clear that we need to have full and robust workshops because one of the principles of the program is that you don’t have a workshop with only three or four people.

Jessica: We’ve learned that having a multi-pronged and aggressive approach to recruiting workshop participants is very important. We keep in constant contact with physicians and our community partners, and leverage local newspaper articles to drive folks to the workshops.

Q **Let’s talk about the third level, which is patient involvement in quality improvement and system design. Tell us about the Patient Partners program.**

Jessica: Leveraging resources from RWJF, the IPA started a community-wide primary care quality improvement collaborative in 2009 with 10 primary care teams, and it was very successful. We decided to do the collaborative again in 2011 to introduce practices to the patient-centered medical home (PCMH) model. When we were planning, it seemed really odd to support practices working to become PCMHs without having patients at the table. So, we took a risk and told the practices, “If you want to participate in this collaborative, you need to recruit a patient to sit on your practice performance improvement team.” We recognized that it was disruptive innovation, but we felt that patients should be a part of the work that the practices needed to do to become PCMHs. It was important to us that both patients and practices felt supported in this new working relationship.

Practices that were early adopters tended to be those that already had implemented a quality improvement structure and were meeting on a regular basis in their practice. They did an excellent job of integrating patients into their efforts without too many problems. Other practices struggled with embracing the quality improvement collaborative structure. Even though they valued their Patient Partners’ perspectives, the practices had a hard time engaging them meaningfully, and sometimes would forget to invite them to a team meeting or miss the opportunity to engage the patient perspective on a certain area.

Overall, the reception to Patient Partners has been very positive. At each collaborative meeting, Patient Partners present their perspectives on a given topic, and their presentations are often rated higher on meeting evaluations than the keynote speakers’.

Q **How have Patient Partners contributed to improve a practice?**

Jessica: In a pediatric practice, the team was talking about how to improve well child visit rates. The Patient Partner said, “I know the practice wants me to make the next appointment as I’m leaving the office, but my kid just received a bunch of immunizations and they’re crying and I’m feeling frazzled. I just want to get out of the office and I forget to stop and make a follow-up appointment. Why don’t you give me a laminated card with what I need to do at the front desk before I leave so I remember?” The practice implemented the idea and it’s been working really well.

Another practice was working on improving colorectal cancer screenings and was sending screening kits out to their patients for them to mail back. They were concerned that no one would send back their kits for testing, and the Patient Partner suggested putting a sticker on the kit that said, “This can save your life.”

Q **The fourth level involves patients in efforts to make changes at the community or governance level. Was it a natural progression to include patients in these projects, like the Surgical Rate Project, given the way they've been integrated into everything else?**

Jessica: Betsy Stapleton, our lead consumer representative and a thought leader for many of our patient engagement efforts, was instrumental in this effort, which she led in conjunction with Martin Love of the IPA. After reading the California HealthCare Foundation's article on variation in preference-sensitive care in California, and observing that Humboldt had 1.5 to 2 times the rate of care for certain elective procedures, she thought, "There is a project here and this community has a stake in it."

We developed a program with a group of community leaders who were not involved in the local health care system, like the chief of staff at the local university and an economic analyst for the county. Then we pulled together a group of specialists and a group of primary care providers to start examining these rates and understanding why some were higher than in other regions.

We focused on four different preference-sensitive conditions, and we brought in experts in each of those surgical areas to talk about indicators for those surgeries. The community group also met with the experts to get the education necessary to have a meaningful conversation.

Melissa: The experts met with each group independently, so each had an isolated, protected space to have these discussions and feel comfortable to ask questions within their group.

Jessica: The three groups came together in a final meeting, and the community group made several recommendations for addressing care variation. One of their recommendations was that we, as a community, consider shared decision-making so that treatment decisions are influenced by a patient's preference instead of some of the external factors that seem to be influencing them now.

We've really noticed a transformation in our approach to patient engagement over the past several years. The Patient Partners program and the Surgical Rate Project have helped us establish a norm in our community to ensure that the patient voice is present when developing new projects.