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# bright spot

cost | payment/incentives | care across settings

## **Humboldt Del-Norte Independent Practice Association Patient Engagement in the Primary Care Renewal Collaborative**

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### **About our organization**

I work with the Community Health Alliance, a community based, consumer driven, not-for-profit organization in Humboldt County. It is the recipient of our community's AF4Q grant and employs the Project Director. It is also the organization that drives and implements the Consumer Engagement portion of the grant work. It employs two fulltime employees in addition to the Project Director. I am a deeply involved volunteer, who has helped envision and implement the consumer engagement work since the start of the AF4Q grants..

### **The problem we were trying to solve/the challenge(s) we faced**

The challenge we faced was how to effectively integrate consumers across the broad spectrum of activities we were involved in, both specific "consumer engagement work", and, more generally, every aspect of the AF4Q process. There were many aspects to the challenge: how to find and recruit consumers, medical system resistance to consumer participation, unsustainable staff time demands when engaging consumers, and consumer frustration and anger at the process they were involved in. Our early attempts at consumer engagement were not satisfying to anyone involved. Meetings often lasted for hours. Consumers broke down in tears, or left angry, "medical personnel" felt their time was wasted and left meetings even less willing to "allow" consumers into the process than they had been at the start. Staff felt frazzled, frustrated and angry.

### **Our bright spot – the successful program, result, or process we want to share**



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Our “bright spot” is a conceptual frame work (see handout) that allows us to match consumers with activities that match their interest, time commitments, and ability to participate in the highly hierarchical, complex, technical, medical world to opportunities for involvement. We see consumers functioning along a continuum of activation/empowerment. At the primary levels of activation/empowerment consumers become ready to start better managing their own care and health. Activities at this level involve becoming better self managers and more effectively engaging with the health system to get the services they, or family members, need. At the next level of activation/empowerment, consumers start voicing their needs and opinions about how to improve the health care delivery system to better meet their needs. A person at this level might participate in a patient council or help a practice to improve by voicing opinions on a patient experience survey. At the highest level of activation/empowerment consumers are full participants in health care system redesign at the policy level. Our differentiation of how to effectively match consumers with the activities that are satisfying to them and useful for redesign efforts have led to our very successful integration of consumers into the “Primary Care Renewal” collaborative hosted by the local Independent Practice Association. Consumers are involved at all levels of activation. We have leaders from “Our Pathways to Health” program (“Chronic Disease Self Management Program” one of CHA’s very successful consumer engagement programs) participating as a team at the collaborative. They are assisting practices with developing processes to effectively and efficiently refer patients to “Our Pathways”, which is both health system redesign and the base level of activation of helping people better manage their own health.

At the mid-ranges of activation/empowerment, we have developed a “Patient Partner” program. Each medical team was required to select and support a patient to participate on the medical office team to continuously offer the patient perspective. The Patient Partners have been highly supported with a meeting before each Collaborative meeting that briefs them and brings them up to speed the topics and issues that are to be addressed at the collaborative. Staff members routinely checked in with both the Patient Partners and medical office personal to ensure that no problems are arising. At the highest level of activation, a CHA staff member Jessica Osborn-Stafness, and I were part of the PCR planning committee, ensuring that consumer needs were considered in every collaborative meeting and that patient needs were always held at the center of redesign considerations. Additionally, the work of having the CDSMP program housed in a community organization, while becoming closely linked to the medical system, is a fundamental redesign effort that gets at cost(full utilization of CDSMP has the potential to substantially reduce costs).

### **The biggest hurdle**

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Our biggest barrier was a lack of outside models to guide us in this type of work. We stumbled along, often creating very tense situations that seemed to go on for weeks at a time. We overcame the problems by the application of “The Model for Improvement” to our work. Every difficult situation became a “learning opportunity” that we studied and then rapidly tried modifying in order to develop a process that was effective. We did not develop a “program” and insist in deploying it no matter what cost or effort. We had a goal- involve consumers at all levels of AF4Q work in ways that were meaningful, effective and sustainable, but continually evolved our thinking on how to achieve it. We used feedback loops (such as meeting satisfaction surveys), to guide our response.

## **Aha moment or lesson learned**

Our Aha was when we finally were clear about some real life constraints and shared them with our consumers. The result was more clarity and harmonious joint work resulted, rather than less. Prior to that occasion we had felt that consumer engagement meant attempting to accommodate every consumer request, which seemed to lead to an ever spiraling level of requests that could not be satisfied with our resources and the political considerations involved. When we finally shared the limits of our ability to pursue some desired consumer driven project there was initial irritation, but it ultimately led to much smoother working relationships. Our lesson learned was to be clear about roles and responsibilities for all parties in our consumer work. We have developed “job descriptions” that detail time expectations, explicit parameters about the work to be done and lines of authority and accountability for consumers, and also for partners working with them like the medical practices. While we were initially somewhat uncomfortable about being this explicit, it has resulted in a flowering of relationships and markedly increased satisfaction by all parties.

## **To share generously (or steal shamelessly), what advice do you offer?**

Be clear about what you want from each party and don't hesitate to share it. Of course, these expectations may change and modify as the process evolves, but starting with clarity gives a firm platform for change to occur on. Don't hesitate to share political complexity (“we can't do that because our partner -the hospital, medical office, the NPO- won't consider it”) and resource limitations (“we don't have enough staff time/money to do that”). Most people understand that these are real constraints.