PATIENTS AND FAMILIES AS LEADERS Transforming Patient Engagement in Oregon January 19, 2012



Background

In the spring of 2010 the Oregon Health Care Quality Corporation launched the *Patients and Families as Leaders* program, which focuses on training both patients and physicians on how to work together within the complicated health care system at multiple decision-making levels.

Assessment

A survey conducted in the spring of 2010 of Oregon primary care medical groups and health plans revealed a strong commitment to patient- and family-centered care. Organizations make financial and personnel investments, and clearly communicate their commitment to patient- and family-centered care to patients, staff, and medical staff. When it comes to putting action behind their words, few organizations have partnered with patients and families in leadership. However, many expressed interest in understanding how to engage patients and families in meaningful ways.

Action

The initiative kicked off with a collaborative event on June 10, 2010 to raise awareness, share local learning, and identify what is working nationally. Bev Johnson, CEO and President, Institute for Patient-and Family-Centered Care (IPFCC) presented and a panel of patient advisors shared their motivations and role as advisors. Quality Corp announced the opportunity to apply to participate in a learning community including technical assistance and seed funding to establish a patient advisory council.

Following a rigorous review, six organizations were selected to participate – five medical groups and one health plan (one medical group dropped out early in the process due to a change in leadership). Project staff provided ongoing support, coaching, and technical assistance to the five pilot organizations – including on-site coaching, conference calls, webinars, and dissemination of additional tools and resources. All learning collaborative members also participated in an intense IPFCC seminar.

"It's been very eye opening to hear direct feedback from our patients on experiences in health care. I think often patients can be intimidated by doctors and executives but when we get them in a room, frankly when there's more of them then there are of us they feel empowered to open up and tell us how they really feel."

"I would like to think that we are just getting started. One day I would like to see one or two patients on every committee and council we have throughout the medical group."

Dr. Joe Siemienczuk
CEO, Providence Medical Group

In addition, *Patients and Families as Leaders* is raising awareness and spreading lessons learned to the broader community through a monthly newsletter and quarterly conference calls. All resources, tools, and stories are available for download at the Quality Corp website, www.Q-Corp.org.

Lessons Learned

One of the biggest challenges of establishing a patient and family advisory council is recruiting advisors. Participating organizations used a number of different tactics to accomplish this task and found the following list of strategies successful:

- Engage leadership in the importance of an advisory council and how they can support the development
- Carefully consider the characteristics to look for when interviewing potential patient advisors
- Enlist providers as partners in recruiting patients
- Consider holding a focus group to see how potential advisors interact in a group and recruit from there
- Engage current patient advisors in the recruitment of new advisors

Advisors need to be oriented to the organization and prepared to work as a team and within the organization. Organizations can facilitate this by providing opportunities for advisors to get to know each other and the organization with casual meetings and orientations specifically for them. Participation in organization-wide meetings and activities is another way to integrate advisors within the organization. Connecting new advisors with patient and family advisors from other local organizations is a great resource for orientation and mentoring for new advisors.

Patient and family advisors are donating their time to create a more patient- and family-centered experience. Make it easy for advisors to participate and use their time wisely by planning and facilitating effective meetings. Select a meeting time and frequency that is convenient for advisors – typically monthly or bi-weekly meetings. Providing a light meal, transportation assistance and child care help to ensure advisors can attend the meetings. Elect a chair to facilitate meetings and help set agendas. Invite organizational leadership to attend council meetings to learn more about the council and deepen advisor knowledge of the organization.

Advisory Council Accomplishments

CareOregon

CareOregon, a nonprofit health plan serving more than 150,000 Medicaid and Medicare recipients in Oregon, established a Member Advisory Council (MAC) in July 2010. The MAC is made up of 13 member advisors who meet monthly to discuss and address issues affecting CareOregon members.

MAC members held a member Open House in January 2011 for approximately 100 members who wanted to learn how to become

"The Member Advisory Committee is valued highly by the staff and Board of CareOregon ...The continual appreciation and opportunities to contribute to the organization has been sincerely demonstrated and the commitment to the Member Advisory Committee's work continues to grow in its importance to the organization."

Diane Meyers
Member Advisor, CareOregon

more engaged in their health care; recorded and shared their health care stories; participated in a staff orientation and lunch with employees to share the member's perspective; participated in Health Care Action Day at the Oregon Legislature; and presented at the Institute for Patient- and Family Centered Care seminar in St. Louis, Missouri.



The MAC is developing a *Shared Care Guide*, a tool to help patients and providers in establishing mutually identified goals and expectations for clinic visits. The hope is to improve the experience of care for the member and promote better communication between a patient and their provider.

Northwest Primary Care

Northwest Primary Care is a primary care medical group in the Portland Metro area with four clinic locations and 23 providers. Their Patient Advisory Council formed in March 2011 with five Advisors. The Council is working on a *Compassionate Healing Relationships* provider and staff development program to shift staff development from "customer service" orientation to "patient-centered." Advisors will present this curriculum on patient- and family- centered care at the next all provider retreat.

Patient advisors also filmed patient interviews which focus on the patient's care experience. The videos will be used during patient- and family-centered care provider and staff presentations. The Council is also part of the multi-disciplinary team working on National Committee for Quality Assurance and Oregon Health Authority designation as a patient-centered medical home.

Oregon Medical Group

Oregon Medical Group is a primary care based multi-specialty group in the Eugene and Springfield area with more than 100 physicians and 13 neighborhood clinics. The Patient Advisory Council has been meeting since June 2011 with six advisors. The council's goal is to work on projects that will help all patients' coordinate their care. The advisors provided input into interior decor of a new office and a new electronic record portal for patients, and created a "goodie bag" for new patients.

Providence Medical Group

Providence Medical Group, part of the Providence Health & Services health system, is a primary care based multi-specialty group in Oregon with more than 70 clinic locations. The medical

"The complexities of the health care system set up patients for failure in the management of their own care. When I was asked to join this patient advisory committee, I felt that my experiences as a patient, but more as a caregiver for my parents, offered me insight and experiences that I could bring to the table as opportunities to improve the system from the patient point of view."

Rae LaMarche

Patient Advisor, Oregon Medical

group established a Patient and Family Advisory Council in March 2011 with 13 advisors who have consulted with medical group staff and providers on a variety of projects as well as initiating projects of their own.

Advisors are working with three clinics selected to be beta sites for patient-centered medical home clinic transformation to assist in the development process and advise the clinics about what patients and families want in their health care experience. Advisors are collaborating on a communication plan to explain the PCMH and clinical transformation to all medical group patients.

Three patient and family advisors are reviewing parts of myProvidence, a secure patient portal with a variety of functionalities for patients to email their care team, schedule appointments, review and pay medical bills and more. Changes to the portal will be made to reflect the patients' input. Patient and



family advisors reviewed a *Heart Care Zone* tool given to patients to assist them in knowing when to call their provider or go to the Emergency Department based on their symptoms. Changes made based on advisor input include language, visual design and overall meaning and objective of the tool.

Advisors have filmed three videos interviewing patient and family advisors directly following their clinic appointment. These videos have been incorporated into meetings and used in employee training opportunities. Patient and family advisors have made 11 presentations to Providence Medical Group providers and staff.

St. Charles Family Care-Redmond

St. Charles Family Care-Redmond, part of the St. Charles Health System in Central Oregon, is a primary care clinic in Redmond with 13 providers. The Patient Advisory Board began meeting in January 2011 with seven members.

The Board is developing patient communication materials to explain the medical home and improve communication between health care providers and patients within the medical home. Materials include a brochure, clinic/community posters, flyers and website information.

"Patient and family advisors have allowed me to step outside the medical system and view our service from a fresh perspective. I am humbled by the board members' insight and tireless volunteer spirit. Those in the medical system cannot identify patient needs as these frequently turn out to be the exact opposite of what we believe patients want."

Dan Murphy, MD Medical Director, St. Charles Family Care-Redmond

The Advisory Board conducted a patient survey to learn how the clinic could better meet the needs of patients and designed elements of a patient clinic brochure as part of the follow-up. The board recommended and obtained approval to create a volunteer clinic greeter position and recommended improvements to the design of the clinic website which were implemented.

