

Patients and Families as Leaders: Transforming Patient and Family Engagement in Oregon

State of the State Report
June 2010



Information for a Healthy Oregon

A project of the Oregon Health Care Quality Corporation
and the Robert Wood Johnson Foundation's *Aligning
Forces for Quality* initiative.

Meaningful patient- and family-centered care requires a cultural revolution in a fundamentally redesigned delivery system. Funded by the Robert Wood Johnson Foundation's *Aligning Forces for Quality* initiative and managed by the Oregon Health Care Quality Corporation (Quality Corp) through *Partner for Quality Care*, this project aims to take the first steps toward revolution in our community by assisting a cadre of patients, families, health care organizations and health plans in implementing structures for meaningful patient and family input. This report summarizes our assessment of current patient and family engagement activities among primary care medical groups and health plans in Oregon. Studies on the engagement of patients cited on the Agency on Health Research and Quality website show that patient-centered care reduces morbidity and mortality, improves health status, and decreases misdiagnoses from poor communication.

What We Learned About Patient- and Family-Centered Practices in Oregon

Background

As the first milestone in our multi-year project to increase patient and family engagement in Oregon's health care delivery systems, primary care medical groups and health plan organizations were surveyed about their patient- and family- centered care practices currently in place. The Institute for Patient- and Family- Centered Care (IPFCC or "the Institute") provided technical expertise in development of these assessment surveys. It is the first attempt at understanding what is occurring in Oregon today. Identifying and highlighting these best practices will create transparency about what can be achieved across Oregon over time.

Primary Care Organizations — Results

Approach

Building on the Institute’s tool *Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings*, we built a shorter version for use with primary care medical groups. Since 2006, the IPFCC has made this tool available to organizations and individuals via their website and has used it in consultations with many organizations and grant-funded initiatives. It has been iteratively improved based on these experiences. Thousands of downloads of this tool have been made from the IPFCC website.

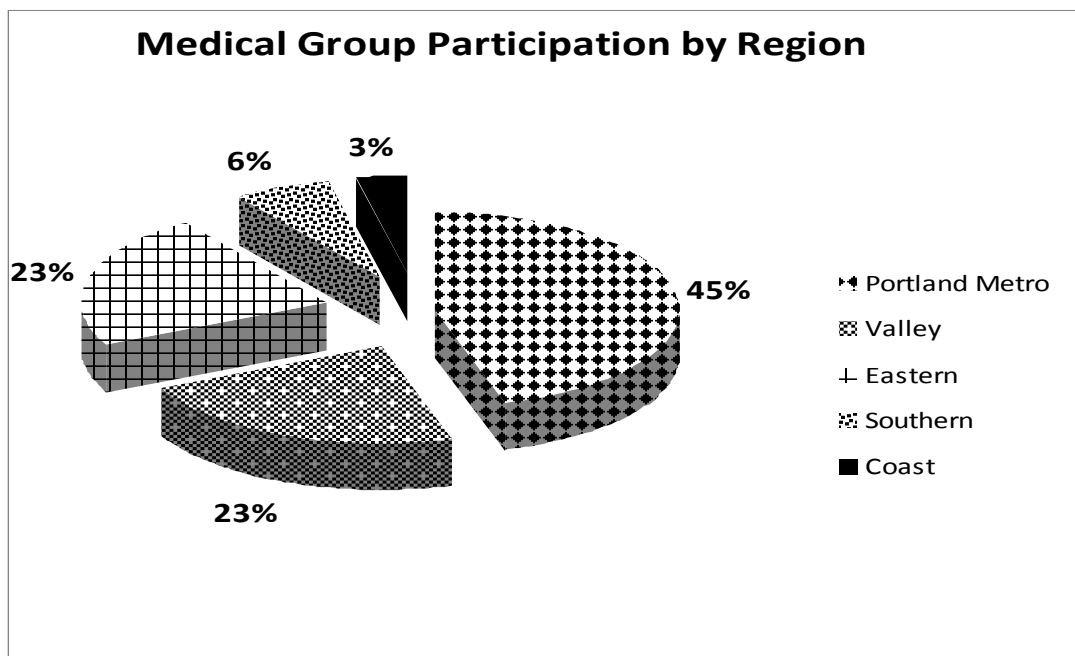
Our primary care assessment survey examined three areas: patient- and family-centered care practices and leadership engagement; patient and family access to information, education and support; and education of staff, medical staff, students, and trainees about meaningful patient engagement.

Using Quality Corp’s electronic distribution list for primary care medical groups, a 15-question survey was sent to key contacts in 94 organizations. Over a 90-day period, two additional email and/or phone contacts were made to encourage survey completion. Additionally, outreach letters were mailed to 48 primary care organizations that have received previous Quality Corp communications inviting them to complete the survey.

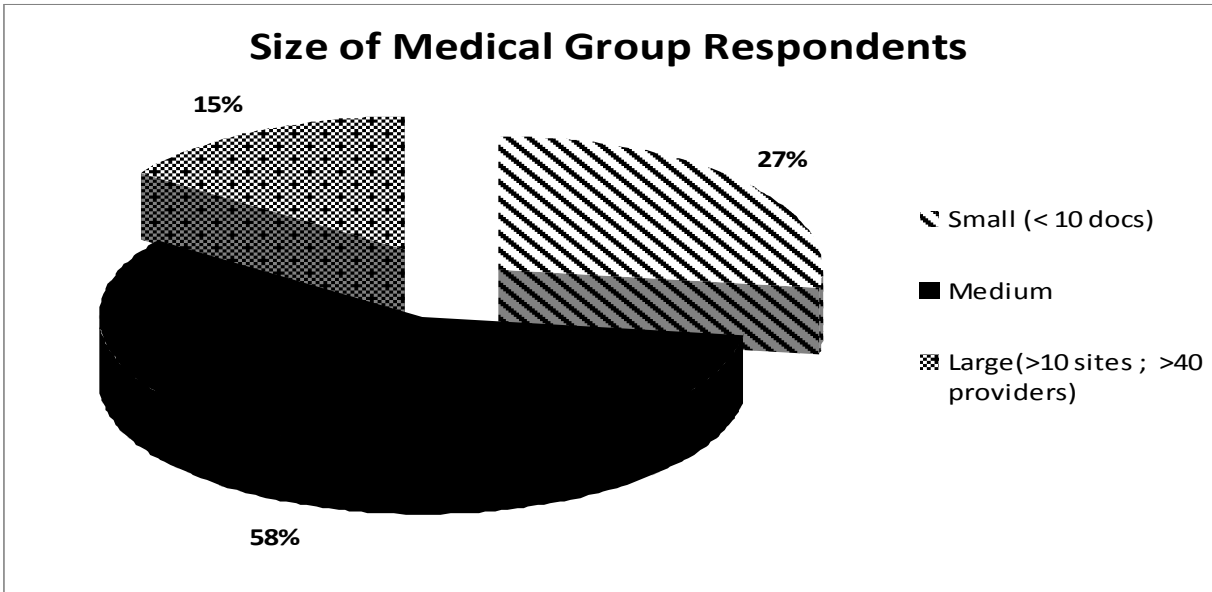
Primary Care Medical Group Survey Response Summary:

- There was a 31.9% [30] response rate from the initial 94 electronic survey recipients.
- There was a 6.25% [3] response rate from the 48 organizations sent outreach letters.
- A total of 33 primary care assessment surveys were completed.

The medical group respondents were geographically dispersed across Oregon (see chart below).



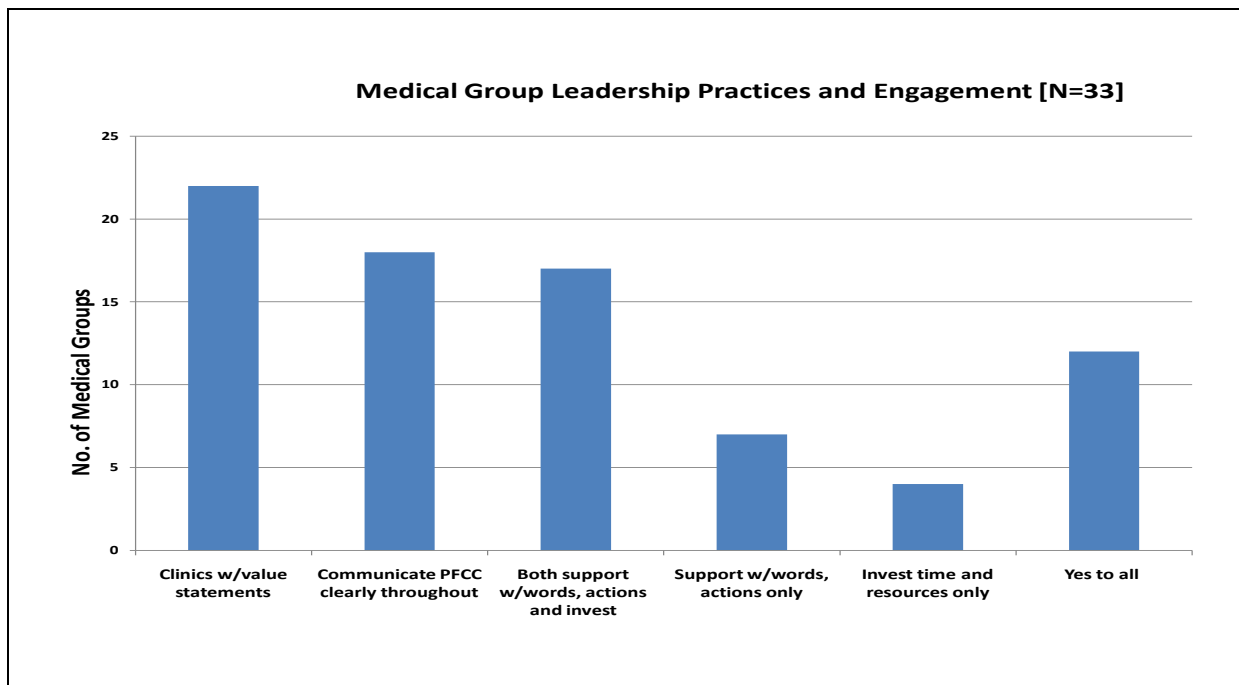
The survey respondents represented the diverse sizes of medical groups across Oregon (see chart below)



Patient- and Family-Centered Care Practices and Leadership Engagement in Primary Care

Studies have shown that establishment of a patient- and family-centered care (PFCC) culture and practice requires alignment of values and mission, as well as real leadership engagement. Of those completing the survey:

- 66% [22] indicated their medical group has a patient- and family-centered care vision, mission, and philosophy of care statement.
- 54% [18] believe they communicate their patient- and family- centered care vision and philosophy with stakeholders within the medical group and to the broader community.
- 52% [17] have leaders that invest both time and personnel resources in PFCC initiatives **and** demonstrate leadership behaviors that hold staff and clinicians accountable for collaborating with patients and families.
- 21% [7] believe they demonstrate leadership behaviors that hold staff and medical groups accountable for collaborating with patients and families.
- 12% [4] invest time and personnel resources to support PFCC collaboration.
- 15% [5] responded they **neither** invest time and personnel resources in PFCC initiatives **nor** demonstrate leadership behaviors that hold staff and clinicians accountable for collaborating with patients and families.



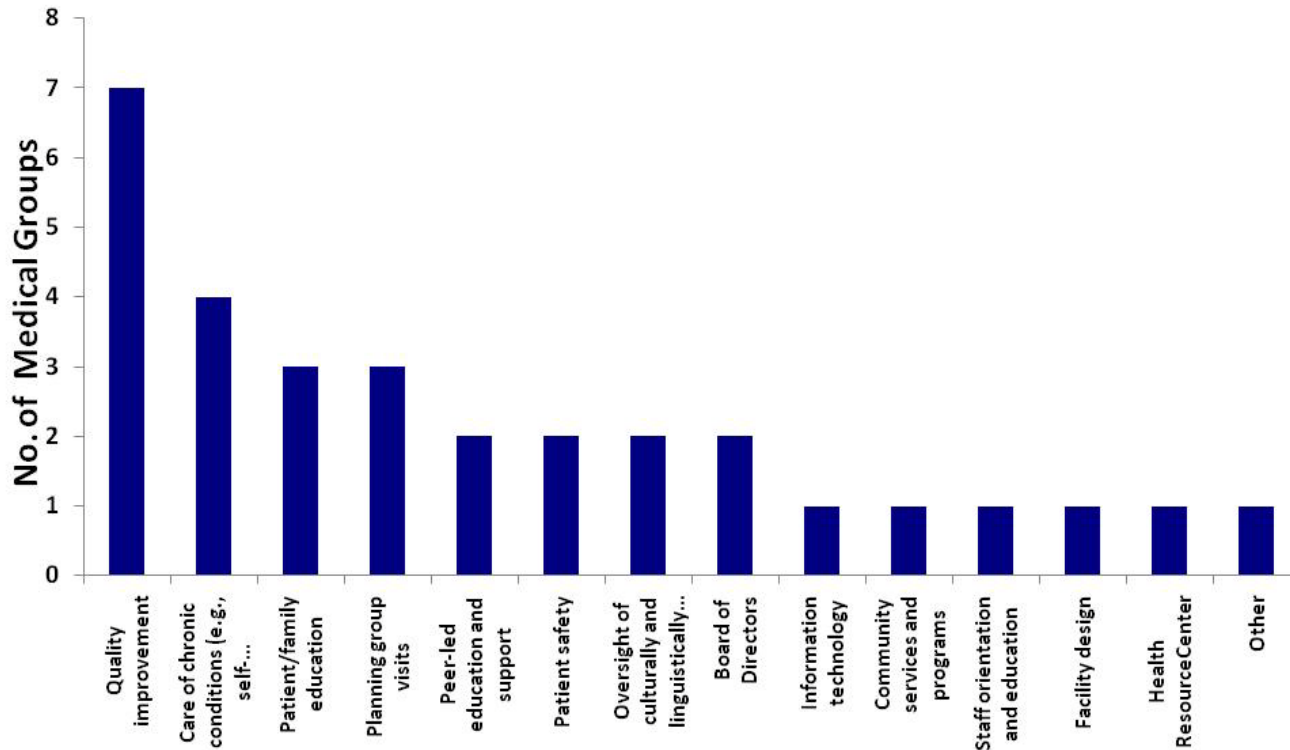
Patient- and Family-Centered Care Programs and Initiatives in Primary Care

In national patient- and family-centered conferences, a variety of health care organizations [i.e., Medical College of Georgia, University of Michigan Medical Center, Magee-Women’s Hospital] have cited data showing improved patient satisfaction scores, better health outcomes and improved revenue as a result of involving patients and families in care and program design efforts.

The survey provided primary care organization respondents with a way to highlight the numerous ways they involve patients and families in their current operations.

- 40% [13] have patients and families serving on committees/patient advisory councils.
- 18% [6] have patients and families involved in three or more collaborative activities.
- 6% [2] have an established Patient Advisory Council.
- The two most frequently reported patient and family collaborative involvement was in quality improvement committees and chronic care self-management programs.

Medical Group PFCC Programs and Initiatives [N=33]



Patient and Family Access to Information, Education, and Support in Primary Care

A key principle of patient- and family-centered care is the degree to which the health care organization provides patients and families with access to meaningful, unbiased information. Some notable practices that ensure access to information are: 1) Provide a range of informational and educational programs/materials; 2) Ensure these materials are consistently available; 3) Make materials available in primary languages and literacy levels of the medical group's population; and 4) Include examples and images that reflect the diversity of the medical group's patients and families. To determine the ways in which medical group materials are patient- and family-centered, the survey included the above topics. Among the medical groups completing the survey:

- 27% [9] reported meeting all four characteristic listed above.
- 55% [18] offer one or more of the practices listed above.
- 18% [6] did not provide access to information in any of the categories.

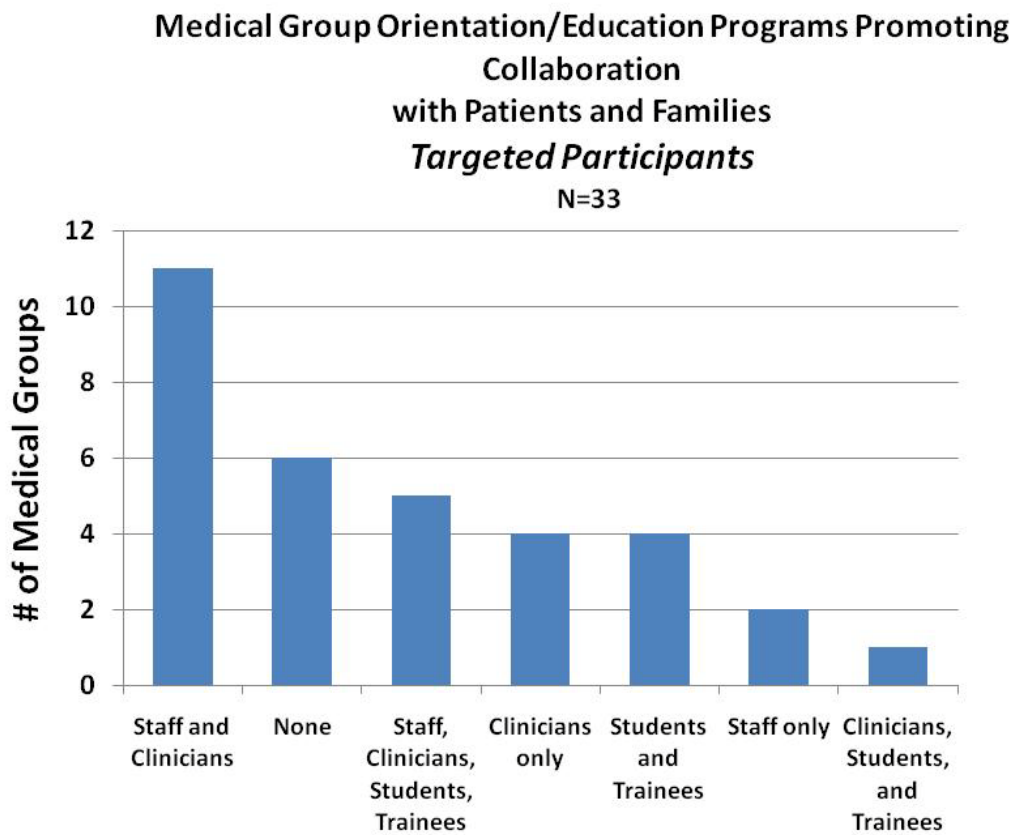
The survey queried medical groups on patient and family access to medical record and interactive web tools as well as the use of peer-led education programs. The results showed:

- 60% [20] provide patients and families access to their medical records [either paper or electronic].

- 39% [13] have web-based opportunities for information sharing and networking available to patients and families.
- 30% [10] offer peer-led education programs that are accessible to patients and families.

Preparing Staff, Medical Groups, Students, and Trainees for Collaboration with Patients and Families

Oregon primary care medical groups were asked to identify if they provide orientation and education programs that prepare their personnel for collaborating with patients and families in care and decision making. A national best practice when such education is provided includes the use of patients and families as presenters in the programs. The chart below represents the range of personnel that receive this collaboration preparation.



- Six [18%] medical groups do not provide any orientation or education to prepare personnel to collaborate with patients and families.
- Only one medical group out of the 33 that responded involves patients and families as presenters.

Health Plan Organizations — Assessment

Approach

As part of the initial planning for this statewide effort, our national scan yielded no existing patient- and family-care assessment tools for health plans. In order to determine state readiness for PFCC, Quality Corp worked in partnership with the Institute for Patient- and Family-Centered Care (IPFCC) to create a survey instrument that would assess the multitude of ways a health plan could influence patient- and family-centered engagement. We were mindful that health plans can provide leadership both within their own organizations and in the medical groups that provide direct care to patients and families. Building on the key principles of patient- and family-centered care, and IPFCC's work with hundreds of other health care organizations, a survey tool was created to use with health plans. Both national stakeholders, including Humana, as well as members of the Quality Corp Board, reviewed the survey tool during its development.

- The survey examined five areas within Oregon health plan organizations: health plan leadership; members and families as advisors; standards of practice; information and education; and measurement and incentives for patient- and family-centered engagement in medical groups.
- Using Quality Corp's electronic health plan distribution list, a 14-question survey was sent to key contacts in nine health plans. Over a three-week period, two additional email and/or phone contacts were made to encourage completion of the survey.
- The survey response categories for some questions were broadened beyond a yes/no response to a scale from "strongly agree" to "strongly disagree."

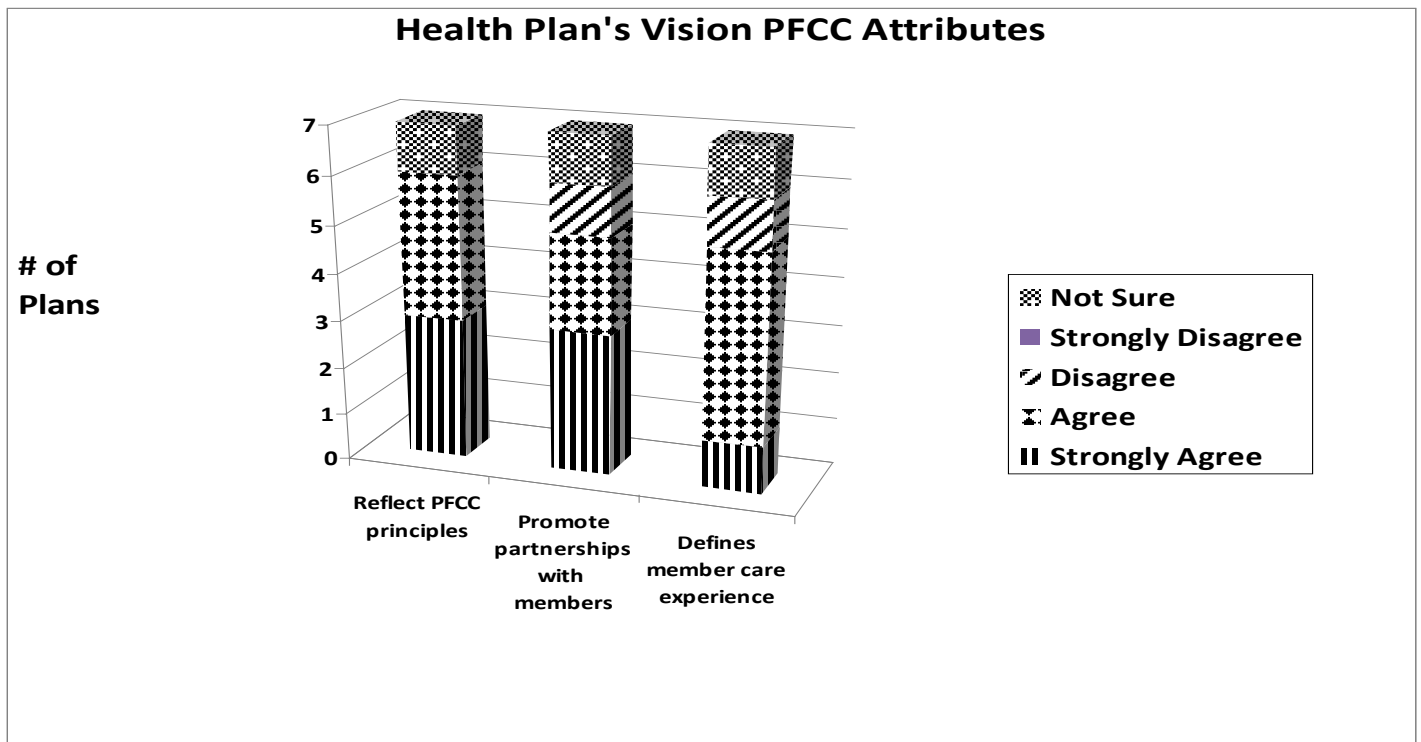
Oregon is the first in the nation to use this survey. There is strong interest across the country in using the survey and the IPFCC will take a lead in distributing it nationally.

Oregon Health Plans' Assessment Survey Response Summary

- Surveys were sent to nine Quality Corp health plan partners.
- Seven health plans completed the survey.

Oregon Health Plans' Leadership Engagement

Studies have shown that establishment of a patient- and family-centered care (PFCC) culture and practice requires alignment of values and mission, as well as real leadership engagement. Oregon health plans were asked to rate themselves with regard to their vision, mission, definition of quality, and philosophy of care statements. The following graph summarizes surveyed health plans' level of agreement that their vision, mission, definition of quality, and philosophy of care statements include specified PFCC values.



One health plan commented, “We do have specific projects where we are learning to do these things. We do have aspirational goals that include becoming proficient in these areas. We are limited in our current practices.”

The Role of Oregon Health Plans in Supporting Medical Group Involvement of Patients and Families

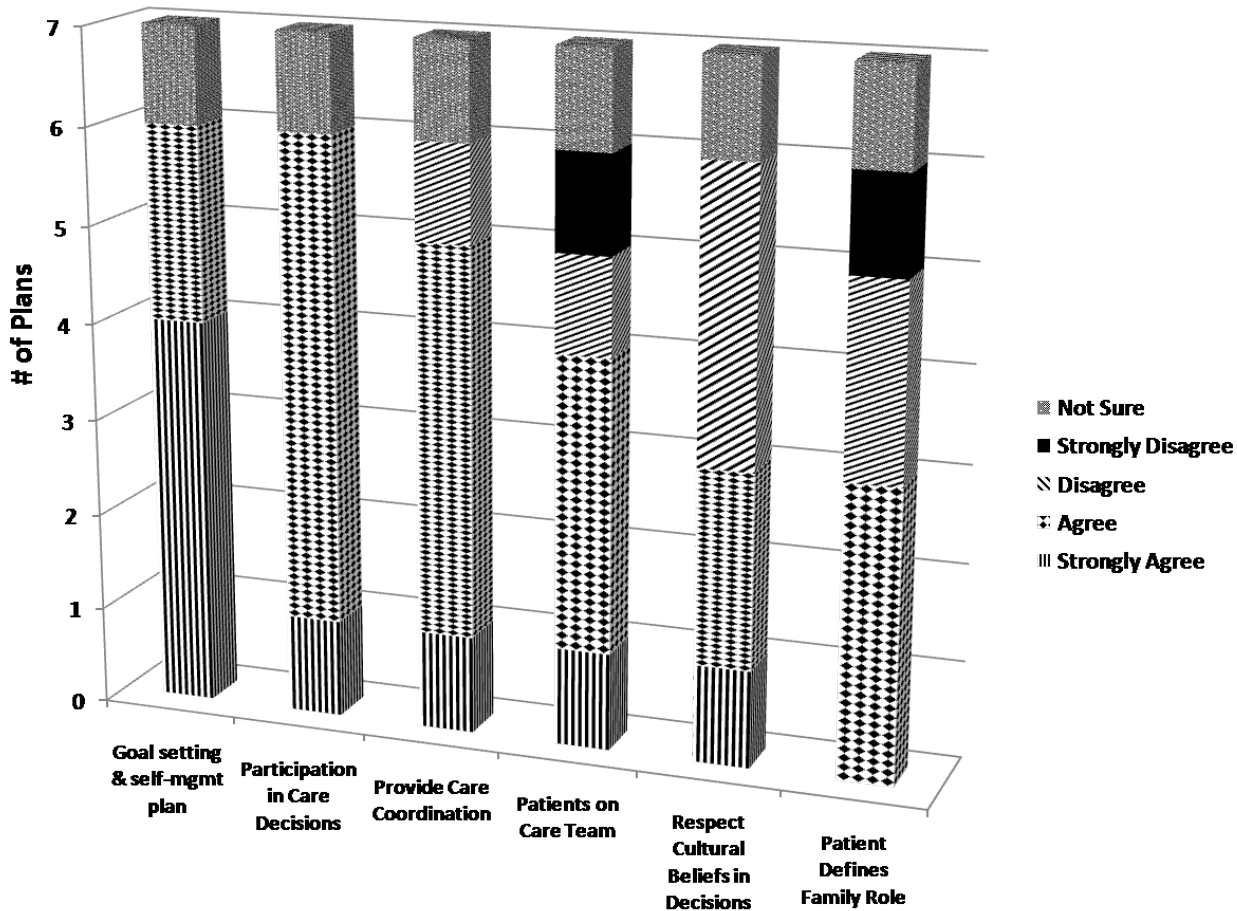
- Two Oregon health plans reported that they provide support and financial incentives to medical groups for promoting patient and family engagement [quality improvement, patient safety, etc.].
- Only one Oregon health plan provides rewards and recognition for medical groups that partner with patients and families in practice redesign, quality improvement, and patient safety.

Health Plans’ Use of Members and Families as Advisors

- Two Oregon health plans have a member and family advisory council.
- These same health plans have members serving on information and education committees.
- Other committees that patients and/or families serve on include a member services committee and a quality improvement committee.
- Five health plans have no patients or families serving on committees or patient advisory councils.

Promotion of Standards of Practice by Oregon Health Plans

Health plans may develop pay-for-performance, medical homes or accountable care organizations that create incentives for engagement of patients and families in health care decision-making. Below is the response from health plans on the degree to which their organizations use these approaches to support the following practices.



Promotion of Standards of Practice

- Encouraging participation in health care decision making and in goal setting/self-management planning are the most frequently reported practices.
- Six plans agree or strongly agree with the practice of encouraging patients to set goals and be involved in self-management. Providing care coordination is also supported by five health plans.
- Four of Oregon health plans use financial incentives for medical groups to implement innovative care delivery models.
- Only one Oregon health plan reports using reimbursement strategies with medical groups that implement innovative care delivery models.

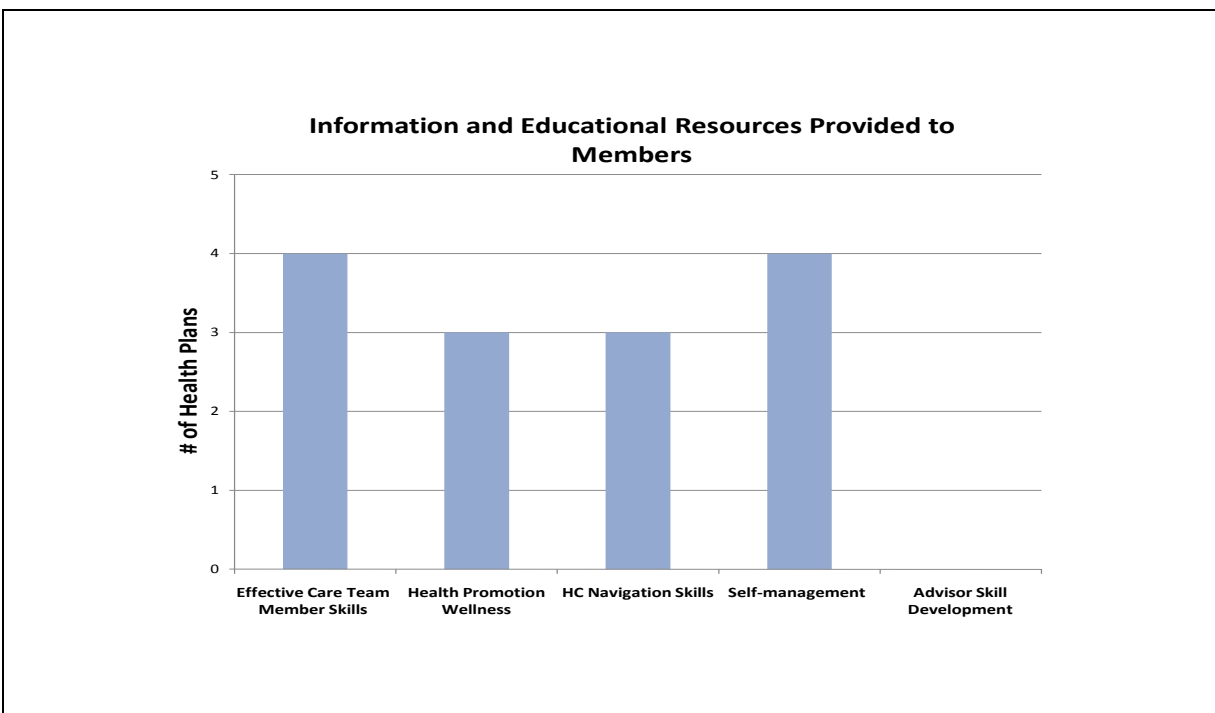
Information and Education Provided by Oregon's Health Plans

Providing support and incentives to medical groups that enhance access to information and education to patients and families is critical to improving the partnership between consumers and health care organizations. Five areas in which health plans can improve access are:

1. Providing information/education in primary languages and at appropriate literacy levels
2. Ensuring access to evidence-based, shared decision-making resources and programs
3. Providing a mechanism for patients and families to collect and organize their personal health information
4. Involving patients and families in development of educational materials
5. Utilizing patients and families as teachers or facilitators in educational programs and group activities

In our survey, only one health plan provides support and incentives in three areas above [#1, 2, 4]. Another health plan provides support for collecting and organizing personal health information. No plans provided incentives to medical groups for the practice of involving patients or families in educational programs or group activities for other patients.

Oregon health plans are sponsoring and providing access to useful resources and programs for members and families. The number of those programs varies among different plans. It is significant that no health plans provide training for patients and families to develop skills to serve as advisors in health care.



Measurement and Incentives for Patient and Family Engagement by Oregon Health Plans

Measurement and incentives by Oregon health plans was surveyed in four areas.

- Three Oregon health plans provide incentives to members who achieve positive health improvement through healthy behavior change. These incentives are offered only to members whose employers choose to sponsor the incentives.
- One health plan provides support for the development of “dashboards” that measure patient/family perceptions of care; health care utilization; and patient safety and quality.
- One health plan provides incentives to medical groups that track and improve measures of patient- or family-centered care [ie. involvement of family members in the patient’s care as desired by patient; useful and easily understood information about their health conditions, etc.].

Finally, health plans were asked if they conduct quality improvement activities and regularly monitor the implementation and effectiveness of patient- and family-centered innovations.

- Two health plans indicated they conduct this type of quality improvement and ongoing monitoring.

Conclusion

This project seeks to raise awareness about the importance of patient- and family-centered care as well as provide intensive technical assistance to help organizations learn how to do it. We are eager to share our findings both locally and nationally. Knowledge is key to transformation. We appreciate the participation of those that responded to the surveys and call to action.

Although our results do not reflect all practices in Oregon, the survey responses of both primary care medical groups and health plans help us begin to understand the strengths and opportunities to improve patient and family engagement with health care organizations in Oregon. A majority of Oregon medical groups completing the survey expressed a strong commitment to a patient- and family- centered care mission, value, and philosophy statements. They make financial and personnel investments, and clearly communicate their commitment to patient- and family-centered care to patients, staff, and medical staff. It is noteworthy that clinics not yet engaged in any particular patient- and family-centered care activity indicated this is a high priority in their organization.

When it comes to putting action behind their words, few medical groups have partnered with patients and families in leadership of their organization. However, many expressed interest in understanding how to engage patients and families in meaningful ways. Some organizations partner with community groups, such as

the Oregon Lung Association, to better understand patient needs. Many of these groups would like to invite their own patients to participate and welcome assistance in areas such as how to use patient/family time effectively. The increase in Patient-Centered Primary Care Medical Home implementation projects also contributed significantly to heightened interest.

The interest in matching practice with vision is encouraging. There are some excellent best practice sites that have created positive partnerships with patients and families. Their stories and experience can be a catalyst for others interested in moving toward full patient and family engagement to improve health care quality.

The response to the health plan survey was excellent. The assessment of health plans shows a wide variation in the degree to which plans engage members in their own activities and to what degree they promote partnership of medical groups with their patients and families in the area of health care services and health care innovation. The number of "not sure" responses and other comments from respondents suggest there is confusion about who "owns" patient- and family-centered care within the health plan organizational structure.

There were two plans that showed a strong commitment through action and incentives to encourage this partnership. They can serve as models in this area of collaboration among the three key stakeholder groups- consumers, primary care and health plans. We look forward to those opportunities as this project moves into its next phase.

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