The Era of Citizen Engagement: Hearing patient and community voices in research, health policy and new models of primary care

Lyle J. Fagnan, MD

As I get older, my hearing is getting better and I am listening in different ways, especially to patients. I search for the patient voice in my office practice, in research studies and in health reform initiatives. The patient voice is getting louder and is changing the culture of medicine. I like the shorthand definition of culture as “the way we do things around here.” It is no longer business as usual as we reach for a patient-centered approach to care, conduct participatory research and implement patient advisory councils and community advisory councils. What are these voices telling us about patient care, research and the way health care is delivered?

The research ORPRN conducts has influenced my approach to patient care and the way I listen to patients. I have become aware of the importance of shared decision making (SDM), patient engagement and patient autonomy. ORPRN has been participating in a five-year study of implementing decision aids for SDM into busy primary care practices. SDM recognizes that uncertainty surrounds many decisions in medicine, such as when to recommend surgery for osteoarthritis of the knee or the best treatment for early stage breast or prostate cancer. Patient decision aids are tools that include evidence-based information on each treatment or testing option, helping patients clarify personal values and preferences—setting the foundation for patients to make informed choices in partnership with their clinicians and families. The mantra for SDM is “No decision about me, without me.” Our study results have shown us the difficulty of making SDM a part of routine practice. The culture of medical care does not change easily.

The emphasis on patient self-management for chronic illness care has led to another major shift in my thinking. Providing patients with tools to increase their skills and confidence in caring for an illness such as diabetes mellitus produces better health outcomes and increases their satisfaction with the experience of care. This spring ORPRN is partnering with family medicine practices in Portland, Springfield, Baker City, and Enterprise to study the implementation of patient self-management support tools into their busy and complicated practice lives. This two-year study is also being conducted with practices in Colorado, Iowa, and Wisconsin. We are measuring patient and practice engagement and the acceptance of these tools.

Medical office culture is also changing by the use of the patient medical record and access to health information. The ways doctors and patients communicate is changing, both in where we talk and how we connect. In the past, communication took place in an 8’ x 10’ exam room where the clinician directed the conversation, “owned” the medical record, and documented the office visit encounter—out of view of the patient. In the past the medical chart was paper-based, with the physician writing or having a dictated note transcribed into the chart. A decade later electronic medical records (EMRs) are a universal presence. EMRs have the potential to record the patient visit in different ways. EMRs have after-visit summaries designed to help patients understand what occurred during the visit, the decisions made, and plans for future
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Outcomes Research Institute (PCORI) by Congress in 2010. PCORI research places a major emphasis on incorporating the “patient voice” into how research is conducted, providing patients and the public with the information needed to make informed healthcare decisions, and on improving outcomes. This research is based on the principle that only patients can articulate the questions and outcomes that influence their medical decision making. Ultimately, research is about creating new knowledge and improving health. Practice-based research networks such as ORPRN are able to move research from the academic “Ivory Tower” into community settings where we actively seek the patient voice.

The organizational structure of health care and the development of health policy is seeking patient input. ORPRN works with a number of projects that fall under the category of practice transformation or what is often termed as the medical home. These initiatives are designed to improve the quality of care and the patient experience of care. In Oregon, we have developed standards for primary care practices under the Patient Centered Primary Care Home (PCPCH) model. Practices attest to meeting these standards with the goal of attaining the Triple Aim of better health, better care and improved affordability of care. PCPCH practices measure the experience of care by conducting surveys of their patients or creating patient and family advisory councils (PFACs). These patient voices inform practices about access to care, coordination of care, patient support, and the quality of communication. Moving beyond using surveys to actively seek patient input represents a cultural shift in medical care and only a handful of practices have implemented PFACs. These early adopters are finding that incorporating the patient voice into how they structure their practice is of high value and worth the investment. A few practices such as the Winding Waters Clinic in Enterprise have added patients to their quality improvement committees. The conversation around quality improvement is enhanced and more meaningful with the patients at the table.

Oregon has embarked on a bold initiative, the Coordinated Care Organization (CCO) model to improve health care at the community level. The primary care practices affiliated with CCOs have a major emphasis on coordinating care and effectively linking primary care practices to community resources. Part of the CCO model is the creation of Community Advisory Councils, which provide the patient and community voice that will inform us on what effective practice community linkages should look like.

“The way we do things around here” is changing. We are in an era of “Citizen Engagement” in health care. As I write this column, we are preparing for our annual ORPRN Convocation of Practices occurring on April 24th. The culture of our convocation is changing and this year we are having a session where dyads of patients and their physicians will inform us about the priority questions we address with community research, practice transformation, and health policy initiatives. These questions will focus on what will help patients and their families and will assist the organizations and people who are dedicated to improving health across the entire village.

Patients who have complex, unusual, or undiagnosed illnesses are frequently trying to find relevant information and answer questions. The answers are difficult to find in the doctor’s office but may be informed by patients with similar experiences. One social media site, Patients-LikeMe (www.patientslikeme.com/), allows patients with a condition such as Parkinson's disease to find patient stories that may help answer their questions. The pattern of doctor and patient communication is changing.

Patient input into how research is conducted and communicated is changing the culture of medical research. The National Institutes of Health is emphasizing the patient perspective in all phases of research with the increasing expectation of stakeholder involvement in deciding the relevant research questions and approaches to finding answers. The commitment to seeking the patient voice in research is realized with the establishment of the Patient Centered
Patients as seeds of change:
Patient and Family Advisory Councils are “cropping up” in Eastern Oregon and making a difference

by Jill Currey

As we continue to navigate and improve the “patient-centeredness” aspect in Patient Centered Primary Care Home (PCPCH), several rural practices in eastern Oregon have decided that in order to truly understand and improve from the patient perspective, they should ask the patient. Patient (and Family) Advisory Councils, or PFACs, are not a new concept in healthcare, nor are they specific to primary care. PACs have been around since the early 1990s, presenting patients with the task to provide guidance for improvements to patient safety, program development changes and even clinical policies. Now, with more incentives tied to improvement, such as the 2014 Oregon PCPCH standard on patient and family involvement in quality improvement and Milestone #4 for the Comprehensive Primary Care initiative (CPC), more practices are taking an interest in hearing the patient perspective on healthcare.

One clinic, Pendleton Internal Medicine, established a Patient Advisory Council (PAC) last fall that consists of 13-17 clinic patients and meets on a quarterly basis. The PAC is coordinated by the office manager, Dian Payant, and is part of CPC. The group discusses a range of meaningful topics, from engaging patients about end of life issues (advance directives), simplifying the medication reconciliation process and asking for input on quality of care surveys (implemented yearly). Dian presented her work with the PAC at the CPC quarterly meeting in March.

In Baker City, St. Luke’s Eastern Oregon Medical Associates (EOMA) implemented their first PAC meeting in September, 2013 with a group of 5-10 patients. Their mission is to “help patients get the most out of their healthcare.” Since their inception, the PAC has developed a bi-monthly newsletter titled “Partners in Health,” which targets clinic happenings of interest to patients. The group’s first quality improvement task is how to reduce medical error and wait time for prescription refills coming from the pharmacy.

Several other ORPRN clinics are actively engaging patients as advisors, including: Grande Ronde Regional Medical Clinic (La Grande), Winding Waters Clinic (Enterprise), Mosaic Medical (Madras and Prineville), Peace Health (Cottage Grove), and Mid-Columbia Medical Center (The Dalles).

“An improvement team cannot address issues of quality without the input from the very customers (parent and children) that directly benefit from the services offered.”
-Don Berwick

What are the benefits of having a Patient (and Family) Advisory Council?

- PACs are an effective mechanism for receiving and responding to consumer input.
- PACs ensure that changes really meet the consumer needs and priorities.
- PACs allow for an increased understanding and cooperation between patients (families) and clinical staff.
- PACs are a cost-effective way to develop creative solutions to problems or challenges.

Adapted from the Institute for Patient and Family-Centered Care; Marlene Fondrick and Beverly H. Johnson; Bethesda, MD, 1998. Revised 2002
The Transformation Center: Helping good ideas travel faster
by Laura Kreger

The Oregon Health Authority’s Transformation Center is the state’s hub for health system innovation and improvement. It was created in 2013 to support coordinated care organizations (CCOs) and the adoption of the coordinated care model across Oregon.

The coordinated care model is a new way of doing business to achieve better health, better care and lower cost for all Oregonians. Key elements include integrated and coordinated benefits and services, local control and flexibility, and a global budget that emphasizes prevention, early intervention and accountability. The coordinated care model was first implemented in Oregon’s Medicaid program, also known as the Oregon Health Plan. It was implemented through 16 coordinated care organizations — regional networks of all types of health care providers (physical, mental and dental) who have agreed to work together in their local communities for people who receive health care coverage under the Oregon Health Plan.

Most of Oregon’s coordinated care organizations have been up and running for more than a year now. The coordinated care model is already beginning to show signs of success, as preventive, primary care visits are on the rise, and emergency department visits are declining. Spreading the coordinated care model is the next step to better health, higher quality care, and creating a more sustainable health care system for all Oregonians.

The Transformation Center’s unique role in these efforts is to help good ideas travel faster, support health and health care innovation, and provide supports and streamlining.

The center does this by providing technical assistance, creating key connections with partners and stakeholders across sectors, and building statewide learning collaboratives to foster peer-to-peer learning and share evidence-based and emerging best practices. There are separate learning collaboratives for CCO leaders, their Community Advisory Council members, and staff and providers addressing the needs of complex patients.

For more information, visit www.transformationcenter.org

ORPRN’s Recent Publications


Davis M, Currey J, Howk S, Boise L, Fagnan LJ, Vuckovic N. A Qualitative Study of Rural Primary Care Clinician Views on Remote Monitoring Technologies. The Journal of Rural Health, Published first online 24 May 2013. DOI: 10.1111/jrh.12027. OHSU featured this article in their “Paper of the Month” online column. To read more and view photos, go to: http://www.ohsu.edu/xd/education/schools/school-of-medicine/about/school-of-medicine-news/research-news/paper-73013.cfm


Springfield Family Physicians joins ORPRN

from Daniel K. Paulson, MD

A couple of years ago, Springfield Family Physicians joined the Oregon Rural Practice-based Research Network (ORPRN). We have greatly appreciated being a part of this group and feel that we have benefited in several ways. Even though we are a suburban-based practice, we often have more in the common with ORPRN members than with many primary care practices in our area that are part of large, multispeciality groups. Some of these shared interests are due to being an independent, physician-owned, single specialty practice. The state-wide connection to similar clinics with shared interests has been valuable to us at a time of rapid changes in health care.

As a member of ORPRN, we have participated in one research study and are beginning a second one. We are participating in the TOPMED study, which has focused on transforming our clinic into a high performing patient-centered primary care medical home. We have benefited from the contributions of our assigned Practice Enhancement Research Coordinator (PERC) who has shared ideas gleaned from other clinics across the network. This input has contributed to our medical clinic in ways that go beyond the confines of the TOPMED* study, providing a forum in which to brainstorm about solutions to other problems and questions that affect the clinic. These meetings have also helped maintain the morale of the management team during this time of rapid changes.

We recently began participating in INSTEPP**, a study that focuses on methods of patient engagement, an area in which we have not done much work on so far, but one which may have a significant impact on the quality of care we provide to our patients.

* Transforming Outcomes for Patients Through Medical Home Evaluation and Re-Design
** Implementing Networks Self-Management Tools Through Engaging Patients and Practices

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ORPRN Collaborates with Samaritan Health Services

by Mark Remiker

Samaritan Health Services (SHS), the Corvallis-based not-for-profit health system, plays a major role in Oregon health care delivery. SHS runs 5 hospitals, 70 primary care and specialty clinics, employs over 5,000 people, and serves communities spanning 5 of Oregon’s most populated counties. Approximately 44% of the combined population of Linn, Benton, Lincoln, Marion, and Polk counties receives some healthcare from an SHS affiliate.

Not only does SHS function as a mainstay for healthcare delivery across the mid-Willamette Valley and central Oregon coast, they have also proved to be a vital part of ORPRN. In the past two years, ORPRN has recruited 11 SHS primary care clinics to participate in 7 different ORPRN projects (see table).

In addition to primary care research, SHS has assisted ORPRN in enlisting key staff members and patients from Samaritan Lebanon Community Hospital and Samaritan Urgent Care – Lebanon to participate in qualitative interviews focusing on the use of the Emergency Department for non-traumatic dental conditions.

The rapid pace at which ORPRN was able to recruit clinics would not have been possible without the support of SHS staff Ryan Combs, Vice President of Primary Care Operations, and Shiloh Erven, Director of Primary Care Physician Clinics – Lebanon to participate in qualitative interviews focusing on the use of the Emergency Department for non-traumatic dental conditions.

When asked to speak on the ORPRN/SHS relationship, Mr. Erven said: “We greatly value our relationship with ORPRN and feel it has opened up many opportunities for interesting and cutting edge primary care research that would not have been possible alone. The value comes from the vast experience the ORPRN team has with other practices like ours. ORPRN PERCs and leadership have experience working with and for rural practices in the past. This experience gives the team a realistic understanding of the pressures and workflow challenges that face rural primary care practices. The ORPRN team members have truly become an extension of our own work families within our rural practices and we look forward to the times when we get to meet and collaborate with them. All members of the ORPRN team have been incredibly supportive of our mission. They have a hard working team of talented, smart and friendly individuals. ORPRN team members have the personalities and work ethic of the type of people I am always on the lookout for to recruit and hire for our own primary care practices.”

With SHS helping ORPRN to expand their primary care research efforts, and ORPRN providing quality improvement support to SHS clinics, the way toward an enduring mutualistic relationship has been paved. LJ Fagnan, MD, Director of ORPRN, states: “We are excited to continue to develop the SHS/ORPRN collaboration through dissemination and implementation of quality improvement initiatives and patient centered outcomes research.”

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### SHS Clinics Participating in ORPRN Studies

<table>
<thead>
<tr>
<th>Project Title</th>
<th>Focus</th>
<th>Participating Samaritan Clinics</th>
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<tr>
<td><strong>Transforming Outcomes for Patients through Medical Home Evaluation and Redesign (TOPMED)</strong></td>
<td>Randomized controlled trial studying practice facilitation of medical home concepts supplemented with population management software. Aims to improve quality metrics, prevent Emergency Department usage and improve patient satisfaction.</td>
<td>Samaritan Medical Home (Lebanon)</td>
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| **Activating Rural Clinics and Women with Disabilities to Improve Cancer Screening (Crossroad II)** | This pilot project will test the impact, feasibility, and acceptability of an innovative approach for overcoming barriers to cancer screening among women with disabilities receiving care at your practice. | Samaritan clinics*  
* To retain anonymity in ongoing ORPRN projects, the clinic names have been withheld. |
| **Evaluation of the AHRQ Workflow for Health IT Toolkit**                    | An evaluation task order that tests the usability and usefulness of an AHRQ Workflow Toolkit in Health IT                                                                                             | Samaritan Family Medicine and Resident Clinic (Corvallis)                                                              |
| **Shared Decision Making**                                                   | This project’s purpose is to gain a better understanding of the current attitudes towards the concept of shared decision making (SDM) and to develop approaches to integrate decision aids (DAs) in clinical practice. | Samaritan Family Medicine and Resident Clinic (Corvallis)                                                              |
| **Partnering to Reduce Falls and Falls Injuries in Your Community**          | This project examines whether having a falls prevention protocol in place in primary care clinics affects outcomes for geriatric patients (age 75+) at risk of falls. | Samaritan Internal Medicine (Corvallis)  
Calapooia Family Medicine (Albany)  
Samaritan Medical Home (Lebanon)  
Mid-Valley Medical Plaza (Lebanon)  
Sweet Home Family Medicine (Sweet Home)  
Albany Internal Medicine Group (Albany) |
| **Comprehensive Primary Care Initiative (CPCI)**                             | This initiative from the CMS Innovation Center will help primary care practices deliver higher quality, better coordinated, and more patient-centered care.                                             | Samaritan Family Medicine and Resident Clinic (Corvallis)  
Samaritan Internal Medicine (Corvallis)  
Samaritan Pacific Internal Medicine (Newport) |
| **ED Dental**                                                                | This project uses mixed methods to explore causes of emergency department utilization for non-traumatic dental problems.                                                                            | Samaritan Urgent Care, Lebanon – A Walk-in Clinic  
Samaritan Lebanon Community Hospital |

“They look pretty happy for a first day on a new EMR!” - Mark Remiker, ORPRN PERC

Samaritan Family Medicine, Geary St. (Albany)  
L to R: Jaton Whitney, Nina Gates, Ryan Combs, Erin Kowanda, Peggy Barr and Misty Gerkman – photo taken on the first day of going live with Epic (March 31).
Columbia Gorge Approved for a Funding Award by the Patient-Centered Outcomes Research Institute

Kristen Dillon, MD, of Columbia Gorge Family Medicine and Melinda Davis, PhD, of ORPRN received a “Pipeline to Proposal” funding award by the Patient-Centered Outcomes Research Institute (PCORI). Thirty proposals were approved to provide seed funds for building communities interested in advancing patient- and stakeholder-driven health research.

Their project will focus on building partnerships and a community interested in understanding the health system transformations in the Columbia Gorge. The specific goals of the project are to:

1. Understand the health system transformations that PacificSource Columbia Gorge Coordinated Care Organization (CCO) is implementing or considering implementing.
2. Engage diverse community and health system stakeholders in conversations on the CCO’s regional community health needs assessment.
3. Foster relationships with network members, build an advisory council, and prepare a list of regional health needs to inform partnership team next steps.

This award is among the first to be made through PCORI’s new Pipeline to Proposal Awards Initiative. These awards encourage the development of partnerships and research ideas among individuals and groups who want to take an active role in health research but may not have opportunities to do so. PCORI hopes these projects will lead to topics and proposals for comparative effectiveness research studies.

Implementing Networks Self-management Tools Through Engaging Patients and Practices (INSTTEPP)

A one-day Boot Camp Translation (BCT) was held in Portland on March 21 to open communication between patients and clinic staff about Self Management Support (SMS). The study aims to improve and evaluate the impact of SMS through group discussion and adoption of tools from an AHRQ online library. Patients, clinicians and care managers attended from Springfield Family Medicine, Winding Waters Clinic, Northwest Primary Care, and St. Luke’s Eastern Oregon Medical Associates. With 25 in attendance, this process for building community was led by a team from the State Network of Colorado Ambulatory Practices & Partners (SNOCAP). Sixteen practices in four states are participating in this study.