the power of the patient voice in improving practice

Don Nease, MD
Green-Edelman Chair for Practice Based Research
Dept. of Family Medicine
Director of Community Engagement and Research
Colorado Clinical and Translational Sciences Institute

donald.nease@ucdenver.edu

University of Colorado
Anschutz Medical Campus
objectives

• recognize the importance of engaging patients in improving care

• understand how to begin or advance the engagement of patients at your practices

• recognize and avoid potential barriers and pitfalls to patient engagement

• successfully begin or advance patient engagement in your practices
overview

• Why involve patients in improving care?
• Basic principles of patient engagement
• Practicalities
• Review
• Discussion
why?

• what’s the evidence?
• does it make sense?
the patient experience

Pt F/T barriers:
- transportation care giver availability to accompany pt.
- lack of $K$ of resources to support F/T
- Lack time to do it
- Discomforts - eg: d.l. labs/needles
- distance to provider/Show care
- Anxiety - of what testing will show necessity/care not available
- Stigma
- low trust in local service care
- Knowing when to F/u w/who + providers
- rx < B>H = "I'm Nuts"
- trust ↓ reliability
medication related burden

Mohammed MA, Moles RJ, Chen TF. Medication-related burden and patients’ lived experience with medicine: a systematic review and metasynthesis of qualitative studies. BMJ Open. 2016 Feb 2;6(2):e010035. PMCID: PMC4746464
cumulative complexity

Fig. 2. The cumulative complexity model.
multimorbidity

- UK based study of illness perceptions and impacts on self-management & outcomes

- Self-management behavior was predicted by illness perceptions of illness consequences

- Self-monitoring and insight was predicted by “hassles” in health services

- Health status predicted by age and patient experience of multi-morbidity

hassles?


- "After controlling for patient characteristics, primary care communication and coordination of care were inversely associated with patient hassles score: as communication and coordination improved, the reported level of hassles decreased."
Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement.

Han E, Hudson Scholle S, Morton S, Bechtel C, Kessler R. Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement. Health Aff (Millwood). Project HOPE - The People-to-People Health Foundation, Inc; 2013 Feb;32(2):368–75.
## Predicted Per Capita Costs of Patients by Patient Activation Level

<table>
<thead>
<tr>
<th>2010 patient activation level</th>
<th>Predicted per capita billed costs ($)</th>
<th>Ratio of predicted costs relative to level 4 PAM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1 (lowest)</td>
<td>966**</td>
<td>1.21**</td>
</tr>
<tr>
<td>Level 2</td>
<td>840</td>
<td>1.05</td>
</tr>
<tr>
<td>Level 3</td>
<td>783</td>
<td>0.97</td>
</tr>
<tr>
<td>Level 4 (highest)</td>
<td>799</td>
<td>1.00</td>
</tr>
</tbody>
</table>

**Source:** Judith H. Hibbard, Jessica Greene, and Valerie Overton, “Patients with Lower Activation Associated with Higher Costs; Delivery Systems Should Know Their Patients’ Scores,” *Health Affairs* 32, no. 2 (2013): 216–22. **Notes:** Authors’ analysis of Fairview Health Services billing and electronic health record data, January–June 2011. Inpatient and pharmacy costs were not included. PAM is Patient Activation Measure. **p < 0.05**
basic principles
basic principles from CBPR

- engagement...
  - recognizes community as a unit of identity
  - builds on strengths and resources within the community
  - facilitates collaborative, equitable involvement of all partners in all phases
  - integrates knowledge and intervention for mutual benefit of all partners
  - promotes a co-learning and empowering process that attends to social inequalities
  - involves a cyclical and iterative process
  - addresses health from both positive and ecological perspectives
  - disseminates findings and knowledge gained to all partners
  - involves long-term commitment by all partners
Patients become our partners * The front desk staff are happy to see me * I can care for myself between visits * The doctor demands my best * I’ve known her forever * The office advocates for me * Our doctors provide community health * My doctor makes eye contact * My office calls to check on me between visits * Help plan your own care * Our practice is the best * The whole office care for me * My nurse listens * My provider gets personal * Trust in your patient * Providing guidance * Health * The practice helps build a healthy neighborhood * I am thankful for my doctor * Trust your doctor understands me * She knows my name * The doctor goes beyond the formal medical questions * The medical home can get emotional * My patient understands * I get letters reminding me to be healthy * I am thankful for my patients * The nurses teach healthy living to our students * The staff know all about me * I can keep track of my blood tests * He knows my kids’ names * My patient cares about her health * They answer all my questions * I get emotional and that’s ok * The nurse works hard to make me comfortable * I learned what an HgbA1c is * The doctor sits down when he speaks to me * The providers care for the whole community * The doctor took my mother seriously * Cared for me as an individual * Communicated with us outside the office * I’m getting top-notch up-to-date medical care

Medical Home is Relationship
it’s about relationships
and expertise

- acknowledge the expertise that everyone brings to the table
“Our culture is based on quick fixes, but for this, there is no easy way out”

“Chronic illnesses don’t just affect patients”

“Diabetes - it felt like a death sentence”
practical applications
A Multidimensional Framework for Patient and Family Engagement in Health and Health Care

<table>
<thead>
<tr>
<th>Levels of engagement</th>
<th>Continuum of engagement</th>
<th>Consultation</th>
<th>Involvement</th>
<th>Partnership and shared leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct care</td>
<td></td>
<td>Patients receive information about a diagnosis</td>
<td>Patients are asked about their preferences in treatment plan</td>
<td>Treatment decisions are made based on patients’ preferences, medical evidence, and clinical judgment</td>
</tr>
<tr>
<td>Organizational design and governance</td>
<td></td>
<td>Organization surveys patients about their care experiences</td>
<td>Hospital involves patients as advisers or advisory council members</td>
<td>Patients co-lead hospital safety and quality improvement committees</td>
</tr>
<tr>
<td>Policy making</td>
<td></td>
<td>Public agency conducts focus groups with patients to ask opinions about a health care issue</td>
<td>Patients’ recommendations about research priorities are used by public agency to make funding decisions</td>
<td>Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs</td>
</tr>
</tbody>
</table>

Factors influencing engagement:
- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)

Stages of Clinic-Based Patient/Family Engagement

1. Clinics adopt engagement work solely to receive accreditation (e.g. NCQA PCMH)
2. Key clinic leader(s) willing to adopt patient engagement work
3. Adoption of patient and family engagement methods influence the clinic culture; there is a spread of the concept
4. Existing patient and family engagement methods adapt to maintain sustainability
## Patient Experience Surveys

<table>
<thead>
<tr>
<th>Pros</th>
<th>Cons</th>
<th>Might Be a Good Fit If:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatively easy to use</td>
<td>Results can only be as good as the questions asked</td>
<td>A practice is <em>very</em> unable to adopt more involved methods on the continuum of engagement</td>
</tr>
<tr>
<td>May be required of clinic by larger (hospital, payer) system</td>
<td>Low response rates are typical and responders are often polarized</td>
<td>A practice is required to do a survey based on institution requirements</td>
</tr>
<tr>
<td>May be more helpful if internally developed with specific questions in mind for informing QI efforts</td>
<td></td>
<td>A practice is unable to protect a staff member’s time to organize other methods of pt/fam engagement</td>
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## Patient/Family Advisors on QI Teams

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<tr>
<td>Allows platform for shared leadership</td>
<td>Requires investment in educating pt/fam advisors about QI</td>
<td>QI team is lead by a strong facilitator who values patient and family engagement</td>
</tr>
<tr>
<td>Patients can serve as powerful source of persuasion for staff or providers reluctant to engage in QI/practice transformation</td>
<td>Requires investment in creating a level playing field during meetings</td>
<td>Clinic has been dissatisfied with patient surveys as a means of engaging patients in improving the clinic</td>
</tr>
<tr>
<td>Allows for patients/families and health professionals to learn from each other</td>
<td>Requires recruitment and selection of patient/family advisors</td>
<td>QI teams are newly forming and have not yet developed implementation plans (i.e. there is opportunity for pt/family input)</td>
</tr>
<tr>
<td>Allows clinic to avoid wasting time on QI projects patients don’t care about</td>
<td></td>
<td>Bulk of clinic’s practice transformation work happens in small, QI teams</td>
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</table>
# Patient/Family Advisory Boards

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<tr>
<td>Allows platform for shared leadership</td>
<td>Requires investment in educating pt/fam advisors about clinic work flows</td>
<td>Clinic has been dissatisfied with patient surveys as a means of engaging patients in improving the clinic</td>
</tr>
<tr>
<td>Requires investment in creating a level playing field during meetings</td>
<td></td>
<td>Clinic practice transformation works happens mostly in all clinic meeting and not in smaller QI teams (advisory board leader can bridge to this meeting)</td>
</tr>
<tr>
<td>Requires recruitment and selection of patient/family advisors</td>
<td></td>
<td>Clinic leadership has capacity/interest to make changes based on advisory board suggestions</td>
</tr>
<tr>
<td>Requires protection of staff member(s) time for meetings, agenda creation, e-mailing, etc.</td>
<td></td>
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Advisor Recruitment

- Provider/Staff Recommendations
  - Start with who you know
  - Snowball from there

- Advertising – waiting room, exam room, clinic bathroom, local paper

- Representation?
  - Advisors are not representatives but…
  - Diversity of experience and expertise matters
  - Is there a voice you are missing?
Qualities of a Good Patient/Family Advisor

- Interview them for these!
  - See the big picture
  - Have ability to listen and hear other view points
  - Do not push personal, professional, or political agendas
  - Have a sense of humor
  - Have to ability to connect with people
  - Can learn and will step outside of comfort zone
  - Are willing to share their opinions and thoughts
Meeting planning

- Timing
  - Noon? Before or after work?

- Payment
  - Be up front about what you *can* afford

- Food

- Gas
points to remember...

• plan carefully… 3x rule
• group dynamics… crock pots & microwaves
• pay attention to and explicitly define roles… both job and group
• share and celebrate successes
Overcoming Commonly Cited Barriers

“We’re just not ready. We need to get our QI teams off the ground and then we’ll invite patients and families to the table.”

- **Common** concern about revealing “what’s behind the curtain” when in reality, patients already know healthcare is messy.
- Patient/family advisors engaged from the onset are more likely to productively contribute
Overcoming Commonly Cited Barriers

“What if patient and family advisors ask us to change something we just can’t change?”

• They probably will…and it won’t be the end of the world.
• These are often the greatest opportunities for discussions that foster mutual understanding of each other’s roles.
Real Barriers to Watch Out For

• Clinic leadership has no direct connection with patient/family engagement efforts… makes implementing change hard

• Meeting times impact who shows up… Keep in mind times that are convenient for staff, may not be convenient for working patients or vice versa.

• Projects that solicit a patient stamp of approval… If there’s no room for changing the project, advisors may feel like token patients

• Failure to report back… Advisors may lose steam if they don’t hear back about what comes of their recommendations
review

• engaging patients in improving our care is good for them *and* our practices

• it’s all about relationships

• take the necessary time to reflect, plan, and recruit

• celebrate your successes together!
questions and discussion