Everyone at the Table: Engaging Patients in Team-Based Quality Improvement

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• Primary care Academics Transforming Healthcare (PATH) Collaborative
“In high-functioning health care teams, patients are members of the team; not simply objects of the team’s attention; they are the reason the team exists and the drivers of all that happens.”

“Shifting the medical culture from one in which patients are passive recipients of care to one that recognizes patients as partners at all levels of care will require both (1) training to empower frontline workers and (2) an organizational commitment to promote and reward patient engagement.”

“Employing simultaneous and complementary ‘bottom-up’ and ‘top-down’ strategies was critical to our organization’s ability to incorporate patient engagement as a core component of practice”

Agenda

• Introductions – Your Engagement Experience
  • What are you doing? What could you do?
  • What excites you about engaging patients/families?
  • What makes you hesitant or nervous?
    What feels like a barrier?

• Patient Engagement Program
• Interactive Activity Using Toolkits
• Research on Program Efficacy
• Wrap-up – Q&A
Learning Objectives

• Evaluate benefits of patient engagement
• Consider solutions to key barriers to PE
• Understand key steps/considerations for engaging patients in team level improvement
• Identify resources to support engagement
• Understand PE program efficacy
What is Patient Engagement?

an **active process** of ensuring that our patients’ experience, wisdom and insight are infused into individual care and the **design and refinement** of our care systems.
How are you engaging patients?

What is happening in your organizations that would benefit from patients’ insights?
Why Engage Patients in Team Based Improvement?

• Patients may not be experts in the business of healthcare, but **they are expert consumers of care** in our organization.

• They bring **new perspectives** to the challenges we may not be aware of.
Health Canada’s Public Involvement Continuum

Level 1: Low level of public involvement and influence
- Inform or Educate
- Communications

Level 2: Mid level of public involvement and influence
- Gather Information
- Listening
- Consulting

Level 3: Mid level of public involvement and influence
- Discuss
- Engaging

Level 4: High level of public involvement and influence
- Engage
- Partnering

Level 5: High level of public involvement and influence

Adapted from Patterson Kirk Wallace

Levels of Patient Engagement

<table>
<thead>
<tr>
<th>Engagement Levels</th>
<th>Definition and Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>PARTNER 5</td>
<td>Patients are full participants</td>
</tr>
<tr>
<td>INVOLVE 4</td>
<td>Patients are advisors</td>
</tr>
<tr>
<td>DISCUSS 3</td>
<td>Patients are in dialog with providers</td>
</tr>
<tr>
<td>GATHER 2</td>
<td>Patients are informers</td>
</tr>
<tr>
<td>INFORM/EDUCATE 1</td>
<td>Patients are recipients of information and education</td>
</tr>
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</table>

- Continuum
- All valuable
- Different levels meet different needs
- The higher the level, the richer the experience; the more input from patients
Exploring More Fully
Your Experience
Motivators and Barriers

1. What excites you about engaging patients/families?
2. What makes you hesitant or nervous? What feels like a barrier?
Myths about Patient Engagement

- We have to do what patients want
- Patients will see our mistakes and judge us
- HIPAA prohibits/limits patient engagement
- Patients don’t know enough about the business of healthcare to add value
- Patients will only vent about own experience
- Skepticism about their interest in QI details
Program Design

• **Readiness Assessment**

• **Trainings**
  – Train the trainers for coaches
  – Large group
  – Individualized meetings with teams

• **Toolkits**

• **Consult** on engagement strategies

• **Support** PE efforts
  – e.g. focus groups, advisory panels
Free Toolkits

• http://hipxchange.org/PatientEngagement
Principles of Engagement

1. Patients Add Value
2. Engage Early and Often
3. Make Sure TEAM is on Same Page
4. Communicate – Shared Expectations
5. Just DO IT!

“Don’t let perfection be the enemy of the good”
Steps to Engagement

1. Getting Started: A Process of Discernment
2. Matching the Engagement Method with Team Projects
3. Defining the Job
4. Identifying and Recruiting the Best Patients for the Job
5. Inviting Patients: Obtaining a Mutually Beneficial Match
6. Creating a Welcoming Environment
Discernment

• Critical not to jump over this step
• Team members need a shared understanding of the value of engaging patients

• Tools include:
  – Team readiness survey
  – Myth and Facts sheets
  – Engagement Ladder
  – Patient and Provider Concerns (and responses)
Engagement Examples
## Patient Engagement Activities Conducted by Teams (N=49)

<table>
<thead>
<tr>
<th>Highest Level Achieved</th>
<th>Number of Teams (%)</th>
<th>Activities</th>
<th>Patient Engagement Contributions</th>
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<tbody>
<tr>
<td>None</td>
<td>5 (10%)</td>
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<td>N/A</td>
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<tr>
<td>Level 1: Inform/Educate</td>
<td>0 (0%)</td>
<td>Visibility walls, patient education materials</td>
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| Level 2: Gather        | 20 (41%)            | Surveys, cycle times, penless surveys, phone surveys, interviews, in-person feedback, paper surveys | • led team to decrease wait time in the exam room  
• Resulted in change in timing of immunizations to prior to the MD visit (90% supported) |
| Level 3: Discuss       | 18 (37%)            | Focus groups, phone conversations/interviews, paper surveys, interviews in clinic, e-mail feedback, | • Phone discussions with patients led to highlighting physician instructions on the After Visit Summary. |
Level 2 Patient Engagement Contribution
Highest Level of Patient Engagement Attained by Teams (N=49)

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• Focus group discussion led to change in waiting room layout to make more welcoming and conversational. |
| Level 5: Partner       | 2 (4%)              | Team member | • Patients participating in team meetings changed the conversation and helped to shift the culture |
“Instead of waiting to see how it will affect the patient, we can just ask her because she’s right there.”

– Microsystem Team Member commenting on having a patient regularly participate in their weekly team meetings
“We want to include you in this decision without letting you affect it.”

“We want to include you in the decision without letting you affect it”
New Era Of Patient Engagement
Choose a Step to Explore

1. Discernment (pg. 8)
2. Matching Engagement Method (pg. 10)
3. Defining the Job (pg. 12)
4. Recruiting (pg. 13)
5. Inviting Patients (pg. 14)
6. Creating a Welcoming Environment (pg. 14)
Outcomes Measurement: Implementation Research Framework
Key Data Sources

• Activity tracking log
• Survey
• Consultant written reports
• Focus group with program leaders
1. I believe that patients bring a perspective to a project that no one else can provide.

2. I am interested in engaging patients in projects.

3. I am confident of my team’s ability to engage patients in projects.
1. List two things you learned about engaging patients during the past 6 months.

2. What, if anything, needs to happen to enable your team to engage patients?
1. What are the key organizational components necessary for patient involvement with care teams?

2. What are the most critical lessons learned from the patient involvement process?
Analysis

• Quantitative
  – Tested difference between baseline and 6 mos, and 12 mos response
  – Mann Whitney U test

• Qualitative
  – Thematic analysis
Results: Acceptability

• Open-ended survey themes:
  – Patient engagement is valuable
  – Patients are excited to participate and appreciate the opportunity
## Perception of Patients Value and Own Confidence Increased Significantly

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Timing</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>P-value (pre/post)</th>
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<tr>
<td><strong>Value</strong></td>
<td>Baseline N=134</td>
<td>0%</td>
<td>3%</td>
<td>12%</td>
<td>57%</td>
<td>28%</td>
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<tr>
<td></td>
<td>6 months N=103</td>
<td>0%</td>
<td>2%</td>
<td>4%</td>
<td>54%</td>
<td>40%</td>
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<tr>
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<td>12 months N=98</td>
<td>0%</td>
<td>0%</td>
<td>11%</td>
<td>48%</td>
<td>41%</td>
<td>0.03</td>
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<tr>
<td><strong>Interest</strong></td>
<td>Baseline N=133</td>
<td>1%</td>
<td>4%</td>
<td>30%</td>
<td>49%</td>
<td>16%</td>
<td></td>
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<tr>
<td></td>
<td>6 months N=103</td>
<td>0%</td>
<td>0%</td>
<td>15%</td>
<td>56%</td>
<td>29%</td>
<td>&lt;0.0001</td>
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<td><strong>Confidence</strong></td>
<td>Baseline N=134</td>
<td>1%</td>
<td>4%</td>
<td>30%</td>
<td>52%</td>
<td>13%</td>
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<td>0%</td>
<td>7%</td>
<td>18%</td>
<td>49%</td>
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Results: Acceptability

• Teams that did not engage patients cited competing demands

• A few teams did not see a role for patients in their redesign work
Limitations

• Generalizability may be limited due to implementation setting

• Data was not collected from patient participants

• Survey response rate declined over time
Key Lessons Learned

• Patient engagement champion on team
• Neutral point person to navigate organizational complexities
• Plan for sustained patient-team interactions
• “Top down” and “bottom up” work toward culture change
• Resources to support the work
Next Steps

- Dissemination and Implementation research regarding toolkits
- Guidance to other organizations implementing and researching patient engagement
Thank You!

Questions?


• Toolkits at: [http://hipxchange.org/PatientEngagement](http://hipxchange.org/PatientEngagement)
• This work would not have been possible without the participation of the microsystems teams and our patient partners.

• Thanks to our PATH and Microsystem Program co-authors: Bill Caplan, Sally Kraft, Stephanie Berkson, Meg Gaines, Bill Schwab, and Pratik Prajapati.

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