Transition Learning Community

February 8, 2017
YOUTH TRANSITION: ENGAGING PATIENTS AND KEY STAKEHOLDERS IN QUALITY IMPROVEMENT

Sarah Davis, JD, MPA

- Center for Patient Partnerships
  - UW-Madison Schools of Medicine and Public Health, Law, Pharmacy, and Nursing
- ICTR– Community Academic Program
- Primary care Academics Transforming Healthcare (PATH) Collaborative
OUR MISSION

To ensure that Patient Experiences Inform Health Care Delivery, Receipt, and Action

Through Partnerships with Patients, Providers, and Policymakers

Professional Education

Individual and System Advocacy

Research & Policy
PATIENTS AS KEY TEAM MEMBERS

“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.”

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

AGENDA

1. Engagement approach for QI
2. Key steps and considerations
3. Addressing key barriers to patient engagement
4. Reflect on unique issues with engaging transitioning youth
5. Discussion
ENGAGEMENT APPROACH
Adapted from Patterson Kirk Wallace

### CATEGORIES OF PATIENT ENGAGEMENT

<table>
<thead>
<tr>
<th>Engagement Categories</th>
<th>Definition and Methods</th>
</tr>
</thead>
</table>
| **PARTNER**           | Patients are full participants  
Examples: members of a team, governance boards, and improvement initiative work groups. |
| **INVOLVE**           | Patients are advisors  
Examples: ongoing Patient Feedback Panels, Patient Advisory Councils, and non-voting participation in patient safety rounds. |
| **DISCUSS**           | Patients are in dialog with providers and clinic staff  
Examples: focus group or interviews. |
| **GATHER**            | Patients are informers.  
Examples: surveys, cycle time, and suggestion boxes. |
| **INFORM/EDUCATE**    | Patients are recipients of information and education  
Examples: brochures, health information posters, and electronic health records. |

- ✫ Continuum
- ✫ All valuable
- ✫ Different methods meet different needs
- ✫ Mix and match
- ✫ Consider each stage of QI
PRINCIPLES OF ENGAGEMENT

1. Patients Add Value – Experience, Wisdom & New Perspectives
2. Engage Early and Often – Continuous
3. Discern: Make Sure TEAM is on Same Page
4. Communicate – Shared Expectations
5. Inclusion and Equity
6. Just TRY IT!

“Don’t let perfection be the enemy of the good”
KEY STEPS AND CONSIDERATIONS
STEPS TO ENGAGEMENT

1. Getting Started: A Process of Discernment
2. Matching Methods with QI Efforts
3. Defining the Job
4. Identifying and Recruiting the Best Patients (and Stakeholders) 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)
### METHODS

<table>
<thead>
<tr>
<th>Inform</th>
<th>Gather/Discuss</th>
<th>Engage</th>
<th>Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mass media (commercials, advertisements, mailings)</td>
<td>Patient surveys</td>
<td>Forums for debate</td>
<td>Patient advisory councils/committees</td>
</tr>
<tr>
<td>Websites and social media (Facebook, Twitter)</td>
<td>Feedback and complaints (interviews, comment cards, hotlines)</td>
<td>Patient panel</td>
<td>Expert patients</td>
</tr>
<tr>
<td>Mailings</td>
<td>Forums</td>
<td>Workshops</td>
<td>Retreats</td>
</tr>
<tr>
<td>Fact sheets and infographics</td>
<td>Suggestion boxes</td>
<td>Public meetings</td>
<td></td>
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<tr>
<td>Displays and exhibitions</td>
<td>Patient diaries</td>
<td>Round tables/Town hall meetings</td>
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<tr>
<td>Presentations</td>
<td>Mystery shopping/shadowing</td>
<td>World cafe</td>
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<tr>
<td></td>
<td>Focus groups</td>
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</tbody>
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Burns, K. K., Bellows, M., Eigenseher, C., & Gallivan, J. (2014). ‘Practical’ resources to support patient and family engagement in healthcare decisions: a scoping review. *BMC health services research, 14*(1)

[https://www.hipxchange.org/DeeplyEngagingPatients](https://www.hipxchange.org/DeeplyEngagingPatients)
Technology is an ingrained part of life for 21st century teenagers.


## MATCHING

<table>
<thead>
<tr>
<th>Engagement Category</th>
<th>QI Examples</th>
<th>Methods – Which shall you use? (Circle)</th>
<th>What QI activities would benefit from this engagement?</th>
</tr>
</thead>
</table>
| **Partner**         | • Include patients as full members of teams, work groups and redesign management committees  
                      • Patients fully engaged from the start                                                                 | • Patients participate fully with teams: help plan meetings and agendas identify aims, craft interventions and as liaisons with other patients |                                                        |
| **Involve**         | • Patients engaged throughout QI process as advisors  
                      • Patients provided enough info about clinic challenges to propose and weigh solutions | • On-going patient feedback panels  
                      • Patients are occasional invitees to team meetings |                                                        |
| **Discuss**         | • Talk with patients about care processes, seek clarification of feedback  
                      • Solicit and share improvement aim ideas                                                        | • Targeted meetings to clarify patient input  
                      • One-time focus grp  
                      • 1:1 interviews (by phone or in person)  
                      • Informal waiting room discussions |                                                        |

- [http://hipxchange.org/PatientEngagement](http://hipxchange.org/PatientEngagement)
STAKEHOLDER MAPPING

- Patients
- Community Leaders
- Suppliers
- Allied Health
- Other Providers
- Management/Leadership
- Family
- ??
STAKEHOLDER MAPPING

1. Identify potential stakeholders through brainstorming
2. Categorize possible stakeholders
3. Evaluate possible stakeholders to further determine the intensity of their involvement
4. Finalize potential stakeholder list and their level of involvement

Stakeholder Engagement for Research Toolkit at: https://www.hipxchange.org/DeeplyEngagingPatients
INCLUSION AND EQUITY

✧ Consider all possible valuable perspectives
✧ Ask people what they need to serve?
  ✧ Transportation
  ✧ Timing of meeting
  ✧ Childcare
  ✧ Compensation
  ✧ Training
✧ Equity: different stakeholders will need different things

WHEN TO ENGAGE
SOLUTIONS TO KEY BARRIERS
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
## MYTH BUSTING

<table>
<thead>
<tr>
<th>Myth</th>
<th>Truth</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have to do what patients want</td>
<td>Trust is built on honesty. Explain to patients that there are many factors to consider when designing a program, and you may not be able to address everything they think is important</td>
</tr>
<tr>
<td>Patients will see our mistakes and judge us</td>
<td>Engaged patients tend to respect the complexity of healthcare delivery and show empathy</td>
</tr>
<tr>
<td>HIPAA prohibits/limits patient engagement</td>
<td>HIPAA is a patient protection law. Patients can waive confidentiality. Meet in non-clinical spaces.</td>
</tr>
<tr>
<td>Patients don’t know enough about the business of healthcare to add value</td>
<td>Patients know about the patient experience – and the realities of their daily lives – that is the expertise you desire from them.</td>
</tr>
<tr>
<td>Patients will only vent about own experience</td>
<td>With appropriate guidance and facilitation, most patients understand the role of a “representative”</td>
</tr>
<tr>
<td>Skepticism about their interest in QI details</td>
<td>Healthcare Reform has been well covered in the media. Many patients are curious and want to see the “inner workings” of improvement in health care.</td>
</tr>
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</table>
UNIQUE ISSUES WITH ENGAGING TRANSITIONING YOUTH

What barriers shall you anticipate with the transitioning youth population?

How can you effectively address them?

HINT: Ask them too!
PUBLICATIONS & RESOURCES


- Patient Engagement for QI Toolkit at: [http://hipxchange.org/PatientEngagement](http://hipxchange.org/PatientEngagement)

- Stakeholder Engagement for Research Toolkit at: [https://www.hipxchange.org/DeeplyEngagingPatients](https://www.hipxchange.org/DeeplyEngagingPatients)

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THANK YOU!

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ACKNOWLEDGEMENTS

This work would not have been possible without the participation of the Microsystems teams and our patient partners.

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

This presentation was supported by the Clinical and Translational Science Award (CTSA) program, previously through the National Center for Research Resources (NCRR) grant 1UL1RR025011, and now by the National Center for Advancing Translational Sciences (NCATS), grant 9U54TR000021. Additional support was provided by the UW School of Medicine and Public Health from the Wisconsin Partnership Program.

CPP is an ICTR-CAP, funded by UWF – Wisconsin Partnership- MERC
# 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>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>5 (10%)</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Level 1: Inform/Educate</td>
<td>0 (0%)</td>
<td>Visibility walls, patient education materials</td>
<td>N/A</td>
</tr>
</tbody>
</table>
| 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. |
## Highest Level of Patient Engagement Attained by Teams (N=49)

<table>
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</table>
| Level 4: Involve       | 4 (8%)              | Advisory panels, patient panel, focus group    | - Focus group helped develop a communication to parents to help prepare for adolescent appointments.  
                                |                     |                                                | - 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 |