Effectively Engaging Patients in Quality Measurement

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VP Patient Experience and Program Evaluation

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Regional Partner Director
Planning a Party

Activity
Planning a Birthday Party

1. Divide into four groups
2. Identify your Birthday Participant
3. Using the Handout, plan a Birthday Party and complete each of the elements
4. Select a Reporter to report back to the large group
The Catch

Each group will have different levels of contact with your Birthday participant

1. Group One: Constant Contact
2. Group Two: May Ask Questions
3. Group Three: May Get Feedback with five minutes left
4. Group Four: Total Isolation
In two minutes or less, describe to us your group’s birthday party.
Debrief

How was each group’s experience?

How satisfied were each of the Birthday participants?
Why Engage Patients and Caregivers?

• Based on our opening activity, what did you discover that can be applied to your work in measure development?

• Why do you want to engage patients, families and caregivers in your work?
Patient Experience in Quality Measurement
Preparation
It was reliably complicated.
The Process
Perspective Matters
Engagement in Measure Development
Engagement in Measure Development

Using the post-it notes, answer the following questions for each stage in the development process and put it on the appropriate flip chart.

• What do you hope to achieve by engaging patients or caregivers in this stage?
• What value does engagement bring to this stage?
Principles for Engagement
Principles for Engagement

• Why do we need principles?

• Why and how did we “create” these principles?
Principles for Engagement

Synthesis of multiple sets\(^1\) of principles related to community and/or patient engagement practices resulted in 5 overarching principles:

- Equity and Partnership
- Mutual Benefit and Co-learning
- Diversity and Representativeness
- Communication
- Accessibility
Principles for Engagement

- **Equity and Partnership**

  No partner (or stakeholder) is more important than others and all partners have a defined role, responsibilities and accountabilities where boundaries are respected. Each partner also has decision making authority, their assets and competencies are valued, and that value is demonstrated.

- **Mutual Benefit & Co-learning**
- **Diversity & Representativeness**
- **Communication**
- **Accessibility**
Principles for Engagement

- Equity and Partnership
- **Mutual Benefit & Co-learning**
  Ensuring that all involved receive something back, and that all partners are invested in learning from each other and the process. This includes ensuring there are processes for shared-decision making, consensus building, and capacity building between all partners.

- Diversity & Representativeness
- Communication
- Accessibility
Principles for Engagement

- Equity and Partnership
- Mutual Benefit & Co-learning
- Diversity & Representativeness

Partnerships are committed to ensuring diversity and representativeness of stakeholders. This includes considerations related to demographic, condition/disease, and treatment. Groups should also commit to understating group and power dynamics, as well as cultivating cultural competency/humility. Factors affecting diversity must be considered when designing and implementing program planning.

- Communication
- Accessibility
Principles for Engagement

• Equity and Partnership
• Mutual Benefit & Co-learning
• Diversity & Representativeness
• Communication
  Major decisions are made inclusively and information is shared readily. Partners are committed to open and honest communication with one another and processes are in place to facilitate this communication. While there is attention to transparency within the group, attention is paid to the confidentiality of individual partners.
• Accessibility
Principles for Engagement

• Equity and Partnership
• Mutual Benefit & Co-learning
• Diversity & Representativeness
• Communication
• 

**Accessibility**

All parts of the project and process need to be accessible to all partners to ensure equitable participation. This includes considerations related to physical accessibility (ex: logistics, time, transportation) as well as accessibility related to language and literacy, technology, cultural considerations, and condition specific needs.
Principles for Engagement

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Tools for Engagement
# Matrix of Engagement Tools

<table>
<thead>
<tr>
<th>Tool</th>
<th>Level of Engagement</th>
<th>Level of Difficulty</th>
<th>Skills Required</th>
<th>Like</th>
<th>Level of Preparation - Patient</th>
<th>Level of Preparation - Developer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus Groups</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Facilitative</td>
<td>Recruitment</td>
<td>Group Discussion: Patient</td>
<td>Low</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Feedback</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Advisory Board</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Recruitment</td>
<td>Planning and</td>
<td>Engagement: Group Discussion: Patient</td>
<td>Low</td>
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<tr>
<td></td>
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<td></td>
<td>Summary</td>
<td>Feedback</td>
<td></td>
<td></td>
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<tr>
<td>Key Informant Board</td>
<td>High</td>
<td>Moderate</td>
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<td>Low</td>
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<tr>
<td>Technical Expert Panel</td>
<td>High</td>
<td>High</td>
<td>Recruitment</td>
<td>Planning and</td>
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<tr>
<td>Measure Development Committee</td>
<td>High</td>
<td>High</td>
<td>Recruitment Planning and Capacity Building-Building Blocks</td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
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<tr>
<td>Survey</td>
<td>Low</td>
<td>Low</td>
<td>Networking</td>
<td>Planning and</td>
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<td>Staff</td>
<td>High</td>
<td>Moderate</td>
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<td>Planning and</td>
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Engagement Tools

Focus Groups
• Pros
  • Varying levels of detail on topics; depth and breadth
• Cons
  • Questions and Facilitation can be tricky
• Key Principles
  • Diversity and Representativeness, Accessibility

Advisory Boards
• Pros
  • Consistent engagement with dynamic group of stakeholders
• Cons
  • Management and availability of stakeholders
• Key Principles
  • Mutual Benefit and Co-Learning, Accessibility
Engagement Tools

Key Informant Interview

• **Pros**
  • Can go very deep into experiences, allows for follow-up and probing

• **Cons**
  • The information only represents a single person’s experience

• **Key Principles**
  • Diversity and Representativeness, Accessibility

Technical Expert Panel

• **Pros**
  • Integrates patient experience into expert discussions

• **Cons**
  • High levels of preparation for both developers and stakeholders

• **Key Principles**
  • Equity and Partnership, Accessibility
Engagement Tools

Measure Development Committee

• Pros
  • Integrates patient experience into the measurement development process

• Cons
  • High levels of preparation, availability of stakeholders

• Key Principles
  • Accessibility, Mutual Benefit and Co-Learning

Survey

• Pros
  • Yields vast amounts of information

• Cons
  • Yields vast amounts of information

• Key Principles
  • Accessibility, Diversity and Representativeness
Engagement Tools

Town Hall
• Pros
  • Engages “community” as community
• Cons
  • Unpredictable, somewhat unstructured
• Key Principles
  • Diversity and Representativeness, Accessibility

Staff
• Pros
  • Fully integrates patient experience into the process
• Cons
  • Let me know when you find one?
• Key Principles
  • Equity and Partnership, Communication, Accessibility, Diversity and Representativeness
Experience

Has anyone used any of the tools we have reviewed or others we didn’t mention?

• What was your experience with planning and implementation?
• What were any lessons learned?
• Where did you succeed or where did you gloriously fail?
Discussion
Thank You!

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References


