Partnering with Patients for Research

The Beryl Institute
April 2016
Jason Morgan, Chair Elect, Patient and Family Advisory Council
Terrell Smith, Director, Patient and Family Engagement
Advisory Council collaborated with leadership and staff to create our Patient Promise.
Patient-Centered Non-Routine Events (PCNRE) to Identify Risks to Best Patient Outcomes

Funded by PCORI, 1IP2PI0000072-1. PI: Matthew Weinger, MD, MS.
Project-Specific Aims

• Determine what aspects of clinical encounters patients and families view as “non-routine” care quality or safety.

• Elucidate factors that influence the reporting of Non-Routine Events (NREs) & affect the nature of the NREs that are reported

• Determine whether NREs obtained from patients/families add to evidence about clinical system failure modes beyond that obtained from clinicians caring for the same patients
Questions

Non-Routine Event: *What is it?*

*How do patients and families perceive them?*

*What affects how they get reported?*

*Can patients and families identify non-routine events better than clinicians can?*
Recruitment

- PCORI research team needed patient and family perspective. Called upon PFAC...
- Members of Vanderbilt Patient and Family Advisory Councils committed time and service.
- For objectivity, different members served at different times.
- All volunteer basis.
Patient Engagement Team

Council members from the Adult and Children’s Hospital Advisory Councils

(Courtesy Dr. Matt Weinger, VU)
PCORI - Patient & Family Advisors

Diane Buckberg
Nashville, TN

Susan Morley
Nashville, TN

Jessica Pasley
Nashville, TN

Jason Morgan
Nashville, TN
Specific Engagement

- Monthly project team meetings (entire team of researchers, site leaders, patients, administrative and research staff)
- Special meetings of the PET arranged according to project needs
- Meetings on patient recruitment for focus groups
- Data coding meeting to refine coding structure to analyze focus group data
- Meetings on the design of the survey instrument for phase II of the study
- Presentation of research results: PCORI Webinar and Washington DC meeting (Susan Morley and Dr. Weinger)
- Collaboration on the publication of two papers
Dear research team,

Below you will find 55 passages from our 10 patient/caregiver focus groups. Each passage contains an “event” in which there was suboptimal information or communication. Our goals are to:

a) Get a general sense of what information/communication non-routine events look like, based on the comments of focus groups participants

b) Identify categories: What are the types of information/communication events? What are the subtypes?

c) Identify relationships: How are events or parts of events related? For example, A causes or precedes B, C is caused by or follows D, E often happens when there is also F, G and H are similar, I and J are two sides of the same coin, K and L are opposites, X and Y are only issues when there is Z, etc.

d) Identify themes and patterns: This is another way of saying “what are the lessons learned from looking at all of these events?” or “If you were writing a book about these themes, what would you call the chapters?” What stands out? What would you want to highlight? Which things recur and therefore might tell us something about what is common or important? What similar things can be said about events across many categories?

On the next two pages, I’ve created a worksheet below that will help you work through the above.
Coding Transcripts
Coding Transcripts

Each team member classified each NRE. Patterns were discovered that:

- clinical members were *less* likely to code non-clinical events,
  
  *and*

- PFAC members were *more* likely to code non-clinical events.

Furthermore...

- most non-clinical NREs were related to patient / provider communication.

If the most common non-clinical NRE is related to patient / provider communication, are only clinicians appropriate to observe and evaluate NREs?
Results and what we learned

Clinicians
Great at identifying **clinical** non-routine events.
• Missed medications
• Surgical complications

Patients & Families
Great at identifying **non-clinical** non-routine events.
• Communication failures
• Scheduling & Coordination

Variable at identifying **non-clinical** non-routine events.
Variable at identifying **clinical** non-routine events.
Results and what we learned

<table>
<thead>
<tr>
<th>Non-Routine Event: What is it?</th>
<th>Clinicians</th>
<th>Patient &amp; Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Based on Clinical Guidelines &amp; Inst. Standards</td>
<td>• Customer-centric expectations</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>How do patients and families perceive them?</th>
<th>Clinicians</th>
<th>Patient &amp; Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Secondary to clinical process</td>
<td>• Integral to patient experience</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What affects how they get reported?</th>
<th>Clinicians</th>
<th>Patient &amp; Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Whether they are observed.</td>
<td>• Whether it is appropriate expectation.</td>
</tr>
<tr>
<td></td>
<td>• Whether they are seen as significant.</td>
<td>• Unknown who to report to.</td>
</tr>
<tr>
<td></td>
<td>• Once observed, what to do with information?</td>
<td>• Where event qualifies as non-routine event.</td>
</tr>
</tbody>
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Can patients and families identify non-routine events better than clinicians can?

Yes!

• Needs PFAC involvement.
Questions/comments