Partnerships, Patients & Research, OH MY!:

The Why, What, When, Who and How of Engaging Patients in Research

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A funny thing happened on the way to my 40s...
Alchemy: The Center for Patient Partnerships
Our wheel house: The Patient Voice.
  – Advocacy + Transdisciplinary Education
  – Organization redesign
  – National initiatives
I am a patient partner in research.
  ~NCRA, DOD Grant, surgery decisional tool, HAI control.
PCORI: A NEW WIND BLOWING

- New funding opportunity
- But, engaging patients is foreign, complex and time consuming.
- Already in Phase 2, after Phase 1 failures.
- How can we maximize the possibility of successful collaboration?
- Why, what, when, who & how can we engage patients effectively?
WHY ENGAGE PATIENTS IN RESEARCH?

Because it is essential to success.

- Increases:
  - Accuracy
  - Relevance
  - Representativeness
  - Effectiveness
  - Implementation
  - Dissemination
WHAT CAN PATIENTS OFFER TO RESEARCH?

- Accurate definition of the problem.
- Identify relevant data.
- Suggest data collection methods, locations & populations.
- Help collect data.
- Offer diverse perspectives in data analysis and interpretation.
- Co-conceive and pilot interventions, interpret results.
- Help refine interventions.
- Suggest implementation strategies.
- Support publicity for implementation and dissemination.
### Patient Roles - PCOR/CER

**Figure.** Enhancement of Comparative Effectiveness Research (CER) Through Continuous Patient Engagement

<table>
<thead>
<tr>
<th>Step in CER Process</th>
<th>Purpose of Patient Engagement</th>
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<tr>
<td><strong>Topic solicitation</strong></td>
<td>- Identify topics that are important to patients, caregivers, and the community&lt;br&gt;</td>
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<td>- Propose topics to be investigated</td>
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<td><strong>Prioritization</strong></td>
<td>- Solicit feedback on relevance and priority of topics&lt;br&gt;- Discuss the urgency of addressing topics</td>
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<td><strong>Framing the question</strong></td>
<td>- Ascertain questions’ relevance and usefulness&lt;br&gt;- Assess “real-world” applicability</td>
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<td><strong>Selection of comparators and outcomes</strong></td>
<td>- Identify comparator treatments of interest&lt;br&gt;- Identify outcomes of interest&lt;br&gt;- Incorporate other aspects of treatment</td>
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<td><strong>Creation of conceptual framework</strong></td>
<td>- Provide a “reality check”&lt;br&gt;- Verify logic of conceptual framework&lt;br&gt;- Supplement with additional factors not documented in the literature</td>
</tr>
<tr>
<td><strong>Analysis plan</strong></td>
<td>- Verify importance of factors and variables&lt;br&gt;- Ascertain whether there is a good proxy for a specific concept&lt;br&gt;- Inquire about potential confounding factors</td>
</tr>
<tr>
<td><strong>Data collection</strong></td>
<td>- Determine best approaches for data collection (e.g., trial registry, medical charts)&lt;br&gt;- Assist with selection of data sources</td>
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<tr>
<td><strong>Reviewing and interpreting results</strong></td>
<td>- Assess believability of results&lt;br&gt;- Suggest alternative explanations or approaches&lt;br&gt;- Provide input for sensitivity analysis</td>
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<tr>
<td><strong>Translation</strong></td>
<td>- Interpret results to be meaningful&lt;br&gt;- Document which results are easy or difficult to understand&lt;br&gt;- Indicate which results are counterintuitive</td>
</tr>
<tr>
<td><strong>Dissemination</strong></td>
<td>- Facilitate engagement of other patients&lt;br&gt;- Help other patients to understand findings</td>
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WHEN SHOULD PATIENTS BE ENGAGED?

- From the start and all the way through.
- Naming the right problem ➔ (the lateness problem).
- Getting the right data ➔ (QoL survey revamp, mosquitos...)
- Data collection ➔ (AAB online goldmine)
- Data interpretation ➔ (why would they say that?)
- Designing the intervention ➔ (have you washed your hands?)
- Testing the intervention ➔ (mosquito netting vs. plug it in)
- Implementation ➔ (the new clinic map snafu)
- Dissemination ➔ (AAB newsletter)
WHO SHOULD BE ENGAGED?

• The "typical patient" fantasy
• The representation trap
• Safety in numbers for patients & researchers
• Those who are “interested” and “emotionally involved" in the research question (Mullins)
• And, it depends on the task...
MATCH PATIENTS & LEVELS TO TASKS

- Continuum, early & often!
- Mix and match levels to meet different needs
- Different patients enjoy different levels
- The higher the level
  ➔ Richer, deeper data
  ➔ More varied input
  ➔ More preparation required
  ➔ More transformational

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<th>Engagement Levels</th>
<th>Definition and Methods</th>
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<td><strong>PARTNER</strong> 5</td>
<td>Patients are full participants Engaged as full research team members from the start</td>
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<tr>
<td><strong>INVOLVE</strong> 4</td>
<td>Patients are ongoing advisors Engaged in a regular manner, when needed, over the course of the project</td>
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<tr>
<td><strong>DISCUSS</strong> 3</td>
<td>Patients provide input and receive feedback One-time focus groups or interactive interviews</td>
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<tr>
<td><strong>GATHER</strong> 2</td>
<td>Patients are informers Surveys, cycle time, suggestion boxes</td>
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<tr>
<td><strong>INFORM/EDUCATE</strong> 1</td>
<td>Patients are recipients of information and education Websites, social media, newsletters</td>
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HOW TO ENGAGE PATIENTS?

• Invite:
  – Intentional invitation
  – Value time, compensation matters
  – Support for research vs. desire for individualized care
  – Think of the little things
• Welcome
  – Whole staff ready, convinced, committed
  – New ways of being together
• Agree
  – A meeting of the minds
  – Job description – discuss, agree, finalize and adjust as you go
  – Patients who understand their roles are more effective (Mullins)
What Does Meaningful Engagement Mean?

- Topic Selection and Research Prioritization
- Review, Design, and Conduct of Research
- Evaluation
- Dissemination and Implementation of Results
PCORI: PATIENT ENGAGEMENT DEFINED

• “...(T)he meaningful involvement of patients, caregivers, clinicians and other healthcare stakeholders throughout the research process – from topic selection through design and conduct of research to dissemination of results...”

• What does meaningful involvement mean to you?
PCOR PRINCIPLES

Figure 1: Conceptual model of patient-centered outcomes research
CO-CREATED MATERIALS

- **Toolkits**
  - Coach version
  - Team version
- **Patient Welcome Packet Template**
- **Additional Patient QI Booklet**
- **Guide to Internal Resources & Policies**

Toolkit at: [http://hipxchange.org/PatientEngagement](http://hipxchange.org/PatientEngagement)


• Toolkits: http://hipxchange.org/PatientEngagement


ALCHEMY: NOUN

“...A seemingly magical process of transformation, creation, or combination...”