Patient Partners in Research – from Concept to Practice

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Patient Partners in Research - From Concept to Practice

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HICOR VCC Summit
Goals for today

- Understand the rationale for patient engagement in research (CCDR)
  - Importance of diversity and cultural competence
- Understand how patients are engaged in all research phases
  - Design
  - Conduct
  - Dissemination
- Describe common barriers to patient engagement
  - Strategies to overcome barriers
Why involve patient partners in cancer care delivery research?
## Levels of Patient and Researcher Engagement in Health Research

### Patient’s Goal

<table>
<thead>
<tr>
<th>Learn/Inform</th>
<th>Participate</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Lead/Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>To ask questions and learn about how to get more involved</td>
<td>To act as a subject or participant in a research study</td>
<td>To provide feedback and advice on specific research activities</td>
<td>To work directly with a research team throughout the project</td>
<td>To partner on equal footing with researchers in all aspects of research</td>
<td>To make final decisions and lead research activities</td>
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### Researcher’s Goal

| To provide information, listen, and answer questions honestly | To act ethically and respectfully in the conduct of research | To seek your input on an ad hoc basis | To include you as standing members in an advisory capacity | To partner equally with you as team members | To follow your lead and support your decisions |

### How This Can Be Done

| In an open atmosphere for sharing through orientation and information sessions, and media campaigns | Through quantitative, qualitative, or mixed methods research | Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels | As members of standing working groups and advisory committees or panels | Patients as co-investigators and research partners, and as members of research steering committees | Through patient or community steering committees and patients as principle investigators |

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**The Engagement Continuum**
Examples of how patient partners are engaged in research
Evidence that patient engagement has an impact – analysis of 126 published PCORI-funded studies

<table>
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<tr>
<th>Acceptability</th>
<th>Feasibility</th>
<th>Rigor</th>
<th>Relevance</th>
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</thead>
<tbody>
<tr>
<td>• Research designs, procedures, interventions intended to be well received by patients or clinicians&lt;br&gt;• Based on burden, usability, alignment with values, preferences and needs</td>
<td>• Mitigating potential or actual research roadblocks&lt;br&gt;• Making interventions, enrollment, retention and data collection more doable in real-world settings</td>
<td>• Choices that minimize bias and enhance data quality&lt;br&gt;• Includes when or how to collect data, selection or assessment of measures, decisions to re-order, shorten or add items to data collection measures</td>
<td>• Applicability and importance of the research for patients and clinicians making decisions&lt;br&gt;• Includes importance of research questions and outcomes, generalizable study samples, interpretations of findings in real-world context, more effective dissemination</td>
</tr>
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Barriers to patient engagement in cancer clinical trials

Results of qualitative interviews of investigators and survey of research patient advocates at SWOG, one of 5 NCTN groups funded by NCI. Deverka, et al. A New Framework for Patient Engagement in Cancer Clinical Trials Cooperative Group Stuides. JNCI 2018;110: 553-559.

- Researchers
  - Do not have a shared understanding of the importance of patient engagement
  - Lack of understanding of team member roles
  - Need for training on collaboration and engagement skills

- Patient advocates
  - Lack of relationship with PI
  - Lack of procedures for working with PI
  - Lack of researcher skills/training for engaging patient advocates
Barriers to patient engagement in CCDR

*Culture is a pattern of learned beliefs, values and behavior that are shared within a group. Shaped by race, ethnicity, religion/spirituality, language, nationality, region, gender, sexual orientation, SES, education, affiliation, customs

- Lack of physical and emotional energy
- Time, transportation, financial support
- Fear/trauma of going back into cancer treatment environment
- Language/Cultural* barriers
  - Minority community mistrust of research and researchers
  - Lack of people of color working as research staff
  - Lack of benefits to the community
Hard-to-reach patient partners

- Racial and ethnic minorities
- Low-income and low-literacy populations
- Children and adolescents
- Older adults
- LGBTQ populations
- Other groups who may not be accessible using traditional recruitment processes and materials.

## Cultural Competence in Research*

**Rationale**
- Understand the needs and perspectives of different groups
- Community outreach and engagement
- Contextualization of research knowledge
- Increase in the community relevance of research findings

**Consequences if ignored**
- Stereotyping
- Tokenism
- Mistrust
- Inability to engage certain communities
- Poor health and research outcomes

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*The ability of researchers and research staff to provide high quality research that takes into account the culture and diversity of a population when developing research ideas, conducting research, and exploring applicability of research findings*
- An ongoing process
- Value and respect for others
- A willingness and openness to change attitudes and behaviors
The path forward

- Adequately fund patient engagement efforts
- Define team member roles
- Provide culturally competent engagement training to patient partners and researchers
- Develop innovative research designs and validated measures to assess engagement processes for CCDR
- Meet patients where they are and use various communication modalities to sustain engagement
Questions?
THANK YOU!

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We don’t see things as THEY are, 
we see things as WE are. 
- Anaïs Nin