Patient-Centered Outcomes Research

What is Patient-Centered Outcomes Research?

- Assists patients and caregivers in the engagement and informed decision-making of health care
- Encourages their voices to be heard in determining the importance of health choices.
- Answers questions and addresses concerns related to the beliefs, preferences, and needs of patients and caregivers
Questions for Patients Answered by Patient-Centered Outcomes Research

“Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”

“What can I do to improve the outcomes that are most important to me?”

“What are my options and what are the potential benefits and harms of those options?”

“How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?”

Aspects of Patient-Centered Outcomes Research

- **Assesses the benefits and harms of preventive, diagnostic, therapeutic, palliative, or health delivery system interventions** to inform decision making, highlighting comparisons and outcomes that matter to people.

- **Is inclusive** of an individual’s preferences, autonomy and needs, focusing on outcomes that people notice and care about such as survival, physical function, emotional and physical symptoms, and overall quality of life.
Aspects of Patient-Centered Outcomes Research

- **Incorporates** a wide variety of settings and diversity of participants to address individual differences, barriers, and facilitators to implementation and dissemination.

- **Investigates** optimizing outcomes while addressing burden to individuals, resource availability, and other stakeholder perspectives.

Why Engage in Patient-Centered Outcomes Research?

- Researchers and clinicians do not fully represent the patient perspective.

- Research findings and interventions developed can be targeted to patients/community needs.

- Putting patients at the center of research shifts the inherent power differential that exists between patients and researchers.
Why Engage in Patient-Centered Outcomes Research?

- Improves relevance of research outcomes to patients' daily lives
- Shifts research focus to outcomes prioritized by patients
- Improves study recruitment and retention
- Improves ability to capture patient voice
- Patient-reported outcome measures (PROMs)

Key Players in Patient-Centered Outcomes Research

- PATIENT +/- CAREGIVER
- CLINICIANS, INCLUDING ALLIED HEALTH PROFESSIONALS
  - Nurses, social workers, dieticians, pharmacists
- RESEARCHER
- HEALTH SYSTEMS ADMINISTRATOR
- COMMUNITY ORGANIZATIONAL PARTNER
- PATIENT ADVOCACY ORGANIZATION
Best Practices for Patient-Centered Outcomes Research

- Determine which patient stakeholders represent the perspectives that are needed to answer the research question
- Choose most rigorous study design to answer research question
  - Consider quantitative and qualitative (mixed-method) and longitudinal studies
- Clearly define roles, responsibilities, and expectations (including time commitment)

Best Practices for Patient-Centered Outcomes Research

- Invest the time, effort, humility to partner with groups underrepresented in research
  - Extremes of age, medically complex, racial or ethnic minorities
- Determine patient knowledge of research question – deliberative sessions
- Determine most appropriate method of patient involvement
  - Telephone/video/in-person individual interview
  - Focus group
Best Practices for Patient-Centered Outcomes Research

• Develop strategies for dissemination beyond peer review and conferences

• Include how the results influenced your practice, knowledge, or skill
  • “Lunch and learn” sessions at study sites
  • Newsletters and social media

• Define clear expectations for data ownership and sharing

• Consider developing a group of registry-based ‘research ready’ patients

Multi-level Barriers to High Quality Patient-Centered Outcomes Research

**PATIENT-LEVEL**

• Age
• Activation level
• Health literacy
• Trust

**DISEASE-LEVEL**

• Stigma
• Physical disability
Multi-level Barriers to High Quality Patient-Centered Outcomes Research

**PROVIDER-LEVEL**
- Time
- Unfamiliarity with processes

**SYSTEMS-LEVEL**
- Cost
- Communication barriers
- Transportation
- Information availability

Strategies to Overcome Barriers

- Spend time to introduce yourself and your study team
- Use time/location convenient for patient partner(s)
- Provide meal and transportation vouchers for meetings or study visits
- Choose compensation in a mode and amount that is deemed appropriate by patient partner(s)
- Use culturally and linguistically concordant language and recruitment materials
- Consider a Patient Advisory Council to guide and iteratively refine processes
Examples of Studies

Bringing Care to Patients: A Patient-Centered Medical Home for Kidney Disease

EMPOWERING PATIENTS ON CHOICES FOR RENAL REPLACEMENT THERAPY

Engaging with Groups Underrepresented in Research

- Partner with community leader/champion
- Consider providing relevant training to community members
- Prioritize areas that are of primacy to stakeholders and communities
  - Define *how study will benefit* patient/community
- Maintain engagement after study close
- Return of results in language and mode that is easy to comprehend
- Ensure equitable allocation of resources and credit
Engaging with Groups Underrepresented in Research

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<tr>
<th>GIVES</th>
<th>GETS</th>
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<tr>
<td>Patient/Community</td>
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<td>Researcher</td>
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*Treat participants as equals/as you would want to be treated*

Involve patient as partners in *all* aspects of research, *early* and *frequently*

1. **Develop** study question
2. **Design** study
3. **Select** study compensation
4. **Conduct study & Store** data
5. **Disseminate** results*
6. **Implement** findings
Cultivate the **time and humility** needed to establish **bi-directional relationships** with patients and community organizations.

No “one size fits all” approach

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**References**


References


