Patient Engagement for Sustainable Partnerships with Minority Patient Communities and their Health Care Providers

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Learning Objectives

• Describe a 10-step framework for patient engagement

• Construct a process for building trust in PCOR studies

• Design a patient-centered approach to engaging hard-to-reach patients
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Take-Away Points

• Patient engagement at every step transforms CER-> PCOR

• Patient engagement is a continuous process
  • Patient engagement requires trust & respect
  • Pre-engagement is a critical component

• Patient engagement should involve diverse patients including hard-to-reach patients
Comparative Effectiveness Research (CER)

- Active comparators (i.e. not comparing to placebo or usual care)
- Broad patient population
- Outcomes that are meaningful to patients

- Innovative Methods
  - Clinical trials
  - Electronic health records
  - Registries
  - Insurance claims datasets
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  • Clinical trials
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• Combination of the above + Patient Engagement = PCOR
Patient Engagement: How?

Building/Maintaining Trust and Respect

Identifying → Partnering → Explaining → Doing → Updating

Building/Maintaining Trust and Respect
Trust

Components of building and maintaining trust:

**Pre-engaging:** Understand the community

**Relating:** Be genuinely willing to partner

**Communicating:** Keep questions simple; Avoid making judgments

**Being there:** Keep “coming back” and interacting with participants
Patient Engagement: Why?

• Makes PCOR *meaningful*
  – Framing the *question* so it is understood
  – Framing the *answer* so it is understood
  – Framing for *cultural appropriateness*
  – Does meaningful imply significant or impactful?

• Helps with patient activation

*Having the essential knowledge, skills and confidence for managing one’s own health and healthcare*
Patient Engagement: How?

There are others along the journey who can help:

- Community Members
- Leaders
- Organizational Partners
Patient Engagement: When?

• Throughout the research continuum
  – Topic Identification
  – Study design
  – While “doing it”
  – When disseminating and implementing

• In between studies
10-Step Process for Conducting CER *

1. Topic Solicitation
2. Prioritization
3. Framing the Question

10-Step Process for Conducting CER *

4. Selection of Comparators and Outcomes
5. Creation of Conceptual Framework
6. Analysis Plan
7. Data Collection

10-Step Process for Conducting CER *

8. Reviewing & Interpreting Results
9. Translation
10. Dissemination

Hard-to-Reach: Who is Hard to Reach?
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Patients identified hard-to-reach by

- Impairments
- Illnesses
- Age
- Where they live
- Social indicators
- What they do
Study participants identified hard-to-reach patients by impairments, illnesses, by age, by where they live, by social indicators, and by what they do.

Practical methods for engaging hard-to-reach patients include:

- Partnering with people
- Meeting in places
- Using media
- Building and maintaining trust
Partnering with People

Runs the gamut of individuals to organized groups:

- **Individuals** (“the man in the trench”)
- **Groups** (Health care professionals, employers)
- **Associations** (Communities and professions)
- **Networks** (Social organizations and federations)
Results – Key Findings

Practical Methods for Engaging hard-to-reach Patients

Meeting in Places
Ranges from public to private spaces:

- **Public spaces** (street corners and local businesses)
- **Community-specific** (centers for recreation and social services)
- **Semi-private** (community clinics and places of worship)
- **Private** (housing and shelters)
Results – Key Findings

Methods for Ensuring Informants’ Understanding

Literacy and Comprehension
• Using plain language vs. “medical language”
• Teach Back method
• Individuals may need to make a decision.

Gathering Information
• Use the appropriate terminology - “Research is an emotionally charged word.”
• Ask open-ended questions to open up opportunities for discussion.
• Methods range from providing information in “chunks” to taking “baby steps”
• Partner with community members who can train advocates
Results – Key Findings

Methods for Ensuring Informants’ Understanding

Disclosure

• Let individuals know exactly what is involved
• Tell individuals why the investigator is doing the research.
• Not only “what you say but who says it.”

Consent Process

• Traditional IRB requirements for consent hinders more than helps
• Consent forms use big words and fine print that people do not understand.
• “Culturally match the consenter”
• Have individuals consent in “their own words.”
In order to effectively engage hard-to-reach patients, researchers need to provide education on exactly what is meant by the term “research”.

- Do not assume participants have the same conceptualization of research as researchers
- The word “research” carries very negative connotations in some communities.
Participants want to be kept abreast of research progress and want a celebration or recognition at the conclusion of a study. Participants would like some feedback at various points throughout the research process; they want the researcher to “give back” to the community.

- Participants are aware of the fact that they “give more to the researcher than they get in return”
- A plan for dissemination should be implemented
- "Giving back" could also take additional forms that meet the needs of individuals or community members.
Community Engagement

Diversity and inclusion of hard-to-reach patients requires bringing PCOR to communities where people live.

- Requiring participants to come to you will often result in including only the most motivated patients.
- Community-based participatory research offers excellent guidance for engaging diverse communities.
Recruitment for PCOR studies should involve the full spectrum of individuals affected by the medical condition or health-related question being examined, including hard-to-reach patients.

- Government funding agencies typically require that sponsored research address priority population.
- Recruitment of patients often reflects a convenience sampling process.
- Diversity alone is insufficient evidence that “the full spectrum” of relevant patients is included in PCOR.
Results – Lessons Learned

1) Trust is the key overarching element for PCOR
2) Patient v. person
3) Outcomes is an unfamiliar term
4) Research is an abstract concept for many hard-to-reach patients
5) Framing and phrasing of questions is critical for eliciting patients’ views
6) Patients come into research with their own agendas
7) Community-based PCOR requires flexibility, compromise and time
8) PCOR investigators should give something back to the community
9) Hard-to-reach patients do not like being asked repeated questions
Evidence Gaps

Future Needs for PCOR Methods Development

• Methods for “pre-engagement” of patients, partnering institutions and community sites
• Mapping of PCOR methods to phases of research
• Methods for building and maintaining trust with PCOR participants and partnering organizations and communities
• Processes for providing feedback to PCOR participants in “real time” as a means for maintaining trust and goodwill without jeopardizing the scientific integrity of research
• Delineating which “best practice” methods used in community-initiated research (or community-based participatory research) can be applied directly to PCOR
FINAL THOUGHT

Who is hard to reach?
Who has trouble reaching whom?