Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research – An International Perspective

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Project Framework

• Discuss the levels of engagement
• Summarize qualitative research strategies and methods
  – Provide specific examples
• Discuss facilitators of public engagement
• Describe three types of scientific research data as part of the engagement process
• Propose a process of engagement
Levels of Engagement

- **Minimal public involvement**: Researchers are the drivers of the project. Researchers respond to public action by providing information or inviting the public for consultations and collaborations on their terms.

- **Consultation**: Public is encouraged to provide diverse and in-depth views, perceptions, preferences, experiential knowledge, and ideas.

- **Collaboration**: Public is empowered to become active partners in an ongoing public-clinician collaboration.

- **Control**: The public is the driver of research projects. Researchers participate on the terms of the public.
Public Engagement as Research

• Is the objective study of the individual experience
• Uses mostly qualitative research strategies and methods
Scientific Strategies the Framework of Engagement

- Phenomenology
- Ethnography
- Grounded theory
- Action research
- Survey
Methods and Processes

• Interviews (one-on-one or group interviews, photovoice)
• Observation
• Documents
• Questionnaires
• Public-physician partnerships
Views, Opinions, Experience as Research Data

• Generates mostly textual data
• That are categorized into themes
• And can be translated into research areas and topics
Case 1

- In-depth one-on-one interviews and focus group interviews
- 40 patients with ulcerative colitis
- Patients identified 9 research areas
- Only during in-depth interview patients asked about prenatal genetic testing for a possible termination of pregnancy if the fetus was affected
Case 2

• Public-Clinician Partnership to develop research topics for urinary incontinence (James Lind Alliance)
  – Lay members and clinicians consult with their peers to include diverse views
  – Systematic reviews are used to generate additional topics and to avoid duplication of research
  – Nominal Group Technique to reach a consensus and prioritize topics
• 8 patient and 13 clinician groups participated
• Final database contained 226 research questions:
  – 79 unique questions from patients
• The group created a “Top 10” list of research questions
• Since then, 5 studies have been funded, 5 new systematic reviews are in progress, 5 questions are under consideration for funding.
Case 3

• Advisory panel to identify research topics and research priorities related to urinary incontinence in women
  – What can researchers study to make your life better?
  – What should we measure to see if your life is better?
Five main research areas emerged:

- Interventions that make seeking help easier
- Information giving and interventions designed to make day-to-day life more manageable
- The true costs of incontinence
- Causes
- Effects of lifestyle modification on incontinence

- Patients considered quality of life the most important outcome measures.
Facilitators that Overcome the Barriers to Public Engagement

• Creating a patient-centered organizational structure
• Supporting members of the public
• Communicating clear expectations
• Provide training
• Using processes that give an equal voice to professional and lay participants
• Using a variety of engagement methods
The Role of Scientific Data

• Comparative effectiveness reviews
• Health disparities research
• Health experience research
Phase 1
Lay members and clinicians are invited to participate in a Public-Clinician partnership

Phase 2
Each group generates topics by consulting with their peers

Phase 3
Each group categorizes emerging research themes

Phase 4
Patient-Clinician Workgroup meeting creates a consensus list of research questions

Phase 5
Public-Clinician partnership publishes the consensus list of research questions

Phase 6
Public-Clinician Workgroup evaluates impact on PCOR and CER

PCORI for research prioritization and funding

Health experience research
Systematic CER reviews
Health disparities analysis