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

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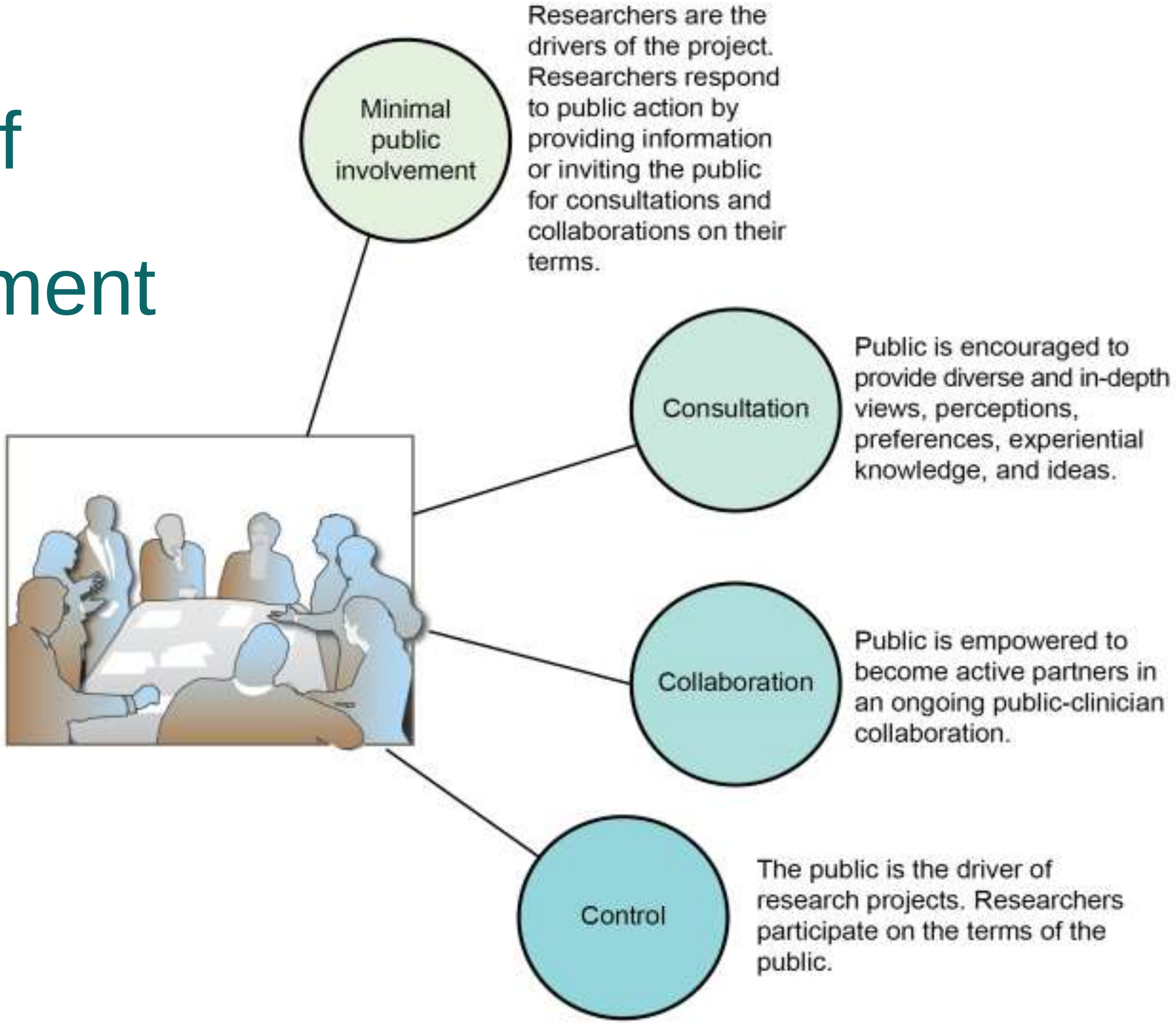
# Project Framework

- 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

Consultation

- Public-physician partnerships

Collaboration

# 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

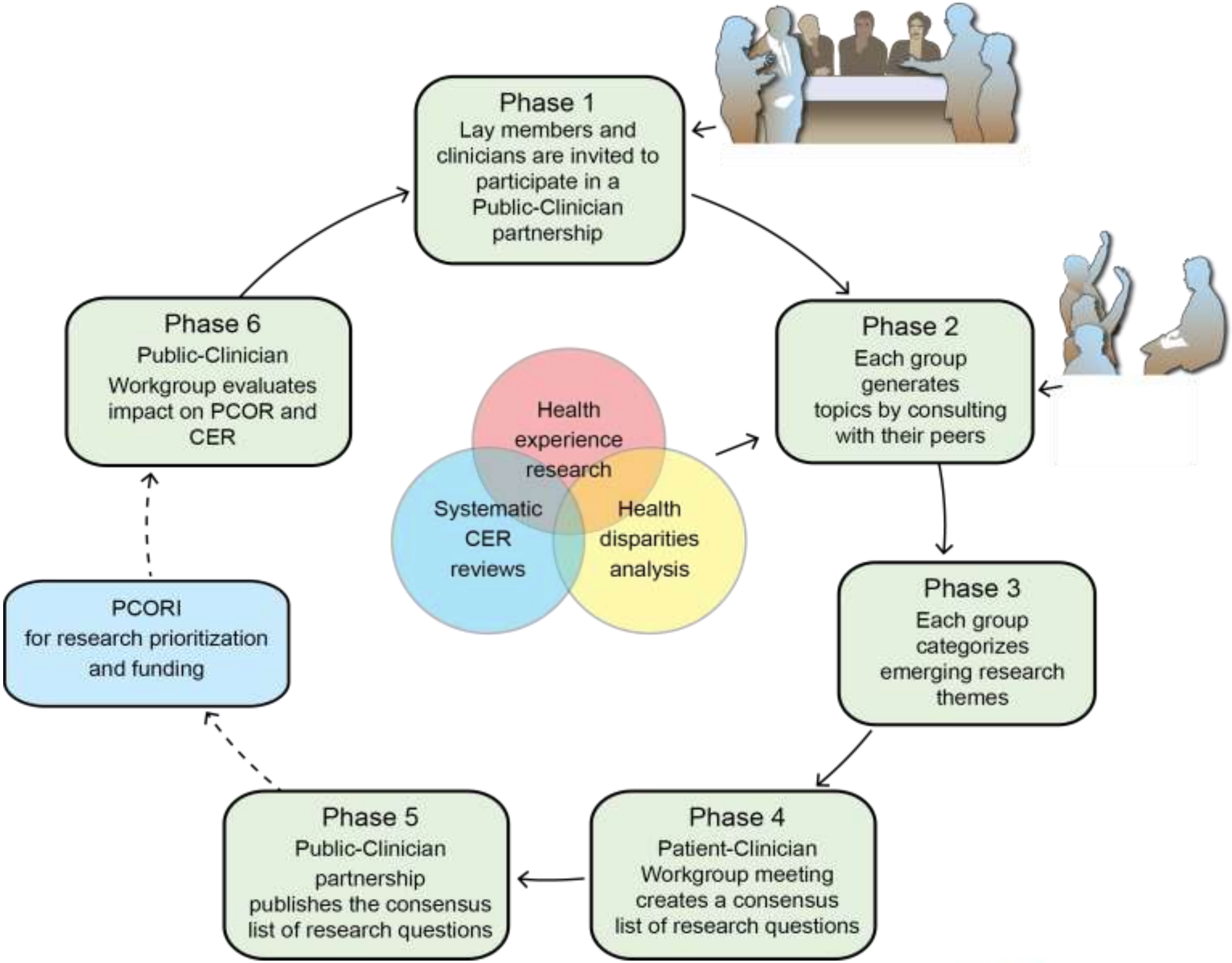
- Patients considered quality of life the most important outcome measures.

# 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 disparaties 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

PCORI
for research prioritization and funding

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

Health experience research

Systematic CER reviews

Health disparities analysis