Participatory Health Research: Challenges and Approaches

April 8, 2020
We’ll get started in just a couple of minutes.

Please be advised that there is no dial-in for this webinar; all audio is provided directly through the Adobe Connect platform.
Welcome!
Participatory Health Research: Challenges and Approaches

Dr. Andrea Robles
Research and Evaluation Manager, Office of Research and Evaluation, CNCS
Introductory Remarks
Participatory Health Research: Challenges and Approaches

Dr. Mary Hyde
Director, Office of Research and Evaluation, CNCS
ININVOLVING COMMUNITIES, PATIENTS AND STAKEHOLDERS IN RESEARCH

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FOCUS ON APPROACHES TO COMMUNITY ENGAGED RESEARCH

Researching Health Together: Engaging Patients and Stakeholders, From Topic Identification to Policy Change

Edited by: Emily B. Zimmerman

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WHY STAKEHOLDER ENGAGEMENT?

- Reduce health disparities
- Increase accountability and transparency
- Improve:
  - research relevance
  - quality of research and interventions
  - sustainability of initiatives
  - dissemination of results
- Translate research evidence into practice
- Increasing research funder emphasis on collaboration
A key starting point is committing to principles of community engagement


CHALLENGES

Relationship building
- Low levels of trust
- Poor historical relations
- Tokenism
- Representation
- Power differentials

Implementation
- Cultural differences
- Geographic separation
- Deadlines
- Participant retention
- Time and resource demands

Infrastructure
- Equity (e.g., sharing resources)
- Providing evidence of impact
- Financial sustainability
- Ongoing infrastructure support
PROJECT GOALS

Develop
- Identify community concerns and research priorities
- Develop and prioritize research questions/topics
- Identify outcomes and metrics (patient-centered outcomes)

Implement
- Improve understanding of health and health care
- Investigate and address social determinants of health
- Develop and test interventions and technologies
- Implement programs

Share
- Translate health messages/guidelines (e.g., Boot Camp Translation)
- Promote policy change
- Evaluation
### Partners

#### Individuals
- University faculty, students
- Community members
- Patients and caregivers
- Local leaders
- Professionals/service providers
- Policymakers

#### Organizations
- Health practices
- Community organizations
- Advocacy organizations
- National associations
- Research centers

#### Systems
- Health systems and payors
- Public agencies

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Virginia Commonwealth University  
Center on Society and Health  
@VCUSocHealth
### Team approaches
- Community-based participatory research (CBPR)
- Shared leadership (research co-PIs and co-investigators)
- Committees (leadership, executive, steering)
- Advisory groups, boards, councils
- Project workgroups
- Expert (or national) advisory committees

### Network/coalition approaches
- Research networks (e.g., patient-powered research networks)
- Practice-based research networks (PBRNs)
- Collective Impact initiatives
WAYS TO ENGAGE STAKEHOLDERS

### Sharing ideas
- In-home meetings
- Town halls and forums
- Community events

### Gathering data
- Community-led data collection
- Focus groups, interviews
- Photovoice
- Mapping/sharing data
- Digital storytelling

### Developing strategies
- Deliberative methods
- Group model building and participatory modeling
- Community engagement studios, community review boards
CAPACITY BUILDING

- Opportunities to learn about the community history and culture
- Research training
- Board member development
- Training in specific skills (e.g., facilitation)
- Advocacy training
- Learning collaboratives
FACILITATORS

**People**
- Diverse participants
- Multi-stakeholder engagement
- Boundary spanner or ‘navigator’ to connect partners
- Employing community members

**Processes**
- Managing power differences (e.g., creating groups)
- Facilitation
- Stakeholder governance
- Aligning missions across stakeholder groups

**Infrastructure**
- Community review (e.g., community engagement studio)
- Engage long-term coalitions/ backbone organizations
- Engage community-based fiscal sponsor
- Institutional support
## LESSONS LEARNED

### Relationships
- Develop more relationships
- Engage a well-known, trusted community lead
- Obtain input from stakeholders as early as possible
- Learn more about the local community

### Processes
- Address history and trauma
- Commit to sharing resources and power
- Set realistic expectations
- Provide opportunities for co-learning
- Regular meetings, ‘check-ins’ and updates

### Sustainability
- Shift leadership for sustainability, focus on leadership development
- Support is needed for administrative infrastructure
SEED METHOD FOR QUESTION DEVELOPMENT AND PRIORITIZATION

A multi-stakeholder engagement method that combines participatory concept modeling and question development to address a health issue of significance to the community.

Brings together diverse local stakeholders to:

- Explore potential causal factors
- Develop and prioritize research questions or action planning strategies
## Types of Engagement in the SEED Method

<table>
<thead>
<tr>
<th>Type</th>
<th>Level of engagement</th>
<th>Description</th>
<th>Example: Richmond demonstration on diabetes and hypertension</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research team</td>
<td>Collaborative</td>
<td>CBPR team that leads the project</td>
<td>Community and academic partners on research team</td>
</tr>
<tr>
<td>Topic groups</td>
<td>Consensus</td>
<td>Diverse stakeholders engaged based on experience and knowledge. Create</td>
<td>3 Topic groups (seniors, adults with low health care access,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>conceptual models, and research questions</td>
<td>service providers). Created 91 research questions in all,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>prioritized 19</td>
</tr>
<tr>
<td>SCAN</td>
<td>Consulting</td>
<td>Provide additional perspective through focus groups/interviews</td>
<td>5 focus groups and 11 interviews</td>
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# SEED METHOD STEPS

<table>
<thead>
<tr>
<th>Identify and engage</th>
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</thead>
<tbody>
<tr>
<td>Prioritize stakeholder groups</td>
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<table>
<thead>
<tr>
<th>Review and gather data</th>
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</thead>
<tbody>
<tr>
<td>Health data</td>
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<table>
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<tr>
<th>Conceptualize</th>
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<tbody>
<tr>
<td>Each Topic group creates a conceptual model</td>
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<table>
<thead>
<tr>
<th>Generate priorities</th>
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<tbody>
<tr>
<td>Each Topic group creates questions or strategies</td>
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<table>
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<tr>
<th>Prioritize</th>
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<tbody>
<tr>
<td>Use consensus process to select priority questions or policies</td>
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<table>
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<tr>
<th>Dissemination or implementation</th>
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<tr>
<td>Disseminate questions or implement action plans</td>
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SEED METHOD TOOLS

Matrices to identify stakeholders for Topic groups

Facilitation guides for Topic group activities:
- Participatory conceptual modeling
- Question development
- Prioritization

Toolkit
https://societyhealth.vcu.edu/work/the-projects/the-seed-method-for-stakeholder-engagement.html
SEED EXAMPLE: OPIOID PROJECT

CNCS 2018 Community Conversations Research Grantee
Virginia Tech and VCU

• 2-year shared experience between community partners and stakeholders to address the opioid crisis in a rural area with one of the highest opioid prescription rates in the U.S.

• Generate stakeholder priorities, including questions, strategies, and policies.

• Facilitate development of action plans and support implementation
## OPIOID PROJECT: STAKEHOLDER PARTICIPANTS

<table>
<thead>
<tr>
<th>Participatory Research team</th>
<th>Topic groups</th>
<th>SCAN participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 2 faculty</td>
<td>• Community</td>
<td>• 4 focus groups</td>
</tr>
<tr>
<td>• 1 graduate assistant</td>
<td>• Service</td>
<td>(community, policy, treatment, recovery)</td>
</tr>
<tr>
<td>• 6 community members</td>
<td>providers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Health</td>
<td></td>
</tr>
<tr>
<td></td>
<td>providers</td>
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OPIOID PROJECT: RESULTS

STRATEGIES
- 68 proposed strategies
- 15 prioritized strategies

COMMUNITY STAKEHOLDER MEETINGS
- 2 Community stakeholder meetings
- Selected 5 high priority strategies

WORK GROUPS
- 4 work groups
  - Establish drug court
  - Establish detox center
  - Raise awareness
  - Prevention education
Thank you!
Sí Texas Partnership-Centered Evaluation

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Methodist Healthcare Ministries

Lisa Wolff, ScD,
Vice President,
Health Resources in Action
Sí Texas: Social Innovation for a Healthy South Texas
Sí Texas Focus Area
Evaluation Overview

8 Distinct Grantee-Level Evaluation Studies
  ◦ 4 randomized control trials, 4 quasi-experimental designs

1 Overall Portfolio-Level Evaluation Study
**Sí Texas Partnership-Centered Approach to Evaluation**

- **Funder-MHM**
  - Authority on requirements, policies, procedures
  - Program & evaluation alignment monitor
  - Federal funder liaison

- **Grantee**
  - Advisor to evaluation plan
  - Community/feasibility expert

- **Evaluator-HRIA**
  - Authority on evaluation rigor
  - Evaluation plan writer

### Planning
- Requirements interpreter/monitor
- Federal funder liaison
- Strategic thought partner
- Intervention implementer
- Study participant recruiter
- Data collector
- Staff trainer
- IRB partner or lead

### Implementation
- Final report oversight
- Federal funder liaison
- Reviewer/owner of final evaluation reports
- Partner in results interpretation
- Co-analyst, if applicable
- Decision-maker for practical/strategic use of results
- Primary analyst
- Final report writer
- Teacher of analytic approaches
- Advisor/consultant

### Analysis & Reporting
- Champion
- Requirements monitor
- Dissemination plan creator
- Lead presenter/author
- Lead for dissemination to community
- Peer thought partner
- IBH champion and expert
- Decision-maker for practical/strategic use of results

Evaluation Consideration: 
Standardization versus Customization

Consistent across grantee evaluations:

• 5 common outcomes (identified through consensus building session among grantees)
• Level of rigor (RCT or QED)
• Type of analysis

What was customized:

• Participant eligibility criteria
• Protocols for data collection
• Patient characteristic information collected
• Additional outcome measures (e.g., anxiety, cholesterol)
Evaluation Consideration: Capacity Building

• Intensive multi-year Evaluation Learning Collaborative & Technical Assistance
  ◦ Quarterly in-person full-day evaluation training sessions for full cohort
  ◦ Virtual and in-person topical “mini-courses” with small groups
  ◦ Individualized TA with evaluator team across project period

• Range of methods
  ◦ Peer sharing & coaching, didactic, role-playing, hands-on activities, games, small group work, etc.
Lessons Learned

• **Navigating dynamics** is complex and constantly fluid. Consider ways to build trust early on.

• Clear and regular **communication** is essential and should be tailored, but **consistency in messaging** is critical.

• Important to **recognize what we don’t know** and that there is **expertise** among all involved.

• **Capacity-building** can provide the foundation for collaboration and can happen in all directions. We need to embrace the end goal of trying to work our way out of a job.
Thank you!

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To learn more about Sí Texas: www.mhm.org/sitexas

Evaluation Reports: CNCS Evidence Exchange

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