Strategies and Models for Community-Based Participatory Research

West Virginia School of Osteopathic Medicine
Center for Rural and Community Health
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Courtney Hereford – Research Coordinator
Objectives

- Better understand community-based and participatory research and how it differs from traditional research.

- Learn more about the importance of community-building and engagement as preparatory and foundational to research.

- Learn how to build capacity and infrastructure for community-based research and engagement.
Agenda

- Introduction
  - WVSOM’s Center for Rural and Community Health

- Community-Based Participatory Research (CBPR)

- Rural Response Grant
  - Community building as preparatory to research

- Greenbrier County Health Alliance (GCHA)
  - Community engagement strategies, impacts & foundations for research

- Patient-Centered Outcomes Research (PCOR) & Next steps
WVSOM - CRCH

OUR MISSION

The WVSOM Center for Rural and Community Health (CRCH) supports the osteopathic medical education focus on team-based and patient-centered care and the integration of prevention and population health to improve quality and efficiency of health care delivery.

OUR VISION

To develop program, collaborations, and resources that promote health, support research, and provide education and outreach to rural communities, students, providers, and practices across West Virginia.
Teamwork
Dependability
Trust
Integrity
Respect
Collaboration
Community Service
Creativity
Innovation
Responsiveness
Commitment to Excellence
Community-Based Participatory Research (CBPR)

- A collaborative approach to research that equitably involves all partners in the research process, sharing decision-making and responsibility and recognizing the unique strengths and expertise that each contributes. CBPR begins with a research topic of importance to the community and aims to combine knowledge with action to achieve social change to improve health outcomes and eliminate health disparities. *(paraphrased: W.K. Kellogg Foundation/Israel et al, 1998)*

- A transformative research paradigm giving underserved communities a genuine voice to bridge the gap between science and practice through community engagement and social action to increase the likelihood of interventional and translational success. *(paraphrased: Wallerstein and Duran, 2010)*
Community Research Continuum

Traditional CBR/CEnR

CBPR

Community Informed

Community Collaborates

Community Drives

Nothing about us without us.
<table>
<thead>
<tr>
<th></th>
<th>Traditional Research</th>
<th>Research with Community</th>
<th>Community-based Participatory Research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research Objective</strong></td>
<td>Researchers define the issues based on epidemiologic data and funding priorities</td>
<td>Community participates in defining research questions that are relevant to their local needs and experience</td>
<td>Community identifies research issues or works with researchers to define and prioritize research goals (increased focus on community strengths) and are involve as part of the funding process</td>
</tr>
<tr>
<td><strong>Study Design</strong></td>
<td>Researchers base design on scientific rigor and feasibility</td>
<td>Researchers work with community to develop culturally appropriate and feasible study design</td>
<td>Researchers communicate the need for specific study design approaches and work closely with the community to design acceptable approaches that will be feasible and provide quality information including type (qualitative or quantitative methods)</td>
</tr>
<tr>
<td><strong>Recruitment and Retention</strong></td>
<td>Based on scientific issues and “best guesses” regarding how to best reach community members</td>
<td>Research consults community representatives on strategies to recruit and retain participants</td>
<td>Community representatives provide guidance on best way to reach intended study participants and keep them involved in the study</td>
</tr>
<tr>
<td><strong>Instrument Design</strong></td>
<td>Instruments are adopted and adapted from other studies based on psychometric analytic measures</td>
<td>Community members involved in some aspects of data collection</td>
<td>Community members contribute to instrument design including development and pilot testing prior to beginning formal research, increasing likelihood of validity and reliability</td>
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## Research Approach (continued)

<table>
<thead>
<tr>
<th></th>
<th>Traditional Research</th>
<th>Community-engaged Research</th>
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</thead>
<tbody>
<tr>
<td></td>
<td><strong>Data Collection</strong></td>
<td><strong>Community-based Participatory Research</strong></td>
</tr>
<tr>
<td></td>
<td>Conducted by academic researchers who have no connection to the community</td>
<td>Conducted BY members of the community, to the extent possible based on available skill sets. Researchers and community members work together to help build community capacity</td>
</tr>
<tr>
<td></td>
<td>Community members involved in some aspects of data collection</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Analysis and Interpretation</strong></td>
<td><strong>Data ownership is shared. Community and research partners work together to interpret results</strong></td>
</tr>
<tr>
<td></td>
<td>Researchers “own” the data, control the analytic process, resources, and data interpretation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Researchers retain primary “ownership” of the data and analysis, but rely on community members to assist with interpretation</td>
<td></td>
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<tr>
<td></td>
<td><strong>Dissemination</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Results published in peer-reviewed academic journals and presented at professional conferences by researchers</td>
<td>Results jointly disseminated in community and academic venues and may contribute to publications and presentations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community member help researchers to decide appropriate venues and mediums to disseminate results in a timely manner, and are included as co-authors</td>
</tr>
</tbody>
</table>

Principles of CBPR

- Recognizes community as a unit of identity
- Builds on strengths and resources within the community
- Facilitates collaborative partnerships in all phases of the research
- Integrates knowledge and action for mutual benefit of all partners
- Promotes a co-learning and empowering process that attends to social inequalities
- Involves a cyclical and incremental process
- Addresses health from both positive and ecological perspectives
- Disseminates findings and knowledge gained to all partners

Values = TRUST, respect, self-determination, sovereignty, empowerment, reciprocity

(Principles should also be partnership-defined!)
Principles of CBPR

- Ethical review
- Community initiation
- Capacity building
- Process oriented
- Community relevance
- Social action outcomes
- Varied methods
- Joint data ownership
CBPR Conceptual Model (2017)


CBPR – so what?

- **Pros**
  - Subjectivity!
  - Community priority
  - Research relevance, application,
  - Enrich quality, validity, sensitivity
  - Diverse expertise for complex problems
  - Utilize existing systems and resources
  - Overcome distrust, bridge divides
  - Enhance agency, capacity, health & wellbeing

- **Cons**
  - Subjectivity!
  - Community self-defined
  - IRB issues
  - Macro approach & Global outcomes
  - Deficient assessment & evaluation
  - Accountability
  - Ends vs. means
  - Time!
Example - Opioid Related NIH/NIDA Partnership Grant

Overdose death heat map by WV counties, 2014; Adapted from WV Bureau for Public Health (BPH)

Table 1. Eight WV Counties

<table>
<thead>
<tr>
<th>WV County</th>
<th>CDC Rank</th>
<th>2014 Pop.</th>
</tr>
</thead>
<tbody>
<tr>
<td>McDowell</td>
<td>2</td>
<td>20,448</td>
</tr>
<tr>
<td>Mingo</td>
<td>7</td>
<td>25,716</td>
</tr>
<tr>
<td>Wyoming</td>
<td>16</td>
<td>22,598</td>
</tr>
<tr>
<td>Raleigh</td>
<td>18</td>
<td>78,241</td>
</tr>
<tr>
<td>Logan</td>
<td>20</td>
<td>35,348</td>
</tr>
<tr>
<td>Boone</td>
<td>22</td>
<td>23,714</td>
</tr>
<tr>
<td>Mercer</td>
<td>147</td>
<td>61,785</td>
</tr>
<tr>
<td>Kanawha</td>
<td>209</td>
<td>190,223</td>
</tr>
</tbody>
</table>
Engage the Community - Community Forums
Organize the Community - Community Workgroups
Trust Community Members’ Ideas

FREE Family Fun Day

Sponsored by:

- Amazing Grace Fellowship
- Aversons Auto Repair
- Mountaineer Drug Pharmacy
- Water Valve Services
- Brent Wells
- Community Connections
Create Sustainable Programs
Boone Opioid Network

https://www.facebook.com/booneopioidnetwork/

Boone Recovery Coach Academy
by David Sanders

DATE AND TIME
Mon, Mar 26, 2018, 8:30 AM – Fri, Mar 30, 2018, 4:30 PM EDT

LOCATION
Madison Baptist Church
426 2nd St
Madison, WV 25130

LOGANBANNER.COM
Recovery Roads: Woman celebrates 18 months clean

RECOVERY PEERS

BLACK BALLOON DAY 2018
March 6, 2016

Raise Awareness
Reduce Stigma
Families are Affected Too
Entire Communities Affected

2nd Annual BLACKBALLOONDAY
Raising Awareness to the effects of
DRUG ADDICTION
#BooneHEARTS
Community Engagement Creates Potential for Community Research

http://www.greenbriercountyhealthalliance.org/
Partnership for Community Engagement

- West Virginia School of Osteopathic Medicine/Center for Rural and Community Health
- WVCTSI Community Engagement and Outreach Core
- Greenbrier County local service providers
- Grassroots community leaders
Maintain Focus on 4 Community Engagement Strategies

- Community Ambassadors
- Mapping of Assets
- Evidence Based Programs
- Local Foods to Meet Local Need
What has happened...?
WVSOM Center for Rural and Community Health
Greenbrier County Health Alliance
Clingman Center For Community Engagement

I WOULD PUT PARTNER DIAGRAM HERE OR FOLLOWING "INCREASED CAPACITY FOR COLLABORATIONS" SLIDE
Partnerships have created trust...
GCHA Engagement Survey (summer 2018)

Survey Participants

- Ambassadors: 20
- Workshop leaders: 12
- Event participants: 6
- Board members: 10
- Community partners: 10
- County partners: 9
- Statewide partners: 8
- Individuals: 6
Participation in GCHA contributed to: (% Agree or Strongly Agree)

- I take better care of my own health: 57.2%
- I gained new skills: 72.5%
- I feel better connected to resources that can help me: 84.3%
- I am more informed and aware of community resources: 92.0%
- I gained more knowledge: 94.1%
Participation in GCHA contributed to:
(% Agree or Strongly Agree)

- I feel a greater sense of belonging within my community. 74.0%
- I made a valuable contribution to work in my community. 82.4%
- GCHA has increased hope across the county. 84.3%
- GCHA lent a greater voice to isolated communities. 84.3%
- GCHA supported me to become more active and engaged in my community. 86.3%
- GCHA boosted community pride. 88.0%
- GCHA made positive change happen 96.1%
GCHA:
(% Agree or Strongly Agree)

- GCHA had processes that were clear and consistent. 84.3%
- GCHA was accountable. 88.2%
- Created and strengthened partnerships 92.0%
- Valued and incorporated participant input and... 94.1%
- Improved collaboration and networking across the... 94.1%
- Helped build trust and respect among participants... 94.1%
- Encouraged a sense of empowerment in participants. 94.1%
- Encouraged diverse and inclusive participation. 96.0%
- Provided information that was helpful, relevant, and... 96.1%
- Created new resources and services. 96.1%
- Helped develop connections between existing... 98.0%
- Was respectful and fair. 98.0%
- Was open and accessible. 98.0%
Engagement process results

- GCHA was open and accessible. 98.0% of participants surveyed.
- GCHA was respectful and fair. 98.0%
- GCHA helped develop connections between existing resources. 98.0%
- GCHA created new resources and services. 96.1%
- GCHA provided information that was helpful, relevant, and understandable. 96.1%
- GCHA made positive change happen. 96.1%
- GCHA encouraged diverse and inclusive participation. 96.0%
- GCHA encouraged a sense of empowerment in participants. 94.1%
- GCHA helped build trust and respect among participants and partners. 94.1%
- GCHA improved collaboration and networking across the county. 94.1%
- GCHA valued and incorporated participant input and feedback into processes. 94.1%
- GCHA created and strengthened partnerships. 92.0%
Building skills, confidence, and capacity

“I have seen our community come together in many ways because of the influence of GCHA. I've also seen growth and improvements in individuals as they've learned ways of self-managing their health. On a personal level, my husband has lost weight and gained control of his diabetes with the support and information made available through the GCHA resources and teachings. We will be forever grateful to GCHA for the impact seen.”
Interest in research

Questions:

• What data to collect, when to collect it, tools for collection?
• How to schedule time and resources for data collection?
• How to reflect on what’s working and not working, and use information for further planning?
• What are my health options?
• How can we address health issues?
GCHA Potential for Research

- Facilitate community-focused and action-oriented discussions on health disparities, priorities, research, and solutions
- Educate community members, researchers, and healthcare stakeholders on community and patient-centered research process
- Develop a community research network with research capacity and tools to support research in Greenbrier Valley to adapt and disseminate throughout WV and Appalachia.
Clingman Community Engagement Center:
Engaging Patients and Providers in PCOR Training & Partnership

- Eugene Washington PCORI Engagement Award: Capacity Building – build community capacity & infrastructure for PCOR
- Dynamic hub for community-based initiatives and programming, evidence-based training, workforce development, culinary outreach, local foods justice.
- Strengthen trust, rapport, partnership, opportunity
- Build knowledge, competencies, abilities of stakeholders as partners with meaningful roles in research
- Discussion, priority, and agenda setting, training, skill-building, workshops, partnership and collaboration, advisory & evaluation panels, shared dissemination & sustainability plans
Health happens outside of the treatment setting.
Patient-Centered Outcomes Research (PCOR)

- Helps people and caregivers communicate and make informed health care decisions, allowing voices to be heard in assessing the value of health care options
- Actively engages patients and users of research in all steps of research process to meet stated goals and improve health outcomes
- Evaluates outcomes that are most important to patients
- Addresses implementation of research findings in clinical care environments
- Subset of CER

- **Comparative Effectiveness Research (CER):**
  - The generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care. The purpose of CER is to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at individual and population levels (IOM/PCORI)

If we asked better questions, there would be better evidence.
PCOR Engagement

- Stakeholders
  - Patients & clinicians
  - Caregivers, healthcare purchasers, payers, policymakers
  - Reps from hospitals, health systems, industry, advocacy and training, orgs

- Process priorities
  - Knowledge, experience, judgment, and values are desireable
  - Values: trust, respect, fairness
  - Outcomes: shared understanding & decision-making that is viewed as actionable and credible to all

- Approaches
  - Research co-investigators & team partners
  - Advisory boards & Community experts
  - Surveys, interviews, opinion polls
PCOR Study Engagement

- Understanding patient/stakeholder needs
  - Share personal & pro perspectives
  - Best approaches for addressing needs and priorities
- Research topics & questions
- Interventions
- Outcomes & measurement
- Recruitment & retention
  - Finding & recruiting participants
  - Training research staff
- Data collection
  - Interviews, focus groups, surveys, tracking
- Data analysis and review
- Dissemination & application
  - Co-presenting, manuscript and newsletters, determining outlets, media interviews, meeting with officials
PCOR Framework

**PCOR Principles**
Trust, honesty, co-learning, transparency, reciprocal relationships, partnership, and respect

**Foundational Elements**
- Awareness of methods for PCOR
- Valuing of the patient perspective
- Interest in PCOR

**Internal**
- Ways for patients and researchers to partner
- Resources and infrastructure
- Policies/governance

**External**
- Initiate and maintain partnerships between researchers and stakeholders
- Facilitate cross-communication among research stakeholders
- Capture, use and optimize patient perspective across phases of research
- Ensure meaningful influence on research
- Train for partnering
- Share and use learnings

**Outcomes**

**Near-term**
- Culture of patient-centeredness in research
- Meaningful & effective partnerships

**Intermediate**
- Research relevant to patients/other stakeholders/questions and outcomes are meaningful to end users
- Use of research results in health decisions
- Quality health decisions
- Satisfaction with health care experiences

**Long Term**
- Optimal health
Limitations

- Lack shared understanding of effective stakeholder engagement in research
- Limited evidence base, data and evaluation
- Extensive training needs for all partners
- Partner selection bias/diversity & inclusivity
- Budget & cost concerns for project
- Time!
- Subjectivity
Findings

- Enhanced patient-centeredness/relevance of study processes and outcomes.
  - Reiterated significance of research being pursued.
  - Increased sensitivity and fit of interventions, materials, data collection
  - Decreased participation burden
  - Outcomes and measures of importance to participants

- Enhanced study design, conduct, and/or efficiency.
  - Recruitment, retention, follow-up, data collection
  - Expanded audience
  - Improved communication
  - Increased credibility of findings
Community Engagement Exhibit

2019 WVCTSI Annual Meeting
optional visit to Montwell Commons

Tour the Clingman Center Barn
April 3
1:00 - 3:00

We hope you can join us!
References


Thank you!

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