Community-Based Participatory Research and D & I Research: overlaps and significance

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2017 D&I Short Course
Objectives

- Understand principles of CBPR
- Understand the importance of Community-Based Participatory Research in D&I Science.
  - Definitions
  - A couple models
  - Examples
- What do researchers have to give up when they use CBPR?
Understand principles of CBPR
A collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.

Minkler M. J Urban Health. 2005
Key Principles of CBPR

Israel, 1998

- Recognizes community as a unit of identity
- Builds on strengths and resources within the community
  - To address their communal health concerns
- Facilitates collaborative partnerships in all phases of research
  - All parties share control over all phases
- 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 iterative process
Addresses health from both positive and ecological perspectives
Disseminates findings and knowledge gained to all partners
12 characteristics of successful community-institutional partnerships

Qualitative analysis of surveys and qualitative summary of meeting notes from combined meeting of 10 partnerships:

- trusting relationships
- equitable processes and procedures
- diverse membership
- tangible benefits to all partners
- balance between partnership process, activities, and outcomes
- significant community involvement in scientifically sound research
- supportive organizational policies and reward structures
- leadership at multiple levels
- culturally competent and appropriately skilled staff and researchers
- collaborative dissemination
- ongoing partnership assessment, improvement, and celebration
- sustainable impact

Facilitators of Partnerships in CBPR

- Jointly developed operating norms
  - attentive listening, openness, caring, inclusiveness, agreement to disagree, identifying and addressing conflicts, opportunity for all to participate, negotiation, compromise, mutual respect, equality
- Identification of common goals and objectives
- Democratic leadership
- Presence of community organizer
- Involvement of support staff/team
- Researcher role, skills, and competencies
- Prior history of positive working relationships
- Identification of key community members
  - Israel, 1998
Facilitators related to research methodology

- Methodologic flexibility
- Involvement of community members in research activities
- Conduct community assessment/diagnosis
- Develop jointly agreed upon research principles
- Conduct educational forums and training opportunities
- Involve partners in the publishing process
- Create interdisciplinary research teams

  - Israel, 1998
Facilitators: broader issues

- Broad support: top down and bottom up
- Provision of financial and other incentives
- Planning grants
  - Israel, 1998, 2001
Understand importance of CBPR to D&I

Definitions
Models
Examples
## Challenges of translational research in community settings, Wallerstein 2010

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<thead>
<tr>
<th>CHALLENGES</th>
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<td>External validity</td>
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<td>Privileging of academic knowledge as the definition of evidence</td>
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<td>Language incompatability</td>
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<td>Business as usual in universities</td>
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<td>Sustainability beyond funding</td>
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<td>Lack of trust</td>
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CBPR helps overcome these challenges
According to the NIH (D&I R01 2009): “Implementation [research] is the use of strategies to adopt and integrate evidence-based health interventions and change practice patterns within specific settings.”

This is an academic-centered approach

Process should be bi-directional throughout

- Wallerstein, Duran 2010
Bidirectional approach

Researcher and community partner together design intervention or adapt it to new context

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Community Partner</th>
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<tr>
<td>Science of what works, key elements</td>
<td>Knowledge of what is feasible to implement and maintain and what has worked in community setting</td>
</tr>
<tr>
<td>Science of who should be in target group</td>
<td>Knowledge of target group – who, what, where, when</td>
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Implementation is more likely to succeed if community is invested from the start.
Use of CBPR can remove bias from knowledge translation

- Adapting interventions within cultural and local contexts
  - Engaging communities as partners in all phases of adaptation maximizes sustainability, reach, adoption, and effectiveness

- Co-development of adaptation with incorporation of local cultural knowledge enhances community ownership and makes sure community members will be most receptive

  - Simonds, 2013
Knowledge translation in the community vs health care setting

- Typical characteristics of KT within community-based settings
  - Usually involves networks of multiple organizations and stakeholder groups working in collaboration
  - Types of knowledge valued by stakeholders are broad and include experiential and local knowledge
  - Advocacy is integral to KT in the community and is a central KT activity
  - Approach is usually at population or public health level

- In health care, often one organization, more narrow types of knowledge valued, advocacy not as central, and approach is curative

- New field of community-based knowledge translation
  - Intersection of CBPR and D&I
  - Acknowledges that differences in setting (health care vs community) may result in need for different frameworks for knowledge translation
A collaborative approach by researchers and communities to “co-create, refine, implement and evaluate the impact of new knowledge that is sensitive to the context (values, norms and tacit knowledge) where it is generated and used.”

- Kitson et al, 2013
Kitson 2013, Co-Creating (co-KT) framework

- The community is involved from knowledge creation stage to implementation and evaluation stage
  - initial contact and framing the issue
  - refining and testing knowledge
  - interpreting, contextualizing and adapting knowledge to the local context
  - implementing and evaluation
  - embedding and translating of new knowledge into practice

- Co-KT depends on
  - the quality of the relationship between community and researcher
  - Strategies to bridge the researcher and the community to facilitate information sharing and a common understanding
Jenkins et al, 2016: collaboraKTion Framework

- Universal knowledge base (essential elements)
- More specific knowledge for specific setting (community, population, culture) = community’s knowledge
- Requires use of community-based participatory research
Process is iterative, moving between steps.

Will need to revise plans due to barriers at each stage.

Jenkins, 2016
Promoting youth mental health – engaging the “community”

- **End-user**: youth collaborators
  - Met weekly with research team to design social networking app to promote youth mental health

- **Adult stakeholders from multiple organizations that have some relationship to youth mental health**
  - 6 meetings with adult stakeholders

- **Outcomes went beyond the app (which was not successful) to increasing connection of youth to community in other ways**
  - Jenkins, 2016
Wallerstein model: CBPR for culturally tailored intervention development

- Devised through academic expert consensus, revised through community partner reflection 2013
- Contextual factors that influence partnerships
  - Social, historical, structural, readiness factors
  - Apply to researchers and communities
- Group dynamics = structural, individual, and relational factors
  - Cultural humility, mutual learning, flexibility, power dynamics
  - Bridge individuals, trust development, researcher’s sense of stewardship to community, role of language, spirituality

If structural and relational processes are sound, then:
- Partnering will be effective in research and intervention design
Revised CBPR Conceptual Model (2013)
Key elements of model

- Changes research to a shared enterprise throughout all stages
- Capacity development and training are integral part
- Process builds community ownership and identifies community resources for sustainability
- Creates an environment that fosters trust as foundational to partnership
Examples of Structures to promote CBPR: Boot Camp Translation, used by Colorado High Plains Research Network

- Community Advisory Council (CAC) = local farmers, ranchers, school teachers, and others to help guide and ground its research in real patient experience.
- CAC decides priorities
- For each project, the core CAC is joined by other key stakeholders in the community: local physicians or other health professionals, health department representatives, hospital administrators, patients with the condition of interest, students, community organization leaders.

  - Norman, 2013
CAC answers two questions: What do we need to say in our message to the community? How do we disseminate that message to our community?

CAC leads all aspects of project and assists with analysis, interpretation of results, and dissemination of findings.

Process involves face-to-face meetings, short teleconferences, emails

- requires about 20–25 hours of participant time over 4–12 months.
Structures to promote CBPR: Integrating CBPR within PBRNs

- PBRN’s provide opportunities for collaboration with practitioners
  - Gap = Most don’t directly involve community members
- Solution = Engage community members in community advisory boards (CAB)
- CAB composition is dynamic, with new members added depending on research question.
- All stakeholders have representation on a CAB
- CAB involved in all phases of research
- CAB decides priorities based on data (i.e. needs assessment)

- Tapp H, 2010
CAB meetings take place at community sites and clinics on a rotating basis.

Steering committee for the PBRN has representatives from:
  - individual community members
  - community advocacy organizations
  - Providers at clinic sites.
Use of CBPR in D&I – summary

- CBPR should be part of D&I in population health settings:
  - Tailor innovation to fit community
  - Tailor implementation strategies to fit community
  - More used in community than health care settings
- Assures attention is paid to context with D&I
- Engages implementers and receivers of interventions as well as other community members (champions, connectors, partners)
- Provides a prescription for how to respectfully gather and utilize end-user and community input in two-way street
What do researchers have to give up when they use CBPR?
Community-based knowledge translation may lead to outcomes other than what the researcher had in mind

- “our view of CBKT is that it should be less focused on enhancing uptake of a specific intervention and, instead, aim to collaboratively identify and create changes within the community setting that have been shown to influence health outcomes. “
- This is different from health care where you are often working to introduce changes to clinicians’ practice to implement proven intervention
  - Jenkins, 2016
Differences in CBPR approach vs Investigator-centered approach

- CBPR starts by asking for community health priorities
  - Then collaboratively develops or adapts innovations

- Nature of evidence
  - Integrates local practices and programs into innovation

- Language of researchers
  - CBPR changes language:
    - “Research subjects” to “research participants”
    - “Patients” to “individuals”
    - “Targeting community” to “engaging community”
    - “Battery of tests” to “assessments”
Example: Using community-based knowledge translation to improve reach of Stepping On

- Why isn’t Stepping On being adopted by tribal communities and by minorities?
- Is the whole term “adaptation” researcher-centric?
- What can happen if translation is shared equally with community?
  - Focus on different implementation of the key elements?
    - Balance and strength exercises
    - Improving awareness of risk factors and engagement to reduce risk
- Begin by asking end users and community stakeholders
Summary

- CBPR is important in designing interventions and adapting them for communities
- CBPR principles ensure development/adaptation of interventions to ensure fit with the community
- Co-KT emphasizes that community and academician equally share in creation/adaptation of new knowledge
  - Wallerstein framework and CollaboraKTion framework
- Examples of strategies to engage communities
  - D&I “Boot camps”
  - Community Advisory Boards to integrate end-users with PBRNs
  - Community bridge (community research associate)
  - Principles of CBPR themselves are strategies to engage communities
- CBPR is hard and time-consuming; researchers need to give up control of research trajectory.