Engaging Communities in Research

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Respect for Persons

Beneficence

Justice
Solutions
Community Consultation

- Learn from the community what issues they are most interested in pursuing
- Incorporate this in the research design or dissemination plan
Why Have a Community Advisory Board (CAB)?

- Obtain community input into research process
- Include perspectives and experiences of diverse community members and advocates into building ethical research design and implementation
- Get feedback on research process, instruments, recruitment, representation in the study, cultural relevance and appropriate methods to engage the community, etc.
- Liaison to potential study participants
- Resource to support ongoing research relationship with the community and assistance with translating research findings into relevant and positive impacts
Defining Community

- Place and People
- Self-identified
- Shared experiences, ideas, history
- Many sub-communities
- How communities transcend borders and are connected geospatially
What Does “Research Partnership” Mean?

- Working together
- Sharing
- Mutual gain – Win/Win
- Common goals
- Commitment
- Equitable contributions
- Recognition of mutual expertise
- Communication about sharing ideas and perspectives
- Building relationships
- Honesty/Transparency
  - Be clear about your goals
  - Discuss their goals
  - Recognize what you can offer
  - Recognize what you represent as a researcher
  - Recognize your own biases
What Is Required for a Good Research Partnership?

- Overlapping goals/common cause
- Mutual recognition that research is important to further the cause
- Ability to dialogue about issues and problems
- Organizational stability
- Mutual respect for knowledge and methodology
- Communications and negotiation skills – flexibility
- Agreements about personnel policies
- Some overlap in organizational cultures
- Cost and other resource sharing
- Willingness to build on organizational strengths
- Broad-based administrative infrastructure and decision-making group
What Is Required to Have a Good Community Advisory Board?

- Diversity in membership representing different sectors of the community
- Professionals and non-professional community members
- Commitment of time by CAB members and willingness to engage in open dialogue
- Non-monetary compensation for their time and efforts (to avoid conflicts of interest)
- Open and welcoming environment for divergent perspectives and deliberation to inform ways to move the research forward and resolve conflicts between researchers and the community
Considerations: Community and Positionality

- Communities are complex; constantly changing, diverse in composition, needs, opinions etc.; multi-sectoral.
- Positionality is relational. It all depends on who we are and who we are talking to.
- In the context of complex, changing, and multi-sectoral communities, awareness of positionality of researchers in relation to community partners may mitigate problems of power differential and biases.
Considerations: Community and Positionality

- Relational
- Based on actual or perceived identity
- Recognition of and negotiation of difference
- Sources of difference (which often but not always involve power differential)
  - Power (e.g., in access to resources, political control, etc.)
  - Race/ethnicity
  - Class/socio-economic status/education
  - Culture (cultural knowledge, language)
  - Age / generational differentials
  - Geography/place of origin
  - Discipline, field etc.
- Recognition and negotiation of similarity
Positionality and the CAB

- What factors need to be considered in the relationship between the researcher and CAB members with regard to positionality?

- How might power differentials both between researchers/research institutions and the community and between different sectors within the community affect the success of the CAB to facilitate research?
Stages of Research Partnership and CAB Development

- Initiation
- Negotiation
- Implementation
- Evaluation
- Re-negotiation/continuation vs. closure
Initiation: Approaching Communities

- Map ("mental", social, geographic, drive through, walk through)
- Find other(s) who have worked and done research in the community
- Volunteer
- Participation in public activities, attend public events
- Go to places where people gather – basketball courts, senior centers, libraries.
- Engage support of community members – "gatekeepers" and others, informal leaders
- Find/connect with one or a network of community organizations (CBO) with interest in the topic or population
- Phone books and advertisements, local papers
INITIATION

Example: Identifying Brooklyn Community Partners

- Hold town hall meeting to introduce myself and prior work
- Let attendees share interests, concerns, ideas
- Discuss my process and overall goals
  - No direct ask (e.g., no discussion of specific projects/recruitment)
- Collect contact information
- Stay in touch (listserv, fb group)
INITIATION
EXAMPLE: BEATS Community Advisory Board (CAB)

- Meet five-six times a year
  - 10 members from various community organizations
    Rick Brown, Senior Site Coordinator; Council for Unity
    Denise Cosom, Director and Founder; Young Gents Society
    Allen Frimpong, Program Manager, Living Cities- Newark, NJ's Integration Initiative
    Dino Johnson, Director of School Based Initiatives; Council for Unity
    Charmaine Peart HoSang, Director of Outreach and Student Services; YearUp Organization
    Dr. Marie Pierre-Louis, Program Director; Haitian Centers Council, Inc.
    Dr. Divine Pryor, Deputy Executive Director; the Center for NuLeadership on Urban Solutions
    Xamayla Rose, Youth Policy Analyst; Brooklyn Borough President’s Office of Marty Markowitz
    Ortez Taylor, IT specialist and personal chef
NEGOTIATION

Partnership Principles Developed by the CT Community Research Alliance (CRA)

I. Involvement of all partners in the research process

II. Respect for and commitment to the community where research takes place

III. Relevance and benefit of the research

IV. Effective communication among research partners

V. The ethical conduct of research

VI. Recruitment in community settings

VII. Capacity-building, resource sharing and sustainability
IMPLEMENTATION Example:
Community Resources Utilized for BEATS Project

- **Identify Good Recruitment Sites**
  - **Fortune Society**
    - Community organization that provides previously incarcerated individuals in New York City with re-entry services

- **Locate Resources for Study Activities**
  - **Brooklyn Public Library**
    - For CAB and other lab meetings
  - **Shakoor’s Sweet Tooth**
    - For CAB and other lab events
  - **Brooklyn Community Foundation**
    - Funder of community events
Example - High level of concurrent sexual relationships, descriptions of criminal behavior

- Engage with community stakeholders about how to disseminate information in a factual manner while respecting concerns
- Think of potential issues ahead of time, particularly questions during presentations (e.g., sex while in prison stereotype)
IMPLEMENTATION
Sharing Research Products and Benefits

- Relationships
- Data (datasets or summarized findings, models, etc.)
- Materials (e.g., interventions/protocols, dissemination materials, tools for using data or improving outcomes, etc.)
- Presentations
- Publications
- New Research
IMPLEMENTATION:
Example of sharing products

- Create lay friendly workshops about research
  - Present to recruitment sites
  - Present to potential participants
  - Present at community events
EVALUATION

- Was the research partnership “value-added”?
- Was there enough goal overlap among parties?
- Were relationships positive?
- Was resource sharing sufficient?
- Were there inequities?
- Was the methodology appropriate?
- Were the data “good enough”?
- Were the results important – did they contribute to science and community/partner advancement?
- Was there parity in publications?
- Is there sustainability of methods, outcomes, effects, relationships?
Year 2

“I think we should have something happen within us in-between meetings. [Pause] I don’t know what it is but I think that it should be something that allows us to see each other in different ways and in different circumstances.”

Group: (people agreeing)

“We have resources around here- we don’t even know what we have and we’re not utilizing it and we have to find a way to do that.”

“How about if we put together an event utilizing solely the resources at this table.”

“That’s a good idea. It’s good”
BEATS Project IMPACT
Continuation / Re-negotiation vs. Closure

- When Is It Time to End a Partnership
  - Insufficient resources
  - Structural inefficiencies
  - Conflicts around differences in organizational policies
  - Unresolved issues over resource allocation
  - Competition over funding sources
  - Gossip and backbiting that worsens
  - Funding ends
How to End a Partnership Without Burning Bridges
Citations

PAR references

Ecological/multilevel Modeling
Schensul, S. Schensul, J. & LeCompte, M.D. 2012. Initiating Ethnographic Research: a mixed methods approach, chapters 5 (formative models) and chapter 8 (intervention modeling)
Schensul J & LeCompte M.D., Ethnography in Action, A mixed methods approach, Chapter 4.

Testing inductive/ethnographically based theories over time

References to introduce system dynamics and systems thinking in public health:
Discussion Questions

- What types of goals do you have for your CAB? E.g., advice on measures, facilitating recruitment, alignment of project aims with participant perspectives, building community trust, etc.

- How can you begin or expand the process of community identification and partnership building?

- Who should be on the CAB? Who will best represent participants, stakeholders, and provide appropriate guidance. Who can best assist you in reaching your CAB goals?

- At what point in your project is it best to convene the CAB? What if they suggest changes to informed consent and you already had IRB approval.
Discussion Questions

- What factors might affect your own positionality? What can you do in relation to these factors when working in the community?
- What are some contextual factors (historic/contemporary) that you should keep in mind that might impact research and recruitment with your specific population?
- What are some cultural factors that might be important to consider when framing your research/questions and design?
- What about your research findings might unintentionally stigmatize your population? What could you do to help prevent/decrease stigmatization?
- What are some strategies you can put in place to disseminate the results of your study to the community?