# Engaging Communities in Research

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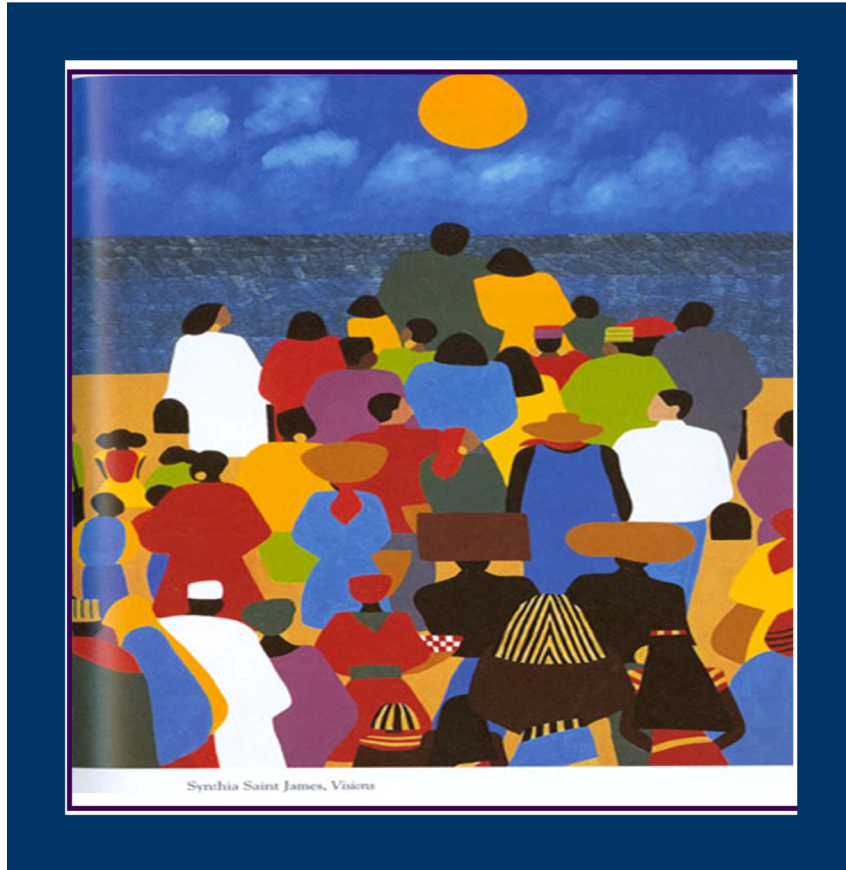**Research Ethics Training Institute (RETI)**
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# Community Consultation


Synthia Saint James, Visions

- **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 <u>ethical</u> 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**

# IMPLEMENTATION
## Example: Partners Identify Potentially Stigmatizing Findings

- **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**

# IMPLEMTATION:
## Example of sharing products

Research 101

- 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**

# BEATS Yearly Qualitative Evaluation

**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."*
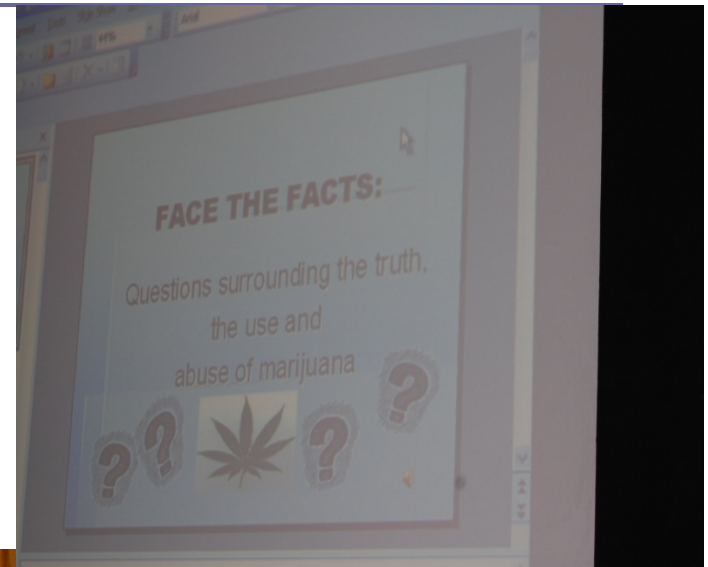
*Group: (people agreeing)*

*"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

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# 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?**