Community Based Participatory Research In Action
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The HIV epidemic in NC in 2010

- NC has the 8th highest percentage of black population in the nation
- ~35,000 people were living with HIV/AIDS (including 7,000 individuals who may have been unaware of their infections)
- Rate of new HIV diagnoses for adult/adolescent blacks (59.7 per 100,000) was more than 10 times greater than that for adult/adolescent whites (5.6 per 100,000)

NC Epidemiologic Profile for HIV/STD Prevention and Care Planning (12/11)
The HIV epidemic in NC in 2010

- Highest rate of new HIV diagnoses: adult/adolescent, black males (94.0 per 100,000)
- Largest disparity: adult/adolescent black females; with a rate of new HIV diagnoses (30.5 per 100,000) nearly 17 times higher than white females (1.8 per 100,000)
- Among adult/adolescent HIV disease cases
  - men who have sex with men (MSM) was the risk category in an estimated 57% of total cases
  - heterosexual transmission risk was estimated in 39%
  - IDU was estimated in 4% of total cases (including 1% among MSM who also indicated injection drug use)
Map 9. North Carolina Newly Diagnosed HIV Disease Cases, 2001-2010, by County of Residence at Diagnosis

Note that the dots do not represent actual locations of HIV cases, but reflect the number of diagnoses in each census tract. 1 dot represents 5 cases. Address information was able to be represented for 92.5% of diagnoses.
By Year Of Diagnosis

Rate per 100,000 population

- 0.0
- 0.1 - 10.0
- 10.1 - 20.0
- 20.1 - 30.0
- >30

Durham County
LinCS 2 Durham: Project Aims
AIMS / protocol language

• **AIM 1:** Implement and conduct a process evaluation of a systematic community-based participatory research model to build support for new HIV prevention technologies in the African American community.

• **AIM 2:** Describe the communities and group affiliations that exist among young (ages 18-30) at-risk African Americans, and measure the relationship among experiences of discrimination, levels of trust, and support for new HIV prevention technologies in this population.

• **AIM 3:** Identify priorities for evaluating and implementing new HIV prevention technologies in the African American community.
By bringing together researchers and community members, we’re accomplishing three goals:

1) **We’re talking to people in the Durham community about medical research and HIV.**

2) **We’re talking with communities of young Black adults (ages 18 to 30) who have a higher chance of becoming infected with HIV.**

3) **We’re bringing community members and scientists together to decide jointly what research needs to be done to prevent HIV in the Black community.**
Stakeholder framework

Components of the Prevention Science Research Continuum

Advocacy/policy
- Advocacy
- Policy Development
- Policy Application

Community
- Community Awareness
- Community Engagement
- Community Ownership

Research enterprise
- Theory/Biological Plausibility
- Conceptual Development
- Phase 1 Safety
- Phase 2
- Phase 3
- Phase 4 Effectiveness

Clients/users
- Hypothetical Acceptability
- Clinical Acceptability
- Experiential Acceptability
- Long-term Acceptability

Service providers
- Formative Operations
- Program Modeling
- Program Implementation

Ethnography

• Ethnographic team approach

• Define the diversity of communities that need to be recognized in order to conduct effective HIV prevention research in Durham

• Ensure unbiased identification of stakeholder groups

• Define an appropriate sampling frame for quantitative survey addressing HIV prevention trial planning including HIV-related behaviors, trust and research acceptability, and attitudes toward HIV testing
Group process

• Initially build on existing relationships among the research team and community stakeholders

• Use the PSRC as a framework to provide a check against bias in our partnership-building efforts by ensuring attention to all critical partners

• Conduct a process evaluation to measure the success of this model in terms of our ability to bring researchers and community stakeholders together to jointly develop a proposal for one or more HIV prevention studies
Coordination network

• The totality of relationships among members, tasks, and tools: who does what, with whom, and how

• The larger the group, the larger the resulting coordination network will be and the less amenable it will be to informal coordination
  – *It’s not the number of people involved but the number of relationships!*
Collaborative Council

Components of the Prevention Science Research Continuum

- Stage 1: Conceptual
  - Advocacy
  - Community Awareness
  - Conceptual Development
  - Formative Operations

- Stage 2: Experimental
  - Policy Development
  - Community Engagement
  - Clinical Acceptability
  - Program Modeling

- Stage 3: Applied
  - Policy Application
  - Community Ownership
  - Experimental Acceptability
  - Program Implementation

- Stage 4: Effectiveness
  - Community Ownership
  - Long-term Acceptability
  - Program Implementation

Working Groups
- Collaborative Council
- Communications
- Ethnography
- Outreach
- Survey
- Research Literacy

Task Forces
- Proposal development

FHI 360
NCCU
DCHD
UNC

Core team
Management team
Field team

Evaluation

Project Coordination
The approach we used

CBPR
Community-Based Participatory Research

• Principles
  – Recognize community as a unit of identity
  – Build on strengths and resources within the community
  – Facilitate collaborative, equitable partnership in all research phases
  – Promote co-learning and capacity building
  – Integrate and achieve a balance between research and action
  – Emphasize local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease
  – Involve systems development through a cyclical and iterative process
  – Involve all partners in dissemination of findings and knowledge gained
  – Involve a long-term process and commitment

Building the partnership

- Initial list of stakeholders identified
- Open house meetings held to introduce LinCS 2 Durham to stakeholders
- Initial partnership meetings held
- Agreement on monthly meeting schedule, location (public libraries)
- Principles established
- Identity established: LinCS 2 Durham Collaborative Council
- Decision-making process established
- Annual retreats
A key element in our participatory approach is the fact that we are not seeking to implement a specific HIV prevention trial in the Durham Black community.

Rather, we are seeking to build a research partnership that will identify one or more appropriate trials to plan and pursue with the community.
Group dynamics: working with diverse stakeholders
Challenges of Diverse Stakeholders

• Collaborative Council includes professionals with strong views and experience expressing them in large groups and community members with less experience and different values and comfort levels re speaking out

• Different levels of information/knowledge re discussion topics and different comfort levels claiming knowledge

• Stakeholders who see themselves in dual roles: members of the research team and the community. What is their primary identity? How do others see them? Paid vs. volunteer?

• Finding a format that works for our priority population: 18-30 year olds
Small Groups & Working Group

• Use of small groups in CC meetings to facilitate greater participation of community members
  – Reduces domination of conversation by a few vocal members
  – Reduces discomfort of speaking in a large group

• Establishment of CC Working Group
  – Includes non-staff members
  – Ensures more shared leadership between research team and community members of CC
  – Forum for thinking through issues in group dynamics
  – Helps with planning meetings & providing guidance to CC
Process Evaluation & TAB

• Process evaluation with outside evaluator
  – Helps identify and address issues of group dynamics
• Targeted Advisory Board (TAB) for 18-30 year olds
  – Recognition that format of CC is not attractive to many young adults
  – Series of 1-time meetings in the community
  – No expectation of long-term commitment
  – Run by and restricted to this age-group
Informed consent: where’s the research boundary?

CHALLENGES
Are CC members also research participants?

• LinCS 2 Durham Collaborative Council is a partnership
  – Goal is to have “a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities” (Israel et al. 2005)

• CC is not intended to be an advisory board
  – Since it is a partnership, research team is included among CC membership
Why we sought informed consent

• Evaluation of the CBPR process is one of the research aims
  – In this study we learn to collaborate by doing it
  – We collect information to help us understand what works and what does not

• Independent evaluator
  – Observes CC meetings
  – CC members must be willing to allow the evaluator to observe meetings and to have access other information (e.g., meeting minutes, other communications, publicly posted comments)
  – Conducts on-line survey and in-depth interviews with CC members
Evaluation ethics

• Potential risks
  – Discomfort at being observed
  – Discomfort responding to survey or interview questions
  – Confidentiality

• Steps to reduce risk
  – Can refuse to participate in survey or interview
  – Can refuse to answer particular questions
  – Recruitment for surveys and interviews conducted solely by evaluator
  – All materials generated as part of process evaluation maintained in a secure, confidential environment separate from research institutions
  – Only the evaluator has access to the raw data

• All CC members are required to sign consent to actively participate, including research team members who participate in CC meetings
Compensation for community members

CHALLENGES
Share fairly

- Among the “Benchmarks of collaborative partnership” as outlined by Emanuel et al. (JAMA 2000;283(20):2701-2711)
  - “Share fairly financial and other rewards of the research”
- If the LinCS 2 Durham Collaborative Council is a partnership, what constitutes sharing fairly?
  - Research team members are paid to be CC members
  - Participation by some non-research team CC members is supported by or benefits their work
    - Service providers, researchers, faculty/students working in the topic area
  - Other CC members are volunteers in the truest sense
CC Volunteer Compensation Guidance

- Compensation guide is the LinCS 2 Durham CC point of reference regarding how and when compensation will be dispersed.
- CC Working Group has discretion to address and respond to extenuating circumstances regarding compensation.
- Tier level activities and compensation:

<table>
<thead>
<tr>
<th>Tier</th>
<th>Compensation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Volunteer activities</td>
<td>Certificate of appreciation</td>
</tr>
<tr>
<td>Up to 15 hrs/month</td>
<td></td>
</tr>
<tr>
<td>2: Non-volunteering activities</td>
<td>Non-monetary compensation</td>
</tr>
<tr>
<td>16-20 hrs/month</td>
<td>e.g., local conference fee support</td>
</tr>
<tr>
<td>3: Special requests for non-volunteering activities</td>
<td>Monetary compensation</td>
</tr>
<tr>
<td>e.g., all day meetings</td>
<td>e.g., gift/gas/grocery card ($20 value)</td>
</tr>
</tbody>
</table>
Additional CC benefit opportunities

• Authorship on journal articles
  – CC members will have opportunities to participate on writing teams and may be listed as a co-author dependent upon meeting authorship criteria noted in the LinCS 2 Durham authorship agreement

• Recognition through CC end of year celebration

• Raffles (quarterly; eligibility based on meeting attendance)

• Professional development
  – Informal learning
  – Training opportunities (certificates provided)
  • Example: Ethics training
How do we know how well we’re doing in working with our community?
Process Evaluation

• AIM 1 of our study is to evaluate the process of developing our CBPR model for building support for HIV prevention technologies.

• Having an outside evaluator (David Napp) assures greater objectivity than trying to do this collectively ourselves.

• Serves as a reality check: Are we meeting our CBPR goals? Are we observing CBPR principles?

• Helps us identify and address various challenges with group dynamics
Process Evaluation

• Mixed methods approach
  – Annual 1-on-1 interviews with CC members (qualitative)
  – Annual surveys of CC members (largely quantitative)
  – Observations of CC meetings
  – Analysis of CC meeting minutes & other documents
  – Tracking members’ participation in project activities
• Findings reported to CC twice a year with follow-up exercises to address key issues raised