

LinCS 2 Durham

Linking Communities and Scientists

HIV Prevention

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)



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The HIV epidemic in NC in 2010

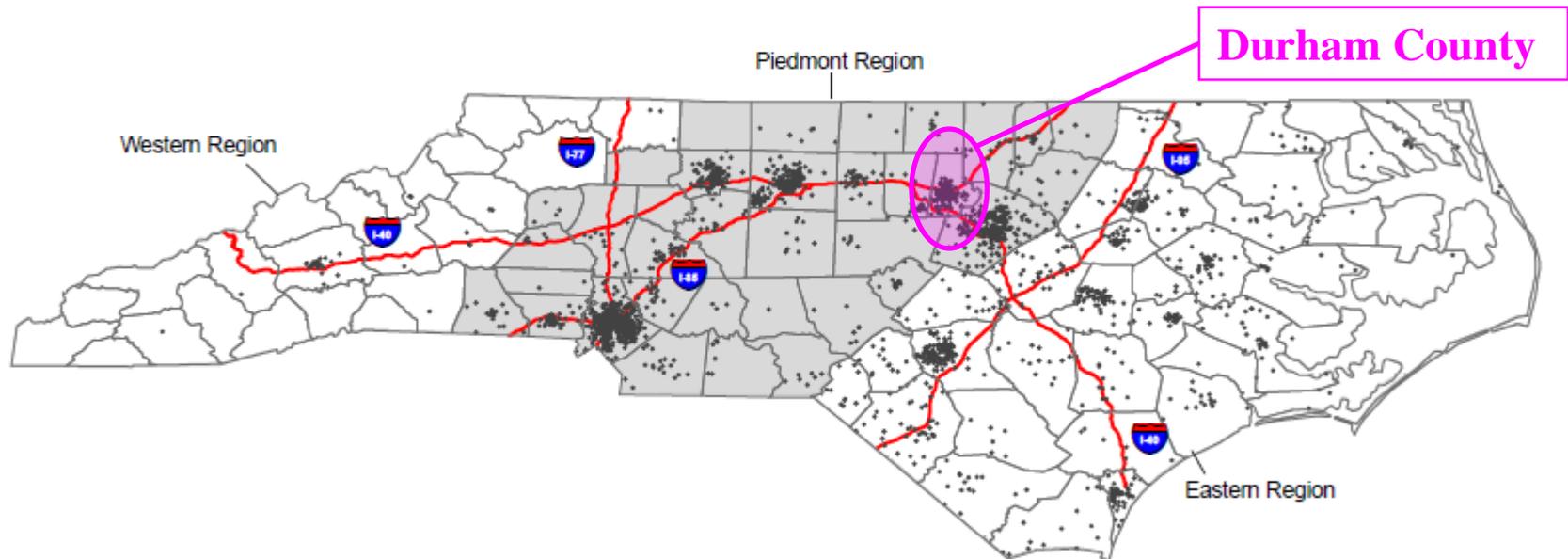
- Highest rate of new HIV diagnoses: adult/adolescent, black males (94.0 per 100,000)
- Largest disparity: adult/adolescent black females; with a rate of new HIV diagnoses (30.5 per 100,000) nearly 17 times higher than white females (1.8 per 100,000)
- Among adult/adolescent HIV disease cases
 - men 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)

NC Epidemiologic Profile for HIV/STD Prevention and Care Planning



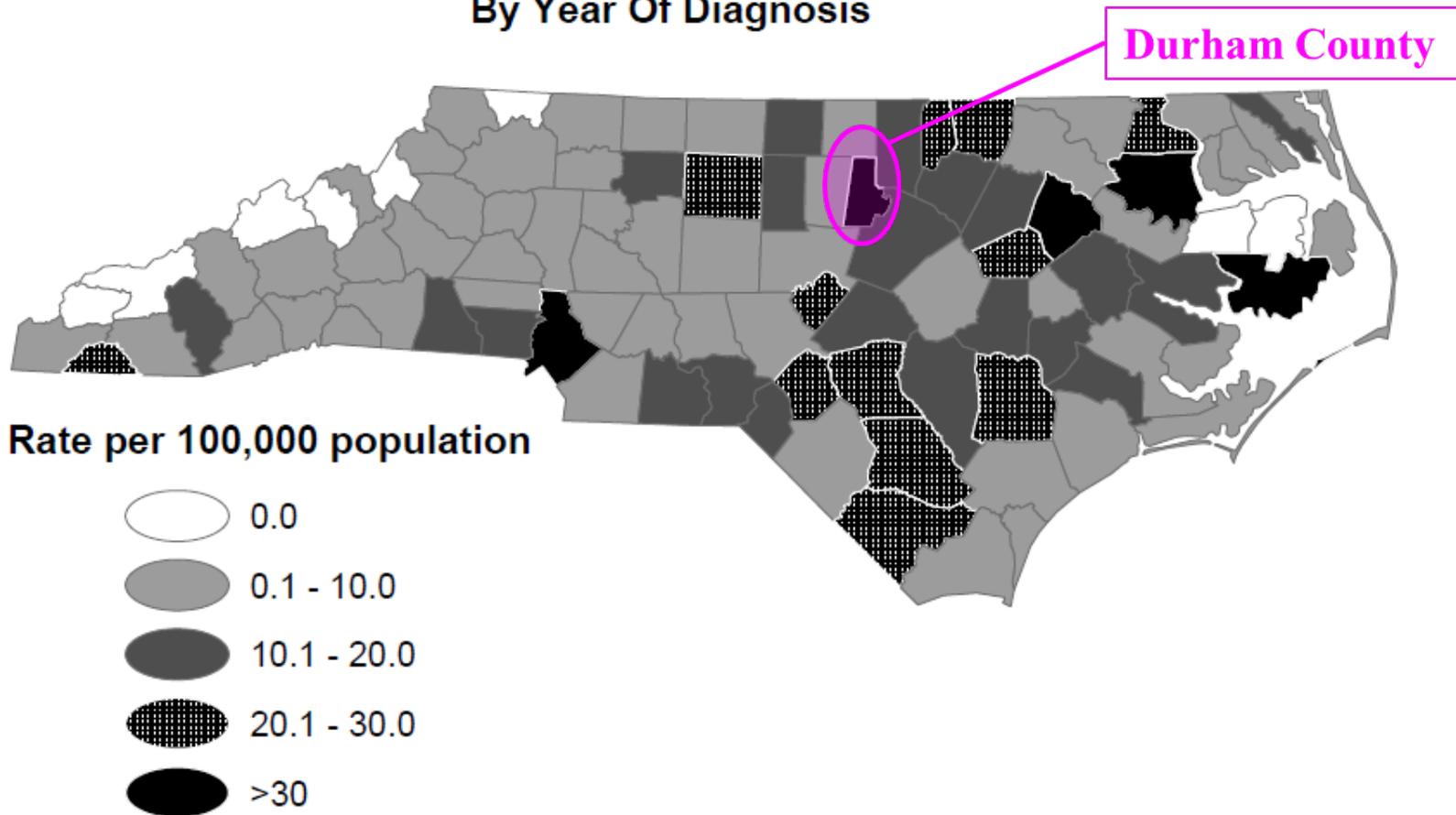
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Map 9. North Carolina Newly Diagnosed HIV Disease Cases, 2001-2010, by County of Residence at Diagnosis



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

Map 12. North Carolina HIV Disease Rates, 2010 By Year Of Diagnosis



LinCS 2 Durham: Project Aims



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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.

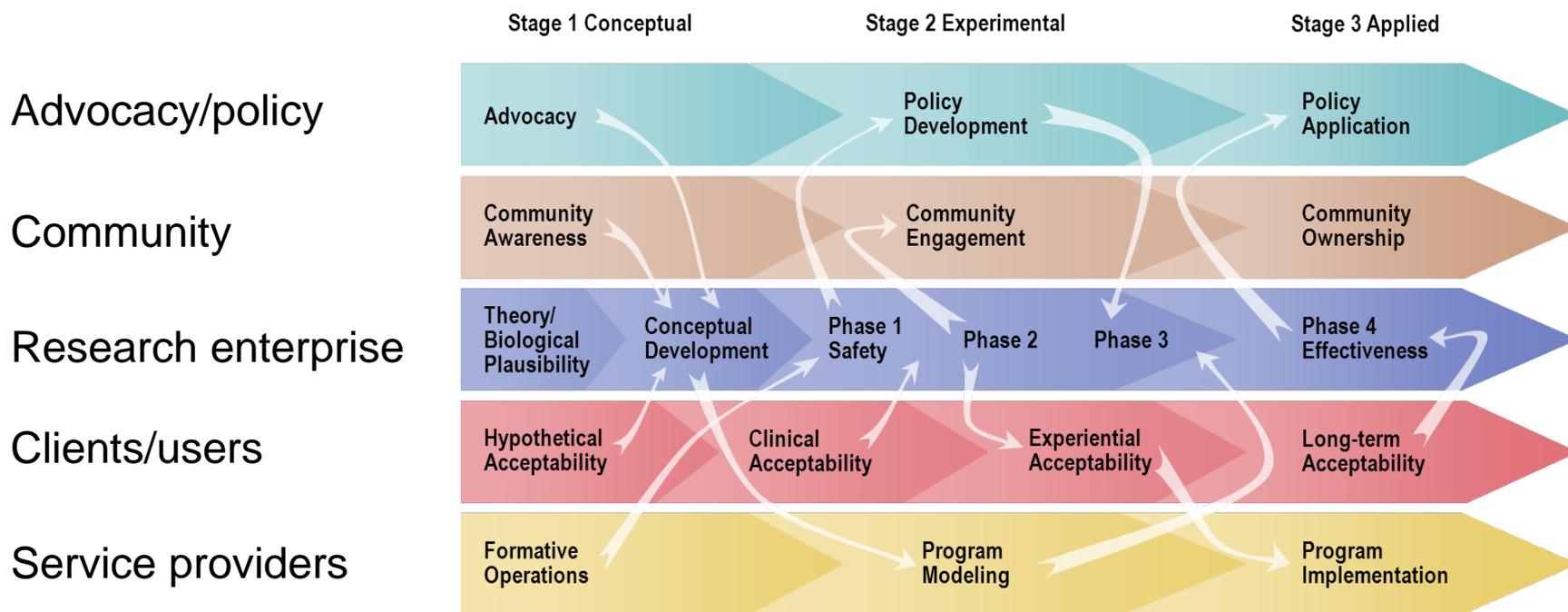
AIMS / breaking it down

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



MacQueen KM, Cates W. *AJPM* 2005;28(5)::491-5.

Ethnography

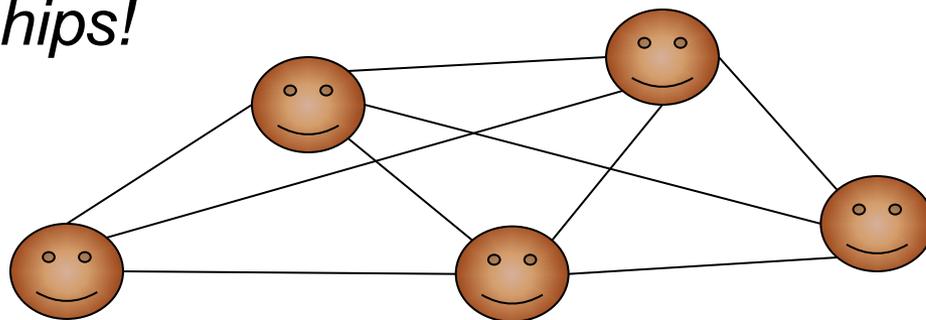
- Ethnographic team approach
- Define the diversity of communities that need to be recognized in order to conduct effective HIV prevention research in Durham
- Ensure unbiased identification of stakeholder groups
- Define an appropriate sampling frame for quantitative survey addressing HIV prevention trial planning including HIV-related behaviors, trust and research acceptability, and attitudes toward HIV testing

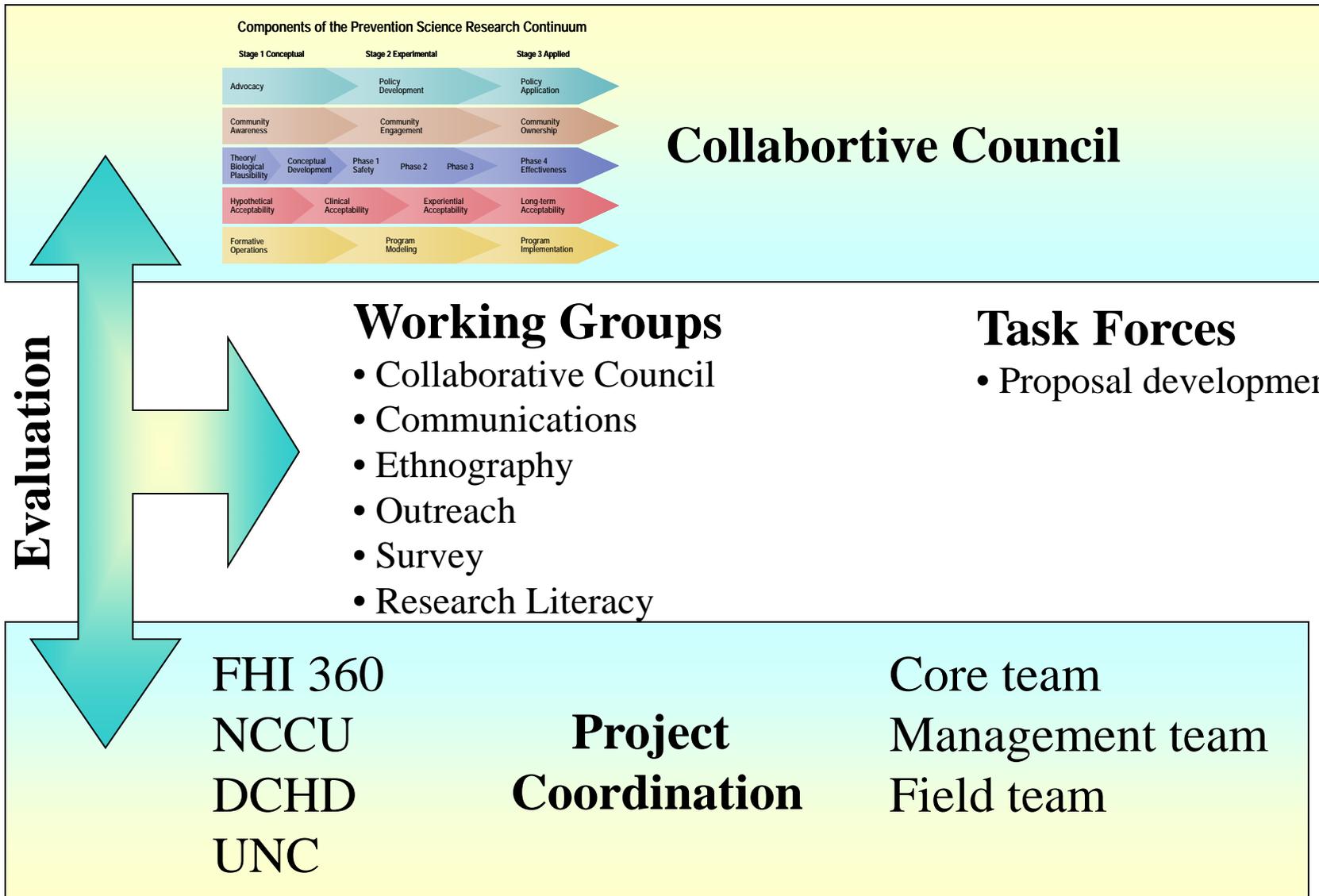
Group process

- 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!*





The approach we used

CBPR



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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

Israel et al. (2005) Introduction to methods in community-based participatory research for health. IN Israel et al. *Methods in Community-Based Participatory Research for Health*. San Francisco: Jossey-Bass, pp.3-26.

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



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Group dynamics: working with diverse stakeholders

CHALLENGES



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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



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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



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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

Tier	Compensation
1: Volunteer activities Up to 15 hrs/month	Certificate of appreciation
2: Non-volunteering activities 16-20 hrs/month	Non-monetary compensation e.g., local conference fee support
3: Special requests for non-volunteering activities e.g., all day meetings	Monetary compensation e.g., gift/gas/grocery card (\$20 value)

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?

CHALLENGES



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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