



Ethical Engagement of Communities, Institutions and Service Providers for HIV Prevention Research

**PRESENTATION AT THE HIV RESEARCH
ETHICS TRAINING INSTITUTE**

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The Bronx Health Link



- We are a clearinghouse of health care information for providers and consumers in the Bronx.
- We coordinate the Perinatal Information Network and the Infant Mortality Reduction Initiative.
- We provide
 - Referrals,
 - Educational workshops for consumers and providers,
 - Health information and promotion and materials for women and their families located throughout the community.

Our mission



- To promote Health Equity and Social Justice by:
- Connecting community residents to health and social support services;
- Engaging community residents, health providers and other CBOs through research, advocacy and programs, and
- Providing information to consumers, providers and policymakers to improve quality of life for all.

What we will cover in this presentation

The BXCRRB

- A brief description of TBHL – “home” of the Bronx Research Review Board
- A report on what we have done so far
 - Why the BXCRRB – what is our mission
 - Recruitment
 - Trainings
 - Review Process
 - What lessons we have learned from the process
- Next steps

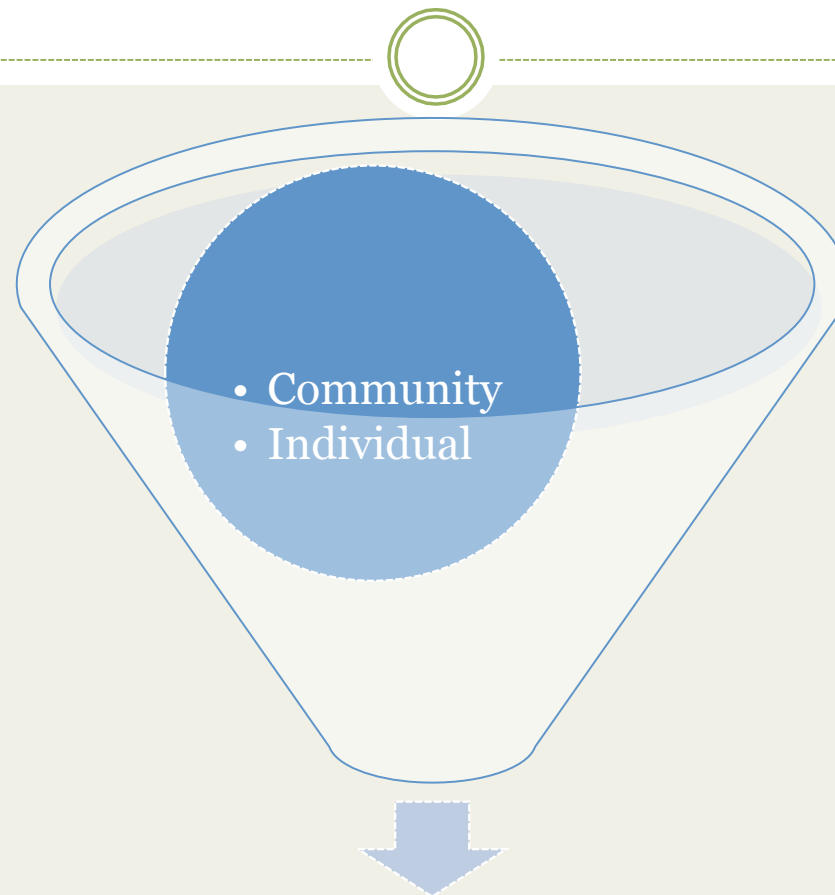


The Bronx: The Community Context



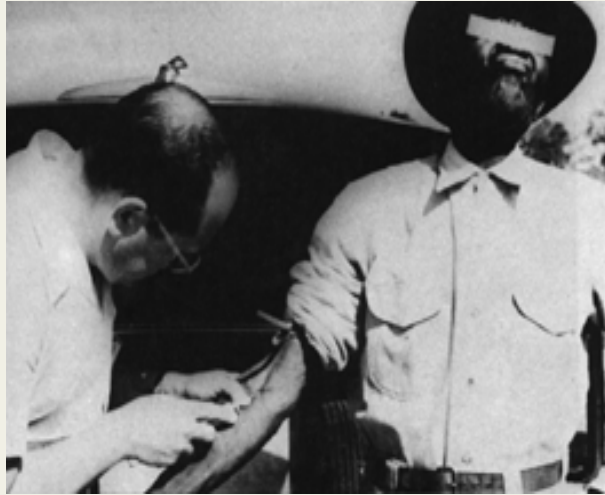
- The total population for the Bronx is over 1.3 million with 47% males, and 53% females.
- The median age in the Bronx is 31.5 years of age, the lowest median age of any borough
- Latinos/Hispanics make up the largest ethnic group in the Bronx - 52% of Bronx residents classify themselves as Latinos/Hispanic.
- 40% of the children in the Bronx live below the federal poverty level
- 28% of adults live below the poverty line
- 31% of the population did not complete high school (compared with 17% in NY) and less than 7% have graduate degrees

Context for the BXCRRB



RESEARCH

Common Images: Abuses of Research



Tuskegee Study of Untreated Syphilis among African Americans, 1930's-1970's



Concentration Camp Experiments, Nazi Germany, 1940's



Sterilization of American Indian women in the 1960's-1970's



Q: WHAT DO THESE INSTITUTIONS IN OUR COMMUNITY HAVE IN COMMON?



A: RESEARCH



First Steps: Key Findings from the Focus Groups



- Respondents indicated that in order to themselves enroll in health research projects, or to be willing to communicate about locally-enrolling studies, they would require detailed and concrete information on the purpose of the project, the research design, background information and more detailed information on the potential risks and benefits of participation.
- While some respondents recommended that trust be established in the community prior to implementation of research initiatives, others felt that having trust in the organizations and agencies performing the research in itself would be sufficient.

Recommendations from the Focus Groups



- Undertaking research that directly benefits the community where the data is gathered as well as the participants;
- Greater transparency in disclosure of purpose, overall benefits/plausible outcomes and risks of participation;
- Reporting of research results to the community and participants as a normal study procedure; and
- Conducting research that seeks to make real changes rather than document problems that are already known.

What is the Bronx Community Research Review Board ?



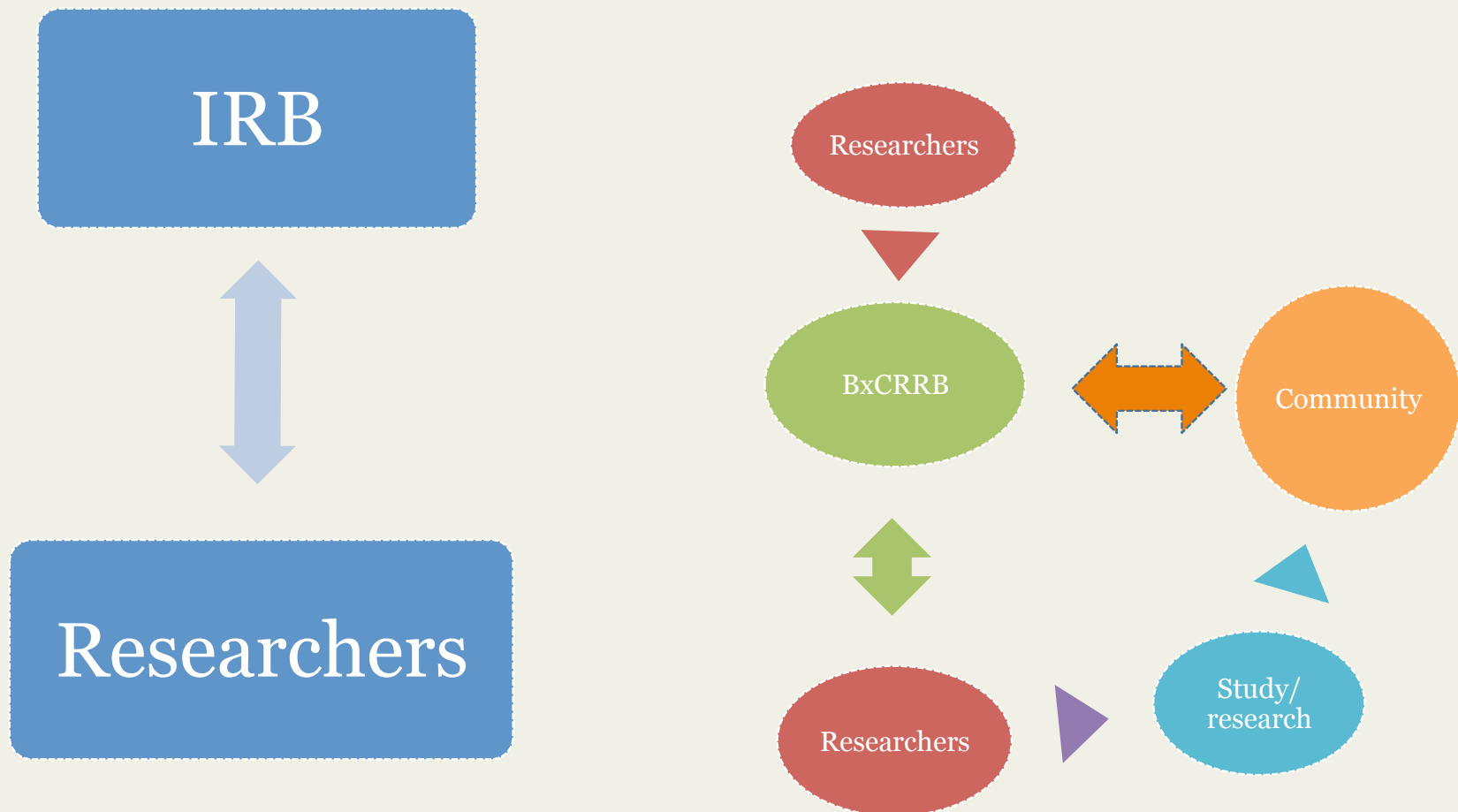
- A community-based, community-driven structure that will give community voice to research
- **Will review research projects to make sure that the:**
 - community is engaged and informed
 - community will benefit
 - projects are sensitive to community's culture and needs
- **BxCRRB will serve as a platform to:**
 - educate the community about research
 - ensure community input into research affecting Bronx populations
 - voice community needs and concerns about research
 - provide feedback loop where research results will be disseminated to the community for its use and its benefit

Goals of the Project



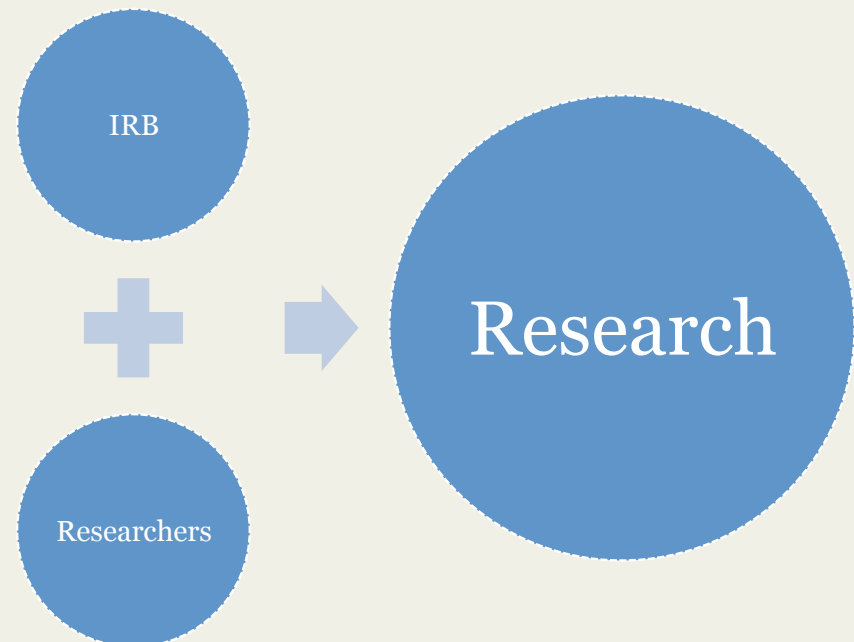
1. Educate Bronx residents about research being done in their communities
2. Increase the community's understanding of and participation in research
3. Empower the community to express their needs and concerns about health research done in the community
4. Get the results of research done in the Bronx back to the community for its benefit

Traditional IRB vs. BxCRRB



Institutional Review Board (IRB)

- Panel to review and approve research and protect human subjects
- IRB consists of:
 - At least five members
 - Experts and representatives from institution and possibly community members
- Review and approval is done through a formal process and discussion between IRB members and researchers



Our Goal – To create a research loop in the Bronx



- Panel to review and discuss research and created academic and medical institutions
- BXCRRB consists of:
 - All community members
 - Expert representatives from the community
- Review, discussion and constant feedback completed through a formal process and discussion between BXCRRB members, researchers and the community

We are not an IRB – our goal is community engagement and protection

Our progress so far.....



- **December 2009 to November 2010**
 - **Community outreach, focus groups, recruitment and project planning**
 - Four focus groups were held to find out community beliefs and attitudes about information-gathering and clinical research
 - Hold information sessions to teach the community more about the project and community-based research and identify potential BxCRRB members
 - Visit and speak with other community research boards and those with experience involving communities in research
- **November 2010 to December 2010**
 - **Candidate interviews and selection**
- **January 2011 to December 2011**
 - **On going Training and review of proposals**

Recruitment and selection of the BXCRRB: Process



- Review and discussion with other community-based entities – list resulted from lit search and google
- Developed an interview protocol
- Called and documented responses from the interviews
- Created a chart with common features

Recruitment and Selection



- Does this person have community networks?
 - If yes, how/what kind of networks?
 - If no, is this an issue? And what else do they bring to the BXCRRB
- Was this person able to communicate well
- Selection based on
 - A group deliberation process that will evaluate each candidate based on:
 - ✦ Membership Criteria
 - ✦ Summaries and Ratings from Interview Team
 - ✦ Final Collective Opinion and Rating of Candidate

Who is the BXCRRB?

Males: 4

Females: 11

African-Americans: 9

Latinos: 5

Mixed: 1

Zip Codes Represented:

10452, 10456, 10457, 10454,
10460, 10469, 10473, 10468, 10461

What Do They Do?

Members come from diverse educational and employment backgrounds



BXCRRB Training and Incentives



- One Orientation
- 6 training sessions
- Food and MetroCards provided at each meeting
- Fifty Dollar stipend provided after attendance at three consecutive sessions

BXCRRB Training: How we conduct the trainings and why ?



- Every session is started with a group lunch and popular education activity to help members get-to-know one another and bond.
- Each training session lasts for three hours. Expert guest speakers help facilitate the session.
- In addition, each session is led by an experienced facilitator who has done community organizing for many years.
- Members are asked to evaluate every aspect of each session.

Training based on the work of Paolo Freire



- Theory of Value: What are the goals of education – should raise awareness
- Theory of Knowledge: Knowledge is a social construct therefore it involves the whole conscious self
- Theory of Human Nature: how do we ensure that as educators we affirm students and create a space for critical thinking
- Theory of Learning: Knowledge is not a commodity passed from teacher to student. Educators must learn how the student understands the world so we can understand how a student learns

Training based on the work of Paolo Freire



- Theory of Transmission: Teaching is a political process – a democratic process. The teacher must be a learner and learners become teachers
- Theory of Society: education is a political act
- Theory of Opportunity: Who is to be educated ?
- Theory of Consensus: There is no life without struggle and disagreement that can lead to growth and a change to the status quo

BXCRRB Training



- Training Session Topics Include:
 - Bioethics
 - The Institutional Review Board
 - Informed Consent
 - The Proposal Review Process
 - Proposal Review Trial
 - Summary and Final Closing Meeting

BXCRRB Training



- **The topics were selected based on:**
 - ✦ Knowledge needed to perform tasks
 - IRB
 - Bioethics
 - Informed Consent
 - ✦ Discussion with other community research boards from around the country

BXCRRB Training: Lessons Learned



- 1) Working in smaller groups helps the training process
 - 1) Gives members time for more in-depth discussion
 - 2) Intimate discussion allows for creativity and co-learning
 - 3) Encourage members to get to know different members of the group each week
- 2) Importance of sharing meals
 - 1) Social and bonding function
 - 2) Doggy bags allowed and encouraged – extends the sense of community outside the

Lessons learned for Collaborators engaged in community research



- Government has said community involvement in research is important
- Need to improve relationship between institutions and the residents of the community
- Benefit will be two fold---for community and researchers

Lessons learned: Value of Community Consultation

- By holding open conversation with researchers about the research projects they want to do in the community, BxCRRB members will be doing something called “community consultation”.
- Community Consultation happens when researchers seek advice, feedback, criticism and suggestions from members of a community.
- By engaging in “community consultation”, it is hoped that the BxCRRB members will help:
 - Educate researchers about the needs and values of Bronx communities
 - Build links between researchers and the Bronx community
 - Encourage researchers to become reliable and responsible to the Bronx community

Research Review Process



- They complete the form which is submitted to the BXCRRB for review with specific instructions on literacy level, use of non-medical language and background information so that they increase knowledge of members
- Researchers present to the BXCRRB in person and without a power point – it is about the conversation and the engagement of parties interested in a common goal – research
- The BxCRRB can request additional details, clarifications and will question the details of the application
- The researcher is asked about the process and is engaged in a feedback – we ask “what did you learn from this process” and what do you need from the BXCRRB”

Research Review Process



- The BXCRRB reaches consensus on the recommendations to the researcher
- The recommendations are recorded and then sent to the researcher
- We invite them back for further discussion of the research and



Thank you

Call us for more
information

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