



Community Engagement in Research, Evaluation, and Related Activities Workshop

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Board (IRB)





Ground Rules

Please keep your microphones on mute

Please enter your questions in the chat box or raise your hand using the reaction buttons

Presentation slides will be available on the IRB [website](#)

Certificates of completion will be available on Talent Works after the training

This training does not fulfill human subjects protection training requirement



Training Objectives

After completing this training, you will have a better understanding

of:

- the principles underlying Community Engaged Research
- the benefits of engaging the community in research
- different strategies for engaging members of the community in your projects
- ethical considerations regarding Community Engaged Research



What is Community?

- “A group of people who are linked by social ties, share common perspectives or interests, and may or may not also share a geographic location” (MacQueen et al., 2001)
- Shared language, occupation, ethnic group, faith, age, activities, goals, sexual orientation
- Organizational membership
- Public, non-profit, or private
- Church, school, club, community-based organization
- Not homogeneous with one voice
- DPH: No standard definition



Community-Engaged Research (CEnR)

- Framework/approach, principles, not methodology
- “The process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being” (CDC 1997)
- Quantitative or qualitative data collection and analysis

Community-Engaged Research (CEnR), cont.

Broad Term

**High community
engagement:
Collaboration**

- Community Advisory Board
- Researcher/community partnership

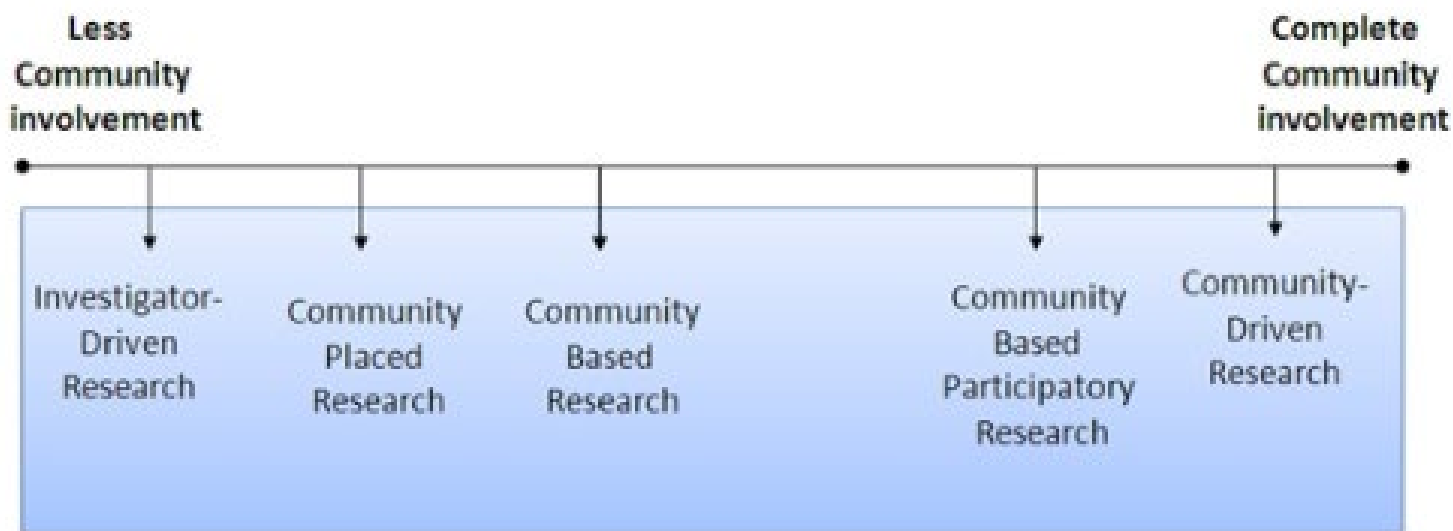
**Moderate community
engagement:
Consultation/Coordination**

- Community-based organization assists in implementing a study design
- Church provides site for research activities

**Minimal/Lack of community
engagement**

- Information and education campaigns, outreach
- Phone sampling, street intercept interviews

CEnR Continuum



Clinical trials, secondary analyses

Community directly involved in recruitment and/or data collection

Community provides research questions, assists with data collection/review, final outcomes distributed to community in formats they understand, and partners share funding received for the research



History and Theoretical Basis of Community Action and Empowerment

Theories

- Anthropology
- Psychology
- Education
- Sociology
- Public Health
- Social Work

- “Action research” to overcome social inequality (Kurt Lewin, 1940s)
- Co-learning (Wallerstein and Duran, 2003)
- Empowerment education and community organization (Paulo Freire and Myles Horton)
 - Participatory action research
 - Empowering poor and oppressed groups
 - Solutions coming from communities themselves
 - Adult education: learners are not empty vessels; learning is not one way
 - Socio-political action



Institutionalization of Community Engagement into Research and Funding Mechanisms

Mid-1980s:

- CDC recommended community involvement in research and demonstration projects

1997:

- Institutes of Medicine formally integrated community involvement into the prevention research framework

Early 2000s:

- National Institute of Environmental Health Sciences
- W.K. Kellogg Foundation

2005:

- National Institute on Minority Health and Health Disparities launches Community-Based Participatory Research Program (CBPR)

2006:

- NIH initiated Clinical and Translational Science Award (CTSA)
- Mandated community engagement at biomedical institutions

2016:

- Presidential Commission for the Study of Bioethics Report underscores the ethical and practical reasons for community input

2021:

- Executive order on “Advancing Racial Equity and Support for Underserved Communities” signed.



Mutual Benefits of CEnR

- Research done IN and WITH communities – a collaboration between partners
- Subject has become participant (NEJM, AJPB)
- Input of those most likely to be impacted: rooted in the concept of justice
- Recognizes unique strengths of each party using an assets-based approach to research
- Empowerment: strengthening community assets and capacity building
- Addresses limitations of “traditional” research
 - A research sample that more closely reflects the larger community yields more generalizable data and is better positioned to inform public policy
 - Create sustainable partnerships that can build trust among the community



Mutual Benefits of CEnR, cont.

- Uses knowledge to bring about action
 - Directly influence health outcomes
 - Tailor interventions to specific communities
 - Effect social change and eliminate/mitigate disparities in health outcomes
- Participants can understand purpose of the research and how the results may affect them
 - Informed consent process
 - Response rates
- Improve reliability and validity of data collection instruments
- Produce culturally sensitive questions and design
- Yields important and culturally sensitive explanations, local interpretation of findings
- Is an intervention in and of itself
- Results likely to be translatable to similar communities



Collaboration

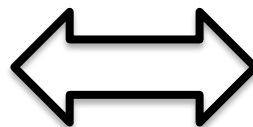
- Contributions from the community may vary depending on community context, experience and background of researchers
 - Infrastructure and capacity of community organization
 - Funding
- Partnerships with organizations
 - Address local health issues important to community
 - The people affected by the issue
 - Development of a solution
 - Way to “give back” to the community

Collaboration (cont.)

**Respect, cooperation,
time, build on strengths
of participants**

Community
advisory board

**Co-learning, bi-
directional**



**Process: long-term
commitment to
sustainability**





Putting it Into Practice

- Research plus capacity-building
 - Vulnerable populations
 - Communities with lack of resources, high risk for poorer health outcomes
 - Equality in some or all phases of research and decision-making
 - Identify problems and work together to build mutual skills and develop solutions
- Not just:
 - For qualitative research
 - After the proposal is written



Terms of Engagement

- Mutually agreed upon
 - Memorandum of Understanding (MOU)
 - Financial support
 - Research activities, roles and responsibilities, outcomes
 - Data ownership and sharing
 - Developing research tools
 - Data collection methods, analysis and interpretation
 - Methods for disseminating research results to both academic and community audiences
 - Products may be collaboratively owned
 - Participants review and contribute



Dissemination

Community-informed strategies more likely to lead to action, more time urgent

- **Community members:**
 - Local newspapers, magazines, radio programs
 - Joint community meetings
 - Peer-to-peer sharing
 - Social media
- **Researchers:**
 - Peer-reviewed journals
 - Program implementation, evidence in legal or legislative campaigns, grant applications
 - Some journals may not publish articles whose findings have previously been published in the newspaper, TV or other media

Multiple dissemination strategies: be creative!



Potential Challenges

- Can equal partnership be achieved?
- Unequal distribution of power
 - Funding sources/finances
 - Infrastructure that supports research
 - Mistrust of researchers



Potential Challenges (cont.)

- Time Considerations
 - Build infrastructure and capacity to work as research collaborators
 - Understand community processes, gain trust and initiate/maintain relationships



The Role of the Institutional Review Board (IRB):

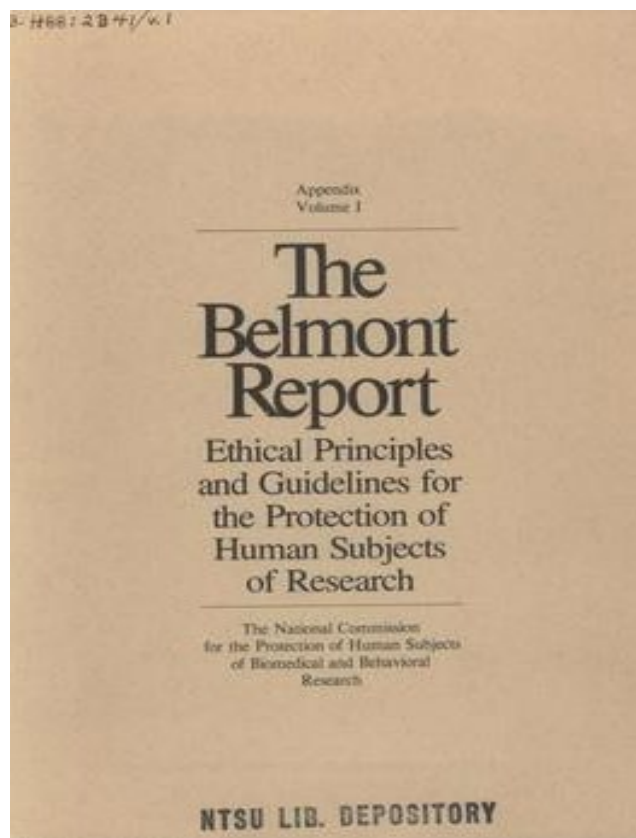
Ethical Considerations





Review: Principles and History

- Tuskegee Syphilis Experiment, 1932-1972
- Willowbrook Hepatitis Experiments, 1955-1970
- Milgram's experiments on obedience, 1960s



Review: Principles and History

- Belmont Report, 1979
 - National Research Act, 1974 - National Commission of the Protection of Human Subjects of Biomedical and Behavioral Research
 - Provided the foundation for the federal human subjects research regulations known as “the Common Rule” (45 CFR 46) then the Revised Common Rule

Review: Principles and History

- Basic Principles of Biomedical Research Ethics
 - **Respect for Persons**
 - **Autonomy**
 - **Beneficence**
 - **Minimize harm, maximize benefits**
 - **Justice**
 - **Equity of risks and benefits**





Review: Principles and Basis

- Common Rule, 1991, revised 2017-2018
- LAC Board of Supervisors, 1999
 - ❖ HIVNet
 - ❖ Lack of community sensitivity and engagement
 - ❖ Institutional Review Board (IRB)

What is the IRB?

- Oversight entity housed in DPH
- Board made up of 13 people
 - Minimum 5 members
 - Diverse across race, gender, cultural background
 - Scientist, non-scientist
 - Not affiliated with institution (community members)
 - Prison advocate





What needs to come to the IRB

1. Traditional “research”
2. Is it routine, standard-practice public health activity, i.e., no innovations or new twists?
3. Is it standard QA/QI activity?
4. Is it internal program evaluation or needs assessment intended only for program monitoring, improvement, etc.?
5. Is it interview-based research **that does not deal with sensitive topics?**
6. Is it observation of public behavior?
7. Is it a study of previously collected data or records (if publicly available or recorded in de-identified manner)?



Where Does the IRB Fit?

- Revised Common Rule does not specifically address CEnR
 - Lack of IRB experience with CEnR
 - IRB Policies and Procedures do not specifically address community risks



Ethical Challenges

- Community risk vs. individual risk - is associating participants with research harmful to community or individuals?
- Reinforcing negative stereotypes?
- Disrupting community cohesion?
- Privacy and confidentiality when community members are part of research team
 - Community members of research team may know the individuals they are recruiting



Ethical Challenges, cont.

- Community consent – how is it to be obtained?
- Compensation for participation (in addition to funding for organizations)
- Conflicts of interest
- How are community leaders involved in decision-making?
- Avoiding exploitation



Some Solutions

- Work with community partners to help discuss stereotypes of the community and advise on how best to approach groups
 - Informed consent about potential of stigma
- Use non-technical language in informed consent, or translating appropriately
- Train community members about data storage and access



What the IRB Requires

- How is the IRB going to apply this to evaluate/approve projects?
- What should “minimum criteria” of level of engagement be?
 - Demonstrated consciousness or frank acknowledgement of the importance of CEnR
 - Outline of the steps that were taken to achieve adequate CEnR
 - Consultation with the community on ways to disseminate findings

IRB Health Equity Initiative

- Addressing health equity in research is a matter of justice and is necessary to ensure that research and related activities produce quality (robust and generalizable) data that can better inform action at all levels.
- As a research goal, health equity is a lens through which all research activities should be viewed.
 - » From study design all the way to dissemination of results

IRB Health Equity Initiative

1

Completed Key Informant Interviews with experienced, local researchers representing the County, academia, and community-based organizations.

- A Health Equity Report summarizing results from the interviews is available on the IRB [website](#)

2

Administered the Health Equity survey to 155 researchers

- Survey results are being used by the IRB to better understand the barriers to achieving health equity and the types of support that the IRB can provide to overcome those barriers.

3

The IRB is developing a Health Equity Standard of Practice that codifies the IRB's role in enabling researchers and project leads to address and measure health equity in research, evaluation and related activities.

- Based on findings from interviews and surveys
- This SOP will apply to DPH projects
- Will provide guidance for collecting health equity metrics

IRB Health Equity Initiative – Key Informant Interviews

“Did you check in with community members and a diverse set of community members? Because I think what happens oftentimes is we assume that one organization has a pulse on an entire community, but they may only interact with a segment of it.”

- Seven informants noted that the research field must do a better job of involving community members and community-based organizations throughout the research process - from the development of the research question and study design to the dissemination of results.



Of these seven informants, four highlighted the value of and need for researchers to integrate principles of CEnR into their work.

IRB Health Equity Initiative – Health Equity Survey Results

Most Commonly Used Methods of Community Engagement

- 1) Community engaged in research design (68.5%)
 - 2) Community engaged in recruitment (62.9%)
 - 3) Community engaged in data collection (60.1%)
 - 4) Community Advisory Board convened regularly (51.8%)
- **Top 3 biggest barriers to addressing health equity in research**
- 1) Availability of funding (38.9%)
 - 2) Lack of trust between community and research field (33.6%)
 - 3) Lack of organizational support (15.1%)





Group Exercise

Scenario: A group of researchers wants to work on obesity prevention in a local neighborhood where high rates of obesity have been found.

- **Question 1:** What would you do before actually designing the project? What would you do before putting together the IRB application?
- **Question 2:** The project is funded. What would do you to make sure there is maximum community engagement in the operationalization of it?



Group Exercise

- **Question 3:** The project is underway but participants are not finishing the surveys. What should you do to solve this problem and be able to collect complete data?
- **Question 4:** How would the project members plan to disseminate the results? What would you do if you found some results that were counter-intuitive and/or stigmatizing?



References and Additional Resources

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- NYC Department of Health and Mental Hygiene, Dec. 2021. [Health of Indigenous Peoples of the Americas Living in New York City Indigenous peoples of the Americas](#), Epi Research Report Workgroup. Accessed May 24, 2023



More Resources - Toolkits

- [Scripps Translational Science Institute Community-Engaged Research Toolbox](#)
- [Minnesota Department of Health Community engagement assessment tool](#)
- [University of Kansas Community Toolbox Box](#)
- [Penn State Engagement Toolbox](#)

There are many more out there!

Any Questions??





We are here to help!

- Please visit our website:

<http://publichealth.lacounty.gov/irb/>

- Email us with questions: irb@ph.lacounty.gov



Thank you!

Evaluation link:

<https://www.surveymonkey.com/r/MXPN6VJ>