7 Ethics of Doing Community-Partnered Research

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Workshop Audience & Objectives

Audience
Non-academic researchers with basic knowledge of medical/scientific research, and those that have completed previous workshops in series.

Objectives
By the end of this session, participants will:

- Understand the principles of working with community in conducting research.
- Be introduced to differences in language used between researchers and academia, and best-used language in community settings.
Social or Scientific Value

- Scientific or health decision-making value
- Developing community capacity
- Sustainability increases value to community and research
- Challenges when studies that have value for community are not considered valuable from the scientific or social perspective

Source: Chen DT, Jones L, Gelberg L
Scientific Validity

- Research must scientifically valid to be ethical
- Community should have a role in deciding the design of a study-certain designs may not be acceptable, thus the study may not be done
- Community input can increase validity of interpretations
Fair Participant Selection

- Should be based primarily on scientific goals-focus on particular racial/ethnic or particular community may be justifiable as fair when chosen for reasons of justice
- Hiring and training community members for outreach, recruitment, & data analysis can increase fairness and community capacity
Favorable Risk-Benefit Ratio

- Risks and potential benefits to community as a whole should be considered

- Determining appropriate risks, benefits, and risk/benefit ratio in communities that lack access to healthcare services

- Risk to individual participants must be justifiable by potential benefit to individual and/or by benefit of findings to society
Independent Review

- Enhance public accountability and minimize influence of potential conflicts of interest

- Independent community review enhances transparency and accountability to community

- Community IRB: same functions as University IRB’s
Informed Consent

- Respects research participants rights to make decisions that are consistent with their values, interests, and preferences

- Community can help design innovative ways to enhance informed consent, help manage misinformation and rumors, and disseminate information to community

- Challenge if trust in community partners leads participants to pay less attention to risk to themselves
Respect

- For potential and enrolled participants
- For community
- For research partners
- Trust and trustworthiness
- Joint development of guiding principles, agreements, and conflict resolution
- Community and Research dissemination
- Recognition of both community and research biases, stereotypes, and politics
Communities and Universities Have Different Languages
Academia Often Uses Jargon…

- This can lead to misunderstandings and marginalization of one partner or their staff and constituents
- Careful planning is the key
- Share documentation such as a website or annual report
- Avoid jargon or make sure it’s explicitly explained
Verbal Language

Don’t Use
- Them
- Those
- You people
- I understand
- We understand
- We feel that you

Do use
- Community or residents
- Identify all parties
- I am aware
- We can relate to
- With common consent of all of parties, it is the feeling that
Verbal Language

Don’t Use

- Your Community
- I know what you mean
- I understand where you’re coming from
- My data

Do use

- This community
- I can relate
- I can empathize with you
- Data collected in the community
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Sometimes what appears to be the end is really a new beginning.

- Author Unknown