The Ethical Value & Challenges of Community Engaged Research

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Overview

- Community collaboration as ethical obligation
- Power, procedural justice & representation
- Respect & exploitation

Background

- **Informed consent: clinical vs. community research**
- **Respect for community autonomy**

Examples of proposed community-wide interventions in obesity prevention

- taxes on sugary drinks
- bans on the sale of large sugary drinks
- limits on the density of fast food restaurants in urban neighborhoods
- the exclusion of unhealthy foods from food assistance programs
- differential health insurance rates (i.e., charging obese people more)
- the range of foods available for consumption in schools

Ethical review of community interventions

- Is IRB review sufficient?
- How can the community as a whole decide whether it is in their interest to participate?

Purposes of CBPR

1. To elicit ideas from community members for potential health interventions
2. To strengthen the capacities of participants to gain control over the conditions that affect health
3. To demonstrate respect for community autonomy

What Makes Research Ethical

Emanuel et al, 2000, 2004

- Social value
- Scientific validity
- Fair selection of study population
- Favorable risk-benefit ratio
- Independent review
- Informed consent
- Respect for participants
- Collaborative partnership

Benchmarks of collaborative partnerships

1. Develop partnerships with researchers, makers of health policies, and the community.
2. Involve partners in sharing responsibilities for determining the importance of health problem, assessing the value of research, planning, conducting, and overseeing research, and integrating research into the health-care system.
3. Respect the community's values, culture, traditions, and social practices.
4. Develop the capacity for researchers, makers of health policies, and the community to become full and equal partners in the research enterprise.
5. Ensure that recruited participants and communities receive benefits from the conduct and results of research.
6. Share fairly financial and other rewards of the research.

Community Engagement in Research

Community engagement is ethically essential for two reasons:

(1) To demonstrate respect for community autonomy and their right to self-determination

(2) To take into due consideration of the consequences of the research for the community as a whole

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- Respect for community autonomy is based on the fundamental right of community members to exercise a meaningful role in determining the conduct of research that affects their lives.
- Community engagement is necessary because **communities are distinct entities with interests that are distinguishable from individual interests** that must be afforded comparable protections accordingly.

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- The **community has a non-negligible stake in the decision to conduct research on its membership**. For example, the community has a collective right to participate in decisions regarding **the use of limited fiscal or social resources** (e.g., health clinic personnel and facilities). The community must have a say in determining **whether scarce resources are being diverted from more pressing priorities, or important opportunities lost**.

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- The use of public resources also calls for **public accountability,** a standard not addressed in individual informed consent processes nor IRB reviews.

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- **Reducing threat of exploitation by equalizing power differentials**

Given the power and prestige of academic health research centers, it is critically important to establish a body with sufficient standing to set fair terms of participation and protect against the potential for exploitation.

The scope of fair benefits cannot be decided or determined by individual participants nor by research institution–based IRBs but only by the community itself.

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- **Additional risks to the community**

Stigmatizing identifiable geographic or social groups

The community has a right to protect itself against potential injuries to its self-understanding and self-respect

Community-Engaged Research

- The success of new health interventions depends on their adoption by the population. If the conduct of the research reinforces negative attitudes (e.g., human beings as ‘guinea pigs’), it undermines trust in research, which impedes the adoption of effective interventions.

Power, procedural justice & representation

Equalizing power differentials

- Representation: who can legitimately speak on behalf of community interests?
  - Distinction between geographic and sociological definitions of community.
  - Constituencies: existing authorities, residents, and potential participants

Respect & exploitation

- Example of work on youth violence prevention and the Men of Color Health Awareness (MOCHA) project