Identifying and Engaging the Community in Community Engaged Research Ethics

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CER and the Community

- Community Engaged Research (CER) begins with identifying and engaging the community partners in the research process.
- However, a “community” is not a static, readily identifiable entity and can include multiple stakeholders with different goals, values, and concerns that can diverge and even conflict.
Group Activity

- Hypothetical Case:
  - You are part of a research team that is planning a community-engaged research project to improve diabetes self-care among Latinos in Milwaukee County. Self-care involves regular monitoring of behaviors associated with diet, exercise, blood-glucose testing, foot care, and smoking.

- Working with others seated at your table, identify someone who can write down your group’s ideas on the worksheet at your table. Next, discuss your ideas regarding:
  - Who are the stakeholders? Who is the community?
  - How can you engage the community in your project?
  - What are some of the barriers you might encounter?

A Brief Introduction to IRBs

- Institutional Review Boards (IRBs) are charged with the protection of human participants in research.
  - This is a Federal requirement.
  - IRBs must review and approve and “Human Subjects Research.”

- IRBs are guided by Federal Regulations, state law, institutional policy, and the Belmont Report.
The *Belmont Report*

- THE ethical guidance for research involving humans in the U.S.
- Extols 3 ethical principles
  - Respect for Persons
  - Beneficence
  - Justice
- These principles are to be BALANCED with one another.

**Respect for Persons**

- Encompasses not only autonomy, but respect for the inherent dignity of persons as well.
- Autonomy is the right of competent individuals to live their lives as they see fit.
- Also requires that persons with diminished capacity and vulnerable populations are protected.
Beneficence

- Do good; The research should offer some potential benefit, either to the subjects or to society at large.
- Also encompasses non-maleficence, or avoid unnecessary harm.

Justice

- Social Justice concerns the fair distribution of benefits and burdens in society.
- In research, this asks whether any one group in society is shouldering an unfair burden for the rest of society.
- The most difficult principle in the Belmont Report to grasp.
What IRBs Do

- Review research protocols, consent forms, etc. to ensure that the rights and well-being of research participants are protected.
- Approve, reject, or request changes to research based on regulations, policies, laws and ethics.

What IRBs Do Not Do

- IRBs are not charged with protecting the institution.
  - They are charged with protecting research participants.
  - There are other entities charged with protecting the institution.
Who Serves on an IRB?

- Physician Scientists
- Other Scientists
- Non Scientists
- Unaffiliated Member
- Community Member

The Challenge

- If a researcher and a community partner are engaged in CER and there is no representative from the community sitting on the IRB, how can the IRB:
  - Identify risks relative to the community?
  - Know whether or not a benefit is a true benefit to the community?
  - Ensure that decisions to participate in research are truly voluntary and informed?
Thank you!