COMMUNITY-ENGAGED RESEARCH

Mina Silberberg, Ph.D.
Associate Professor
Vice-Chief for Research and Evaluation
Duke Division of Community Health

Presentation for the Duke Office of Clinical Research
“Research Wednesdays”
March 12, 2014

What is community-engaged research?

Community-based research takes place outside the walls of the researcher's clinical or academic home.

Community-engaged research: “begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.”

Community-based participatory research is a “collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings.”

*WK Kellogg Community Health Scholars Program

What does community-engaged research look like?

- Community stakeholders on project steering committees and other deliberative and decision-making bodies
- Community advisory boards
- Compensation for the community’s time and other contributions
- Dissemination of results back to the community
- Takes time!
What community-engaged research is NOT

- Focus groups or interviews
- A research methodology
- A bolt-on
- A one-size fits all approach
- Appropriate for all research
- Recruitment of minority research participants
- A relinquishing of all insight or control by researchers

Why Conduct Community-Engaged Research?

- Generates research questions and answers that have important practice/translation implications.
- Practitioners are invested in research from early on, creating greater potential for translation and sustainability of practice change.
- Enhances community benefits from research and promotes fair compensation.
- Can improve the research product - more culturally appropriate research instruments, greater understanding of the role of context, improved recruitment.
- Allows you to go more “up-stream” on the determinants of health.
- Is a muscle that gets stronger with use. Increased trust and increased experience working together create new opportunities for collaboration.
- New funding opportunities, e.g., PCORI

NIH/CDC/ATSDR Principles of Community Engagement*

- Be clear about the purposes of engagement and the populations you wish to engage.
- Become knowledgeable about the community.
- Establish relationships.
- Collective self-determination is the responsibility and right of the community.
- Partnering is necessary to create change and improve health.
- Recognize and respect the diversity of the community.
- Mobilize community assets and develop community capacity to take action.
- Release control of actions and be flexible to meet changing needs.
- Collaboration requires long-term commitment.

*Principles of Community Engagement, 2nd edn. (2011)
DUHS Principles of Community Engagement*

- Proposed projects should be based on a need identified by the community that benefits the community.
- Scope and timeline of project should be clear to the community.
- Partners must be willing to commit time and resources to the project.
- Trust is key for building mutual respect among partners.
- A diverse range of community members and agencies need to participate to ensure that proposed activities meet the needs of a diverse population.
- A safe environment exists for all participants of all backgrounds to share ideas without fear of ridicule or criticism. No blaming or judgments. Keep lines of communication open.
- Partners must be good stewards of project data and include the community in outcome reporting, evaluation, potential programmatic interventions, education opportunities, and future program planning activities.

*http://communityrelations.duhs.duke.edu/modules/ocr_engage/index.php?id=1

The Art and Science of Community-Engaged Research

- Progress in Community Health Partnerships: Research, Education, and Action

Ethical Considerations in Community-Engaged Research*

- Being thought through. Not yet codified in regulation.
- The Belmont Principles focus on the rights of the individual.
- Lacks ethical precepts:
  - community collaboration and consideration of culture
  - the ethical conduct of research with community partners
  - community-level risks

Individuals vs. Communities

- **Individuals**
  - Make decisions for themselves
  - Are able to provide informed consent
  - Are protected if incapable of giving consent

- **Communities**
  - May not have an organization who can make a decision for the community
  - May include a wide range of diverse opinions

Belmont Principle: Respect for Persons

- **Individuals**
  - Individual autonomy; protection for individuals with reduced autonomy

- **Community**
  - Autonomy and protection to include community organizations and agencies.

Belmont Principle: Beneficence

- **Individuals**
  - Maximize benefits and minimize risk for individuals

- **Communities**
  - Maximize benefits and minimize risk for individuals and communities
Belmont Principle: Justice (fair distribution of burdens and benefits)
- The Belmont Report does include:
  - Justice considerations at the individual and social level
  - The need to distinguish between groups who can and cannot bear the additional burdens of research
  - Recognition that research should benefit the community and not exploit it

A Real-Life Example
The Havasupai and Arizona State University*
Study researched genetic link for diabetes
AND
Suggested high degree of in-breeding
Contradicted community's origin story
Showed genetic links for schizophrenia, metabolic disorders and alcoholism
AND
Did not help the community with diabetes prevalence or management


SUMMARY
- Community-engaged research is an approach to the research enterprise that takes into account the needs and assets of the community.
- Principles have been developed to guide community-engaged research and a science is developing to support it.
- Community-engaged research raises new ethical considerations.
- Community-engaged research has benefits for community and researchers.