1 Community Based Research

Community based research (CBR) is research that is conducted as an equal partnership between academic investigators and members of a community. In CBR projects, the community participates fully in all aspects of the research process. Community is often self-defined, but general categories of community include geographic community, a community of individuals with a common problem or issue, or a community of individuals with a common interest or goal.

Where research is being conducted in communities, investigators are encouraged to involve members of the community in the research process, including the design and implementation of research and the dissemination of results when appropriate. The NC TraCS will assist the investigator in developing such arrangements. The NC TraCS Community and Stakeholder Engagement (CaSE) program provides support to UNC-Chapel Hill researchers who seek to engage in community-academic partnerships to conduct research.

1.1 Community Partnerships in Research

Increasingly research design involves members of the community under study in the design and implementation of this research. These approaches include community engaged research and community based participatory research (CBPR).

Community-engaged research encourages the participation and influence of nonacademic researchers in the search for new knowledge. Community members, organizations, and researchers work together in all aspects of the research process. Community-engaged research is done with communities and not on communities. This approach to research recognizes the strengths of the community and builds on those strengths.

Health-related research studies may develop new treatments or find ways to prevent disease. But it can take years before these treatments become available in most clinics, doctors' offices, or community health centers. This is especially true for research that involves disadvantaged communities. Community-Based Participatory Research (CBPR) actively involves the community in the research process. CBPR seeks to directly benefit the public in a process that:

- Is a collaborative approach that equitably includes community members, organizations, and researchers in all aspects of the research process.
- Enhances the understanding of a mutually shared area of public health interest.
- Puts findings into action to improve the health and well-being of community members.
In CBPR, community members are also involved in getting the word out about the research and promoting the use of the research findings. This involvement can help improve the quality of life and health care in the community by putting new knowledge in the hands of those who need to make changes.

These processes may present challenges for both researchers and IRBs, including whether the community partners are subjects, members of the research team or both; what training is required; how to manage conflicts of interest; when is it appropriate to establish community advisory boards; how to solicit their input in ongoing involvement; whether and what kind of collaborative agreements are required; and how/when to disseminate results. In many cases it will not be necessary or appropriate to apply the same policies and requirements to community partners that are applied to University-based members of the research team. For example, it may be more appropriate for the principal investigator to provide training that is tailored to the role of community partners (e.g., church members, barbers, community advocates) than it is to require completion of the same online CITI modules that investigators complete.

1.2 IRB Review

Questions to be considered as CBR studies are developed, and issues that the IRB will consider when reviewing CBR are as follows:

- How was the community involved or consulted in defining the need for the proposed research (i.e., getting the community’s agreement to conduct the research)?
- How was the community involved or consulted in generating the study research plan?
- How will the research procedures, including recruitment strategies and consent processes be assessed to ensure sensitivity and appropriateness to various communities (e.g., literacy issues, language barriers, cultural sensitivities, etc.)?
- How will the community be involved in the conduct of the proposed research?
- How will community members who participate in the implementation of the research be trained and supervised?
- How have “power” relationships between investigators and community members on the research team, and in subject recruitment strategies been considered to minimize coercion and undue influence?
- What are the risks and benefits of the research for the community as a whole?
- How will boundaries between multiple roles (e.g., investigator, counselor, peer) be maintained, i.e., what happens when the investigator/research staff is the friend, peer, service provider, doctor, nurse, social worker, educator, funder, etc.)
- How will the research outcomes be disseminated to the community?
- Is there a partnership agreement or memorandum of understanding to be signed by the University of North Carolina at Chapel Hill (UNC-Chapel Hill) investigator and community
partners that describes how they will work together?

When CBR studies are proposed, the above information will be included in the submission materials. When the IRB reviews CBR studies, it will include, either as members or consultants, individuals with expertise in community-based research.

2 References:

Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards

Sarah Flicker, Robb Travers, Adrian Guta, Sean McDonald, and Aileen Meagher


Published online 2007 April 10. doi: 10.1007/s11524-007-9165-7.

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