

Guidance on Community-Based Participatory Research

The University of Georgia's Human Research Protection Program (HRPP) is committed to supporting community-based participatory research and to promoting research designed to engage the communities served by UGA. Community-Based Participatory Research (CBPR) is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR typically begins with a research topic of importance to the community, and has the aim of combining knowledge with action and instituting change to improve the well-being of the community. The community generally actively participates in the full spectrum or majority of the research process, such as the conceptualization or design, conduct or implementation, analysis and interpretation of data, conclusions, and communication of results. Other terms used are community action research, community engaged research, participatory action research, community-based action research, participatory rapid appraisal, and empowerment evaluation.

A. Additional Information and Considerations in CBPR

If you are conducting community-based participatory research, in addition to the relevant human research protection regulations, policies and guidance, the IRB submission should also consider and include the following:

- Community Involvement A description of the aspects of the research wherein community members will be involved, as well as how they will be involved. Often, the researchers involve the community members in the research design or conceptualization, conduct or implementation of the study, and dissemination or distribution of study results. In some topics or research areas, it may be necessary to involve the community members as well in the analysis and interpretation of data, and to seek their input into how the results or findings will be distributed or shared with others. This gives the community members the opportunity to include their views about the interpretation prior to final publication.
- Community Consultation Researchers should work with the community members to
 identify any risks and potential issues (e.g., literacy, language barriers, local or cultural
 beliefs and attitudes) the researcher may not have considered. Risks should be
 considered for both individuals and the community. Appropriate measures to minimize
 any foreseeable risks can also be established in consultation with the community
 members.

- Collaborative IRB Review Some groups, agencies or entities (e.g., tribes, retirement communities, and school districts) may have their own ethical review process for research. If this is the case, researchers should apply to the local ethics review body for review and approval of their research. Institutional and/or investigator agreements may also be necessary.
- Plan for Modifications In CBPR, it is often necessary to make changes to the procedures or survey/data collection instruments as the research progresses or is implemented in the field. Researchers must anticipate and plan for this by including in the IRB application information that is sufficient enough to allow for a thorough review but general enough to allow flexibility. For example, describe a range of procedures that may be employed; avoid the use of specific dates but rather indicate a time period (i.e., state that "interview will be conducted in late fall of this year" rather than "interview will be on October 31"); avoid the use of specific locations unless necessary when describing where interview will take place (i.e., state that interview will take place at a "mutually agreed location" rather than "Room 123 in Building A"); if the questions cannot be fully listed as in a semi-structured interview (with possible follow-up questions based off earlier responses), describe instead the nature or key areas of the questions and the parameters or boundaries (limits) of topics to be discussed.
- Plan Disclosure of Research Findings Most group harms result from inappropriate
 disclosure of research findings. Researchers should work with the community to inform
 the members about the research findings and how they plan to disclose these as well as
 possible implications of disclosure. This approach may reduce the possibility of harms
 resulting to the community as the research is published or presented.
- Make benefits available to groups Researchers should design studies so that they will
 provide benefits to the communities involved. Productive partnerships between
 researchers and community members should be encouraged to last beyond the life of
 the project. This will make it more likely that research findings will be incorporated into
 ongoing community programs and therefore provide the greatest possible benefit to the
 community from research.

B. Human Subjects Office (HSO) Support and Additional Resources

HSO staff members are also available to assist with education, project-specific questions, and submission requirements related to CBPR, such as the following:

- Regulatory considerations related to researcher engagement, performance sites, and involvement of vulnerable populations
- Training requirements
- Institutional and/or investigator agreements
- Use of community advisory boards
- Involvement of participant advocates
- Establishing partnerships with community-based organizations

Training Presentation: <u>IRB Review of Community-Based Participatory Research</u>

C. Questions

Please contact the Human Subjects Office (706-542-3199 or irb@uga.edu) for any questions or assistance.