

UNIVERSITY OF SOUTHERN MAINE
Office of Research Integrity & Outreach

Procedure #:	HRPP-052
AAHRPP	Element I.4.C.
Date Adopted:	
Last Updated:	
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Updated By:	
Reviewed By:	IRB Chair; IRB; ORIO
Procedure Title:	Community-Based Participatory Research

1.0 **Objective**

- 1.1. To describe the primary ethical considerations applied to Community-Based Participatory Research covered by the University of Southern Maine (USM) Human Research Protection Program (HRPP).

2.0 **Responsibility**

- 2.1. Execution of this SOP is the responsibility of the Institutional Official (IO), Office of Research Integrity and Outreach (ORIO), Research Compliance Administrator (RCA), and Institutional Review Board (IRB).

3.0 **Definitions**

- 3.1. **Community-based participatory research (CBPR)** is research conducted as an equal partnership between academic investigators and members of a community. Community members actively participate in all phases of the research process, including the design and implementation of research and the dissemination of results when appropriate.
- 3.2. **A community** includes a geographic community, a community of individuals with a common problem or issue, or a community of individuals with a common interest or goal.

4.0 **General Description**

- 4.1. CBPR is a collaborative research approach that equitably involves all partners in the research process and recognizes the unique strengths that each may bring.
- 4.2. The process typically starts with a topic of importance to the community and aims to combine knowledge with action to institute change to improve community well-being.

- 4.3. Research and community partners join to develop models and approaches to building communication, trust, and capacity, with the final goal of increasing community participation in the research process.

5.0 Procedures

5.1. Investigator Responsibilities

- 5.1.1. Investigators must follow the subsequent principles when conducting CBPR studies in addition to those required for all human subjects research:

- 5.1.1.1. Ensure the research topic addresses a community-defined need, question, or problem.
- 5.1.1.2. Recognize research as a partnership (i.e., engagement of research projects is to be led by a team of academic and community Co-Investigators as partners).
- 5.1.1.3. Respect the community partner's interest in the research.
- 5.1.1.4. Be open to the guidance of community insights and experiences.
- 5.1.1.5. Maintain a balance in decision-making between the investigators and community participants.
- 5.1.1.6. Provide continuous feedback to enhance the partnership and its outcomes.
- 5.1.1.7. Disseminate research findings to community collaborators and participants.
- 5.1.1.8. Recognize that partnerships can dissolve, and investigators should develop a plan for study closure.

- 5.1.2. When submitting an application to the IRB for CBPR studies, investigators must consider and include the following:

- 5.1.2.1. Community Involvement

- 5.1.2.1.1. Investigators should include a description of the aspects of the research wherein community members will be involved and how they will be involved. Often, the investigators 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 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. Doing so allows

the community members to include their views about the interpretation before final publication.

5.1.2.2. Community Consultation

5.1.2.2.1. Investigators should work with the community members to identify risks and potential issues (e.g., literacy, language barriers, local or cultural beliefs, and attitudes) that the investigator may not have considered. Investigators should consider risks for both individuals and the community. Investigators can consult with community members to establish appropriate measures to minimize foreseeable risks.

5.1.2.3. Collaborative IRB Review

5.1.2.3.1. Some groups, agencies, or entities (e.g., tribes, retirement communities, and school districts) may have an ethical review process for research. If this is the case, investigators should apply to the local ethics review body for review and approval of their research. Institutional or investigator agreements may also be necessary.

5.1.2.4. Plan for Modifications

5.1.2.4.1. Changing the procedures or survey/data collection instruments is often necessary as the research progresses. Investigators must anticipate and plan for this by including sufficient information in the IRB application to allow for a thorough review but general enough to allow flexibility.

5.1.2.5. Plan Disclosure of Research Findings

5.1.2.5.1. Most group harms result from inappropriate disclosure of research findings. Investigators should work with the community to inform the members about the research findings, how they plan to disclose these, and the possible implications of disclosure. This approach may reduce the possibility of harm to the community as the research is published or presented.

5.1.2.6. Make Benefits Available to Groups

5.1.2.6.1. Investigators should design studies that will provide benefits to the communities involved. Productive partnerships between investigators and community members should be encouraged to last beyond the project's life, making it more likely that community programs will incorporate research findings.

5.2. IRB Responsibilities

5.2.1. ORIO staff will provide IRB members with periodic continuing education that covers topics related to the design, implementation, and dissemination of results of CBPR studies.

5.2.1.1. Continuing Education may include but is not limited to, the presentation of pertinent information during an IRB meeting or the distribution of articles covering aspects of CBPR methodology.

5.2.2. When the IRB reviews CBPR studies, it will ensure that the membership of the IRB includes, or engages as consultants, individuals with expertise in CBPR. See HRPP-022 IRB Use of Additional Expertise.

5.2.3. The IRB should ensure that investigators conducting CBPR studies have provided enough information to assess whether the study adequately meets the criteria for approval, including:

5.2.3.1. Evidence of an equitable partnership between the investigator and the community partner.

5.2.3.2. The Investigators have defined the relevant community or communities.

5.2.3.3. The investigators have identified the appropriate community or communities for the project.

5.2.3.4. The community Co-Investigator has identified the appropriate research partner for the project.

5.2.3.5. Community engagement is an integral part of the research.

5.2.3.6. Letters of support (from the community) are clear and well-defined.

5.2.3.7. There is an appropriate division of funding (if applicable).

5.2.3.8. There are adequate training opportunities for investigators and community members.

5.2.3.9. The research environment is adequate.

5.2.3.10. The community benefits from the presence and implementation of the research.

5.2.3.11. The research is conducted in an environment that enhances the likelihood of success.

5.2.3.12. The research strives for positive change in the community's outcomes.

5.2.3.13. The research fosters long-term beneficial relationships between USM and the community.

6.0 References

- 6.1.** West Virginia University SOP 040: CBPR Research
- 6.2.** Boston Children's Hospital CBPR Policy/Procedure