17.0 Community-Based Participatory Research

In some instances, the design and implementation of research can be enhanced when individuals from the community in which the research will be conducted are involved in the design, conduct, and analysis of data from the research. This can occur for an individual study or group of studies. Pennington Biomedical Research Center facilitates the involvement of community members by supporting researchers who wish to conduct community-based participatory research or other types of research that involve community members.

17.1 Considerations for Investigators Involved in Community-Based Research

- Does the community partner have an IRB and/or approval process?
- If community partners are involved in research activities, are the partners considered "engaged" under federal law. If the community partners are considered engaged, they must complete all mandatory education criteria outlined in Pennington Biomedical Research Center Institutional Policy 106.00.
- Consent forms should be reviewed to ensure the reading level is appropriate for the planned participants. An 8th grade reading level is suggested.
- The IRB will need to know how the data will be shared with the community partners.

17.2 IRB Review of Community-Based Research

The IRB office follows the federal regulations and established policies and procedures when reviewing Community-Based Research protocols.

The following detail the IRB review of community-based research:

- The IRB will include members with experience conducting community research.
- Under Pennington Biomedical policies and procedures, the IRB may contact a consultant to review any research study where additional expertise is required, including community-based research.
- The IRB will review the research with the same policies and procedures outlined in the HRPP policies and procedures manual Policy 3 IRB Review.

17.3 Additional Consideration in the IRB Review of Community-Based Research

- Does the community partner have an IRB and/or approval process?
- If community partners are involved in research activities, are the partners considered "engaged" under federal law. If the community partners are considered engaged, they must complete all mandatory education criteria outlined in Pennington Biomedical Research Center Institutional Policy 106.00.
- Consent forms should be reviewed to ensure the reading level is appropriate for the planned participants. An 8th grade reading level is suggested.
- If any of the research will take place in participants' homes, the investigator must address issues of mandated reporting under state laws, if sensitive questions are being asked.
- Issues of privacy, confidentiality and coercion must be addressed.

17.4 Involving Community Members in the Research Process

- To understand the potential role of racial and cultural differences among population groups and how such differences may impact research study design, analysis and interpretation, the institution, its researchers, and administrative departments foster relationships with various community partners, churches, community centers, and local organizations to determine how best to engage diverse populations in research. Free glucose screening, diabetes prevention education, and advertisements (e.g., local newspapers, billboards, and social media platforms) directly target these populations.
- To help researchers identify relevant community members to involve in the research process, PBRC Recruitment Department maintains relationships with local community resources with expertise in hard-to-reach populations.
- Through partnerships with the Baton Rouge Mayor's office and local organizations, the institution provides resources and expertise to hard-to-reach populations.
- The institution's Research Computing and Recruitment Departments maintain listservs and various data on study volunteers and community demographics that aid investigators as they plan research proposals.
- The institution evaluates the racial or ethnic demographic characteristics of subjects enrolled in research to evaluate whether participation in research reflects the demographics of the community, when appropriate. This information is documented in the facilities report and is decimated to the Associate Executive Directors with approval by the Executive Director.

• The Community Members of the IRB, who are unaffiliated with the institution and can be scientific or nonscientific, are expected to provide input regarding their individual knowledge about the local community and be willing to discuss issues and research from that perspective.