Education and Outreach

The UH has numerous vehicles for communication and education to increase public awareness and educate potential research participants on human subjects research, as well as mechanisms for receiving feedback from participants and communities.

211.1 Online Resources and Educational Materials

Along with the Human Studies Program website (https://manoa.hawaii.edu/researchcompliance/human-studies) as described in Section 210.1, there are a number of other UH resources on HRPP:

- **RCMI Multidisciplinary and Translational Research Infrastructure Expansion (RMATRIX)**, hosted by the John A. Burns School of Medicine, provides research support for UH clinical Investigators to conduct human participant research.

- The **Social Science Research Institute (SSRI)** serves as the sponsored research division of the College of Social Sciences. They provide administrative support for pre- and post-award activities related to extramural research and training grants and contacts in the College.

- **SONA** is the participant pool platform often utilized by faculty and student researchers conducting human participant research in the Department of Psychology and the Department of Communicology.

- As steward to the university’s institutional data, the **UH Institutional Data Governance Program** provide training such as Information Security Awareness Training.

211.2 Participant Research Inquiries

Using a database of studies, HSP staff may provide PI contact information to prospective and enrolled participants for active research being conducted at UH.

The Human Studies Program website also provides a list of resources regarding participant’s rights and other information pertinent to participants, including contact information of appropriate individuals or entities.
Community-Based Research

Increasingly research design involves members of the community. Community members, organizations, and researchers may work together in all aspects of the research process. Depending on the level of involvement, community-based research ranges from community-engaged research to community-based participatory research (CBPR).

Community-engaged research encourages the nonacademic researchers to participate in and influence research. It is done with communities, not on communities. This approach to research recognizes the strengths of the community and builds on those strengths.

CBPR actively involves the community in the research process. Research development can take years to reach most clinics, doctors' offices, or community health centers, not to mention disadvantaged communities. CBPR seeks to directly benefit the public in a process that

• includes community members, organizations, and researchers in all aspects of the research process;
• enhances the understanding of mutually-interested public health issues; and
• puts findings into action to improve the health and well-being of community members.

In CBPR, community members are also involved in informing others about the research and promoting the use of the research findings. This involvement can help improve the health and well-being of the community by putting new knowledge in the hands of those who need such information to make changes.

Community-based research presents challenges for both researchers and IRBs, such as whether the community partners are subjects, members of the research team, or both; what training is required; how to manage conflicts of interest; when it is appropriate to establish community advisory boards and how to solicit their input in ongoing involvement; whether and what kind of collaborative agreements are required; and how or when to disseminate results. In many cases it will not be necessary or appropriate to apply the same policies and requirements to community partners as those applied to UH Investigators. For example, it may be more appropriate for the Investigator to provide training tailored to the role of community partners (e.g., church members and community advocates) than through the completion of online CITI modules.

Because there is a continuum of involvement between researchers and communities, a single set of guidelines is not appropriate. One thing is common though: the fact that Investigators interact with the community that goes beyond interactions with individual potential research subjects. So Investigators shall consider the risks and benefits to the entire community, not just individual subjects. In addition to those principles for human subjects research, researchers conducting community-based research shall follow best practices for respectful and productive relationships. The following are guidelines for community-based research depending the level of involvement with the community.

1. In conducting community-engaged research, the Investigators shall
   (a) be aware and respectful of community interests that go beyond those of individual potential research subjects;
   (b) identify potential community stakeholders as well as individual research subjects;
   (c) inform the community stakeholders and potential research subjects about the research; and
(d) invite feedback regarding concerns about the research from community stakeholders and individual potential research subjects.

2. In addition to the above principles, the Investigators conducting basic community-partnership research shall
   (a) respect the community partner’s interest in the project and be open to ways that the community may want to use the information.
   (b) disseminate research findings to both community stakeholders and individual research subjects.

3. In addition to all above, the Investigator conducting CBPR shall
   (a) have the research topic addressing a community-defined need, question, or problem, and strive to combine knowledge with action to achieve necessary changes;
   (b) recognize the research as a partnership and be open to the guidance of community insight and experience;
   (c) balance the decision-making power between the researchers and the community participants to a point that is mutually acceptable;
   (d) strive to communicate with community partners openly and clearly so to understand each other’s needs and interests;
   (e) recognizes race, ethnicity, class, and other aspects of culture matter and talk openly about these issues;
   (f) obtain feedback from all stakeholders in the partnership, with the goals of continuously improving the partnership; and
   (g) realize that partnerships can dissolve and plan a closure process.

211.4 Evaluation

Evaluation is an ongoing process. The various departments within UH’s HRPP evaluate their impact on an ongoing basis. The Human Studies Program website allows prospective and active participants, and their communities to provide feedback by submitting comments either through the website or by emailing the HSP office directly.

All HSP staff, IRB members and Chairs are requested to report both positive and negative feedback about all HRPP outreach activities to the Quality Improvement and Education Units, who track this input in order to make changes to improve outreach activities.