

Hunter Alliance for Research & Translation (HART) Principles for Ethical Community-Engaged Research

The [Hunter Alliance for Research & Translation \(HART\)](#) at Hunter College of the City University of New York conducts interdisciplinary, community-engaged research, broadly focused on gender and sexuality. We partner extensively with local, national, and international collaborators, applying psychological theories and research methods to develop innovative strategies that improve health equity and access. HART's mission is to translate research findings into practical implications for service and advocacy organizations, and to develop trainings and technical assistance tools that accelerate the pace of empirically-based practice.

In general, HART grounds its approach on the model of [Good Participatory Practice \(GPP\)](#) developed jointly by the United Nations Programme on HIV/AIDS (UNAIDS) and AVAC Global Advocacy for HIV Prevention in 2011. Although these GPP guidelines were developed specifically in the context of HIV research, they are informed by decades of theory and research on community participation, and can be applied broadly to the development of research agendas, projects, and dissemination. According to GPP, there are six guiding principles that should shape engagement with community stakeholders and provide a framework for all project activities: respect, mutual understanding, integrity, transparency, accountability, and community-stakeholder autonomy. The GPP perspective privileges context in the research endeavor, acknowledges inherent power inequities among different stakeholder groups, and offers concrete strategies to address and integrate these pivotal dynamics.

To complement its commitment to GPP, HART's community-engaged and community-responsive research collaborations are based on an addition **six core ethical principles for partnership:**

1. **Equitable budgeting.** Too often, even extraordinarily well-funded research projects provide limited or token support to the community partners who engage in the bulk of recruitment or data collection activities. Every HART project is budgeted in collaboration with our community partners commensurate with the actual work undertaken by each partner. For the majority of our large-scale NIH grants, this translates into 40-50% of the total budget being awarded to our community partner; for smaller-scale projects, we provide support that corresponds to the level of effort being requested. No community partner should be asked to engage in uncompensated research work, and no staff members should be asked to attend meetings that do not directly benefit the community partner without adequate compensation.
2. **Partnership in the development of both research agenda and methods.** All of HART's research projects have been developed in collaboration with our community partners, rather than brought to them. We design research projects to test ideas generated from the experiences of clinicians or other service providers; we develop strategies for analyzing program evaluation data that can support fundraising efforts; we design implementation research projects to test novel program models designed by our collaborators. Much of our work combines research with capacity building. For example, we developed a research internship program in collaboration with a LGBTQIA+ youth services program, which supported the seven youth members (all LGBTQ youth of color) over 10 weeks to design and develop a research project, collect and analyze the data, and present their findings to the NYC Department of Health Race to Justice initiative. In every project that we undertake, we ensure that a diversity of stakeholders are represented, and this includes making sure that our research teams themselves are representative of the populations with whom we work.
3. **Integration of research activities into the ongoing work of the clinical site.** Another feature that is unique about HART's research approach and strategy is the extent to which research protocols are developed to be integrated into the ongoing work of a setting, and attempt to minimize additional burden on staff and systems as much as possible. Because of our team's past experience as staff

members (rather than as researchers) in community-based clinical settings, we are extraordinarily mindful of the ways in which research protocols can tax an already highly burdened setting. In each of our studies, we work with staff, supervisors, and administrators to streamline processes as much as possible. Our goal is for research activities to add value to clinical settings as much as possible. For example, patient visits for our PrEP demonstration project were tracked through a template integrated into the clinic's existing electronic medical record, and the patient tracking system developed for use by our project coordinator became the basis of the system currently used in practice by regular health center staff.

4. **Prioritizing the “patient” rather than the “participant.”** By definition, individuals who are engaged in research in clinical settings are both patients and participants. But too often, research projects prioritize their participant role, and neglect the higher purpose of ensuring that they are served and cared for by the setting. In all of our collaborative projects, we always emphasize the extent to which the human being takes precedence over the research. For example, we limit exclusion criteria in our research protocols to ensure that as many patients have access to participation as possible, even if it means more work on the data analysis end. We provide a variety of methods for individuals to participate in our studies, including creating systems that allow participation from home or provide computer access for individuals who need it. We actively limit the number of visits required for participation in our studies, and try to ensure that study participation can happen at the same time as an individual's regular visit to the health center.
5. **Ensuring community-focused dissemination.** For all of our projects, we ensure that we report back to our community partners about research progress and findings, and we make ourselves available to present not only at scientific conferences, but at community events and forums as well. We provide regular data-driven research updates for all our collaborative partners, in setting including: health department staff meetings and retreats, medical center grand rounds and community health center staff meetings, community network coalition meetings, citywide HIV Prevention Planning Group meetings, the National Biomedical Prevention Summit, the Gender Conference NYC, and the National Transgender Health Summit. HART is developing a virtual townhall webinar series to respond to community interest about our research projects, and is committed to ensuring that our research products and tools can be utilized by a diversity of individuals and settings
6. **Planning for sustainability.** Finally, one of the pitfalls of many research projects is that they provide an infusion of resources or programs into a community setting, which are withdrawn as soon as the research has ended. All of HART's research projects that develop new programs include the development of a sustainability plan, in order to ensure that the setting is able to sustain the services at the end of the research period. For example, our PrEP demonstration project provided 12 months of free medication and support services to research participants; we developed a transition protocol with the health center to plan at each participant's 9-month study visit for the way in which they could continue on PrEP at the health center following their 12-month study visit (if so desired). In collaborations for the development of new services program, one of the central components of each project is a cost-estimation/cost-effectiveness analysis, which will provide leadership with the information they need to fund the program as a regular part of the budget once the research is complete.