

Include Community Partners in Data Collection

UCLA CTSI Community Engagement & Research Program
Partnered Research “How To” Series

BACKGROUND

The Healthy Community Neighborhood Initiative community and academic leadership established a memorandum of understanding which put a special emphasis on incorporating staff from community partners in data collection protocols to increase trust and success of the project.

PROCESS

We used the following process to include community partners in data collection:

Staffing

When possible, all data collection teams consisted of equal representation of community and academic research associates (RAs). Teams were composed of:

- A University staff RA who administered the consent form and face-to-face interview.
- A Community RA (phlebotomist or trained nurse) who conducted the health screening and laboratory data collection

A subset of university RAs were bi-lingual to conduct the consent and interview in Spanish, and translate for the phlebotomist during exam. Although funding for the project was held at the academic institution, subcontracts were established to fund RA effort at community organizations. All members of the study team completed HIPAA and CITI Good Clinical Practice training. Phlebotomist also held certificates for blood borne pathogen and medical waste management.

Manual of Procedures

The study staff reviewed manual of procedures (MOPs) from previous studies to identify appropriate procedures for our study. The community and academic leadership reviewed the proposed MOPs and established HCNI protocols that gave equal responsibility for data collection to community and academic representatives of the study team.



KEY COMPONENTS FOR SUCCESS

- Memorandum of understanding (MOU)
- Shared funding to support staff
- Comprehensive training for all staff led by both community and academic leadership
- Partnered Manual of Procedures (MOP) for supplies, equipment, and data entry and tracking

Training for Data Collection Staff

Special emphasis was placed on training community and academic staff to build capacity for partnered research in all partnered organizations. All training sessions were conducted at a community partner site and at no cost to trainees. All trainees had to attend the training session, perform mock tests and obtain the trainer’s approval before collecting data in the community (*see table next page*).

Supplies and Sample Storage

As part of the study MOP, a checklist of supplies needed for each data collection visit was jointly created by University and community RAs. Supplies and equipment were maintained and invoiced prior to the visit and a log was kept to ensure timely replenishment. Collected bloodspot samples were stored at a community partner site and samples were transported in batches to the University site for analysis.

Data Management

Interview responses and exam results were collected on paper forms created and approved by all members of the study team. After a data collection home visit, the forms were returned to the university and were data entered into Redcap. University programmers and analysts worked with the study team to clean, review, and summarize the data and respond to the questions asked at the community and academic meetings.

Healthy Community Neighborhood Initiative (HCNI): A community-partnered participatory research project

HCNI was a CPPR project with the Los Angeles Urban League, Healthy African American Families II and the UCLA CTSI. The goal is to address health disparities in a low-income African American and Latino community in South Los Angeles.

More information on HCNI: http://ctsi.ucla.edu/patients-community/pages/research_projects#greenic

All study RAs were given training on components listed below:

Training	Trainer	Training Content
Working with the study population	Community partner leads	<ul style="list-style-type: none"> ▪ Cultural competency ▪ Personal safety when conducting community research ▪ Protecting the privacy of participants
Basic life support (BLS) class certification	Certified trainer by American Heart Association	<ul style="list-style-type: none"> ▪ Completion of BLS sequence according AHA guidelines
Informed consent and interview administration	Community and academic leadership	<ul style="list-style-type: none"> ▪ Survey administration in a minimally invasive manner ▪ Referral of participants to health care and social services included in Community Resource Guide ▪ Procedure for alarm value readings (i.e. high blood pressure or high depression score)
Health screening exam administration	Representatives from CTRC	<ul style="list-style-type: none"> ▪ Completion and signature of research documents and equipment checklist by data collection team ▪ Set up & calibration of equipment ▪ Protocols for height, weight, waist circumference, and blood pressure measurements ▪ Protocols for chair stand and grip strength measurements (for participants ages 50 and older)
Laboratory examination	Representatives from CTRC	<ul style="list-style-type: none"> ▪ Universal precautions ▪ Fingertstick to collect bloodspots ▪ Protocols for handling and storage of bloodspot samples ▪ Calibration of point-of-care CardioCheck machine

Study Progress Log

A participant enrollment and survey completion log was updated by University RAs and presented at the weekly community and academic meetings to keep all study members informed on the progress of the data collection progress. During these meeting, the study team discussed any protocol issues and revised as needed.

Report Results to Participants

Blood pressure, body mass index measurements, and cholesterol readings were given to participants during the home visit. After blood spot analyses were completed, University RAs

prepared laboratory results packets which included an informational sheet with an explanation of the tests and reference values as well as a certificate of completion and thank you note. Community partners reviewed the packets and mailed them to participants.

Concluding Thoughts

Bringing together community and academic expertise in all phases of the data collection process including protocol design, data analysis and training allowed us to build a partnered research infrastructure that community and academics can use in future studies and interventions for data collection, interpretation and dissemination.

“If you want to go fast, go alone. If you want to go far, go together.” - African Proverb

UCLA CTSI Community Engagement and Research Program (CERP)

Develops, implements, and refines models of community engagement and community capacity building, and facilitates research collaborations between academics and community partners.

Additional resources on community engaged research:

<http://ctsi.ucla.edu/patients-community>

