

## **Research Ethics Training for Community-Based Collaborators**

When KUMC investigators conduct community-based participatory research, they typically involve members of the community on the research team. Those community representatives must be trained in research ethics as appropriate to their role in the study.

Generally, all KUMC research personnel, KUMC staff and affiliated staff who have any role in research involving human subjects must complete a seven-module tutorial on human subjects protection and privacy regulations. This includes community representatives on the research team where, normally, completion of the seven-module tutorial would be necessary as a one-time requirement.

However, the Human Research Protection Program (HRPP) recognizes that our typical seven-module tutorial may not be beneficial for all community representatives who participate in our research, either because of differences in backgrounds or because of language barriers. The HRPP can assist investigators in developing the most appropriate means for training these individuals to fulfill their important role in the research.

### *Goal of training*

The overall goal in training community representatives is to communicate their key responsibilities:

1. Serve as an effective representative of the study and of KUMC.
2. Ensure that study information is coming from individuals who understand what they are being asked to do and freely volunteer to participate.
3. Collect information that is accurate and protected from loss.

### *Key topics*

Investigators should discuss the following topics in their training session(s) with community representatives:

- Potential study participants must be treated with respect. Be polite to the individual even if they decline participation.
- Communicate the voluntary nature of research. Everyone is free to decide whether or not they participate. Even when individuals choose participation, they are still free to decline any portion of the research, such as refusing to answer a specific survey question or refusing to participate in a follow-up session.
- Clearly explain the purpose of the research. Community representatives who obtain informed consent must be trained to provide specific and accurate information about the study.
- Potential participants must be given ample time to ask questions and consider study participation. The investigator should anticipate questions that may come from potential participants and train the community representative to either field questions or know how to the obtain answers.
- The community representative should never force participation on an individual who appears uncomfortable or confused or unable to make a decision.

- A participant's right to privacy must always be respected. Interviews on sensitive topics should take place in a setting where the conversation will not be overheard. Written materials and data collection forms should contain only the minimum necessary identifiable demographics. Data collection forms should be protected from loss or exposure to individuals outside the study team.
- Community representatives must understand their obligation not to disclose information obtained from participants to others in their community.
- During the training on proper data collection, investigators should stress the importance of consistent practices across all participants and settings in order to ensure data integrity.
- Community members should be trained and encouraged to report any potential problems, inconsistencies or questions to the investigator. Investigators may need to take extra steps to assure the community member that they can make these reports without retribution.

#### *Training methods*

The training topics can be delivered by the investigator in a manner that is appropriate to the educational, professional and cultural background of the community representative. Delivery may take the form of an individual conversation or a group training session. Members of the HRPP are available to assist the investigator in developing materials or conducting training sessions. To reinforce the importance of research ethics and scientific integrity, investigators are encouraged to create a document summarizing the key topics and have the community representative sign the document to indicate their agreement.

#### *Additional resources*

Members of the KUMC Frontiers Clinical and Translational Science Award provide resources and guidance on conducting community-based participatory research. Investigators may also refer to a field training guide developed by the Johns Hopkins Bloomberg School of Public Health. The guide is posted at: <http://www.jhsph.edu/offices-and-services/institutional-review-board/Training.html>.