Session Title: Whose Reality Counts? Community-Engaged Research and Research Ethics

Co-Presenters:

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Notes of the small-group activity discussion

Elaine: Whose reality counts? Always be aware of layers. Robert Chambers, who I was fortunate to study with, talked about “uppers and lower”. There are always hierarchies with those relegated to a lower status for whatever reason. So which group would like to share what they came up with? Who is the community in this scenario? Who voice is heard in that community?

Audience: Community can be defined by geography or by cultural similarity. Who defines the “community” depends on who you’re talking to.

Audience: I think the issue is more fundamental. The question is what is the research intended to tell you? If it’s to tell you the perception of people living in one of the 18 neighborhoods in Milwaukee, then it doesn’t make sense to bring in other people. There are pieces of information missing here. The community in this example is the Latino community. What’s our research question?

Elaine: We purposely made this scenario vague. Who should be invited to the table? To formulate the questions? To participate in the research? To share in the funding and resources? What ideas did you come up with on how to engage the community?

Audience: To begin engaging the community we would do a community needs assessment and assets mapping assessment.

Elaine: That’s good. Find out what’s currently happening in the community and what still needs to be done. What kinds of barriers did you discuss?

Audience: Most of the barriers were already touched upon. Others we came up with included language and translation issues. Which group of Latinos are you interested in?

Elaine: That’s a good point. Not just linguistic translation but cultural translation is so important. The Latino population is very diverse. If you’re not familiar with Latinos in
Milwaukee, you’ll find there are different groups; Mexicans, Puerto Ricans, Central Americans. Any other barriers?

Audience: Trust is vital. Not only having trust but how you go about developing it.

Elaine: Gatekeepers, trusted people already embedded in the community, are so important. If you’re new to the community, get to know who those gatekeepers are and let them get to know you.

Audience: We looked at who we might work through and work with. Another barrier we identified was immigration status.

Elaine: Good point. Even with issues like incentives and consent forms, one needs to be sensitive to immigration status. We need to make sure that incentives aren’t so high as to be coercive but another issue at least at Medical College of Wisconsin (MCW) is that with some incentive amounts, participants need to give their social security numbers which may serve as a barrier to the undocumented. Having to sign a consent form may also pose a barrier for that population. Great job everybody.

IRB overview discussion

Audience: With community-based participatory research approaches there is a fine line between participant and researcher. How do you deal with ethical issues?

Elaine: Who are the co-researchers, the advisory board?

Ryan: In a case like that there are potential issues of confidentiality as well as issues of coercion in terms of community members who are being paid to be researchers but are also participants.

Audience: Most of the risks considered in the IRB review process seem to be aimed at the individual level. Could you comment on respect for community, benefits to the community?

Ryan: That’s a good point. Consent is obtained on an individual basis. The IRB needs to also focus on risk to communities.

Elaine: While working with an indigenous community in Alaska, I learned just how important it is to imagine how potential statements can harm people that identify with the researched group but are living outside the researched area. Dignitary harm also needs to be considered when thinking about potential risks. We just published a paper on some of the challenges that non-academic researchers face with IRBs including defining community and risks and benefits. We need to be aware of cultural dignities as well as scientific concerns.
Ryan: This doesn’t mean that we shouldn’t do the research. But we do need to find a way to do it respectfully and still get the data.

Audience: What about vulnerable populations you’re trying to protect. You have worked so hard to engender trust and then you pull out a consent form. Is there a way to have the consent process be less written and more verbal?

Ryan: You can apply for a waiver of documentation of consent. This is not a waiver of the consent process itself, but of having to sign a form.

Elaine: Actually, I’m working on a project and we’ve been working hard to shorten the consent forms we have to use. We have it down to two pages. If it gets approved, I’ll share it!
Hypothetical Case:
You are part of a research team that is planning a community-engaged research project to improve diabetes self-care among Latinos in Milwaukee County. Self-care involves regular monitoring of behaviors associated with diet, exercise, blood-glucose testing, foot care, and smoking.

Working with others seated at your table, identify someone who can write down your group’s ideas on the worksheet at your table. Next, discuss your ideas regarding:

Who are the stakeholders? Who is the community in your project?

- County – health care policy makers, community members (those that interact with target population) and target population
- Groups that live in geographical area, have cultural similarities
- Funders define groups/communities without the community members being aware of the classification
- This question can be answered by looking at what the research is intended to tell, community then includes target of research

How can you engage the community in your project?

- Talking to community
- Community needs assessment
- Asset mapping
- Community inventory

What are some of the barriers you might encounter?

- Translators would be needed
- Cultural education, awareness of different ethnic groups with a given culture
- Addressing trust, how to go about doing this
- Working with gatekeepers of community is key
- Identifying who to work through and with is important