Response to Questions

Promising Practices of Meaningful Engagement in the Conduct of Research

September 19, 2013

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Q: What specific strategies have worked for your group to share both authority and responsibility? Co-chairing and writing agendas together are great examples. Others?

A: Community engagement activities that level the playing field:

- Two-way knowledge exchange approach
- Memorandum of Understanding with voting rules
- Joint trainings to build capacity
- Budget allocation and review authority
- Joint analyses and publications and presentations
- Review of press releases
- Joint ownership of data and products

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

Q: In my previous life as the director of a community health center, I learned that "community" is not monolithic. How do you develop consensus when there are major disagreements among members of a community?

A: We have open discussion of different views and work to get diversity at the table. We design the initiative when possible to have some win for everyone, even if all features aren't a top priority for everyone. We view conflict as important to growth. We use relationship building to keep people at the table even when there is disagreement. We also can agree to disagree.

About This Document

This document answers questions that were submitted by participants of the *Promising Practices of Meaningful Engagement in the Conduct of Research* webinar, held September 19, 2013. The respondents were Ken Wells, Loretta Jones, and Pluscedia Williams of the project "Long-Term Outcomes of Community Engagement to Address Depression Outcomes Disparities" and David Loring of the project "Cognitive AED Outcomes in Pediatric Localization Related Epilepsy."

Questions are listed in the order that they were received. Language that includes personal or organization identifiers has been redacted.

PCORI plans to host more webinars in this series. Visit pcori.org/events/ more details.

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed healthcare decisions.

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Sometimes, if appropriate to the project, we can compare approaches when there are legitimate alternatives. Sometimes it doesn't work out and someone decides to leave the project or opts not to engage. Even so, we often adopt some feature of their point of view to improve the overall fit of the project with the community.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

Q: Was the community engagement and planning part of the PCORI grant or done before submitting the grant application?

A: It was done beforehand. We had developed the model in the Witness for Wellness project and developed the specific version for depression in an NIMH grant; now we are further building the model with PCORI funding by adding a stronger focus on engagement of clients/patients.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

A: Our community engagement plan was developed specifically for the PCORI project, but it relied on relationships that had been previously established.

Answer provided by David Loring

Q: Any suggestions on how to pay patients/stakeholders?

A: Look at how much time and money is spent on transportation and childcare, as well as on the work activities. Also, ask stakeholders what is reasonable compensation, given the scope of the grant and limitations of mechanisms. And look for other sources for community support.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

A: Stakeholders other than patients have not been remunerated; they have been asked to volunteer their opinions as part of general professional citizenship. Early on, our patient stakeholder similarly volunteered her expertise, but now she is compensated for her contributions at formal meetings, such as our Investigators Meeting.

Answer provided by David Loring

Q: Can the group provide additional community engagement exercises it used to open meetings?

A: Here is a link[1] to two exercises, and more are discussed in our manual found on the website of the Community Health Improvement Collaborative[2]. We almost always have an object, such as yarn, keys, pieces of a puzzle, or a ball, flashlight, cell phone, puppet, etc., as a vehicle relating to a concept the group is working on, as well as a set of reflection questions, an activity involving sharing, or a game requiring discovery and sharing back.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

Q: How do you involve patients, even patient stakeholders, in a methods project, for example, related to causal modeling techniques? What kind of feedback/input contributions should we be looking for from patients?

A: We involve patients and community members without technical backgrounds in methods aspects of projects. For qualitative projects, community members or patients may be trained to review material for themes alongside researchers, and we may track responses separately or integrate them. For sampling, community views are used in defining community boundaries or identifying relevant vulnerable populations. For example, each community in Community Partners In Care[3] (CPIC) was allowed to select two vulnerable populations relevant to its community for oversampling, and each community selected different vulnerable populations. For randomization, we described some of the methods we used. For sophisticated analysis methods, it is very important for community or patient leadership in the project to understand the reason and principles. For example, we have held community meetings on imputing missing data and used presentations and games to understand why it is important to address missing data, how it is done, and the importance of doing sensitivity analyses to look at what such methods do to inference. We include patient and community representatives on methods work groups, and those leaders get more exposure and can be spokespersons in the community meetings for transparency, along with the academic leaders. Generally, we find that complex methods can be explained simply using common language, and our statisticians have become very adept at this kind of translation or get help from our community partners.

As noted in our presentation[4], we also use book clubs that include stakeholders at all levels. These may combine a discussion of a methods issue with music or poetry on the substantive or even methods issue (such as “chance” as a theme). This approach makes building this kind of capacity engaging and fun.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

[1] Available at communitypartnersincare.org/community-engagement/cep/.
[2] Available at communitytrials.org.
[3] Available at communitypartnersincare.org/community-engagement/cep/.
[4] Available at encore.meetingbridge.com/MB005418/130919/.

Q: We are impressed by the truly integrated approach taken by the workgroup that presented on depression research. We would appreciate advice on how to design the proposal to allow for flexibility depending on where the community input takes the study design.

A: Our approach was to explain briefly in the proposal where alternative choices might be made, give a most-likely scenario, and even include brief quotes from stakeholders on the importance. We cite other work that used this approach successfully. Not all reviewers will understand, and today there is some risk, so this feature does need careful alignment with the funding agency and project officers to be prepared for changes. One must be prepared to seek additional funding if responding to community priorities yields a more complex idea and project, as in our case. But then, that is not that unusual in the research process.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

Q: Were patient-partners trained in, at the very least, the basics of the research process?

A: Yes. Some of this comes from an initial orientation, for which we use experienced patient partners to help support and orient, and some of this comes from ongoing involvement in the group leadership process. Pairing up patient or community partners is a good idea.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

A: Partners from the Epilepsy Foundation have backgrounds in research, and the Epilepsy Foundation funds research projects. The patient partner on our Executive Committee (Brandy Parker) has no formal training in research methods, although that has never been a limitation because her primary contributions are not related directly to study design and implementation. As a member of our executive committee, Brandy engages in active dialogue, and when ideas cannot be implemented for design or similar considerations, it is part of the hands-on learning experience for her in increasing her knowledge of clinical research.

Answer provided by David Loring

Q: Have you partnered with community health workers/promotores de salud to engage the community? If so, what was your experience?

A: We have used community health workers extensively in both the Los Angeles project described and in a large post-Katrina mental health recovery effort in New Orleans led by Ben Springgate. This experience was highly successful and was a major feature leading to and incorporated in our Los Angeles depression initiative. Many of the workers trained were nonprofessional case workers or health workers.

They also participated in co-leadership and larger forums to give input to the project and had an excellent knowledge of the community.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

Q: How many patients do you include in your executive board/committee? Do you worry whether a particular patient represents opinions of a variety of patients?

A: Currently, half of the members of our executive committee and council leading our projects are either community members or patients. We do not specifically designate who is a patient because, really, all members are patients of some kind, not just with the designated illness being studied. Now we are specifically building in more co-leadership with patients identified with mental health illnesses. We have had at least two all along, but we are now building up patient membership within the council having patient members in each workgroup, and having a patient-provider stakeholder advisory group that our council meets with regularly.

We do not expect patients to represent all patients, or community members to represent all community members, or researchers to represent all researchers. In other words, people represent themselves, their agency if they are authorized to speak for their agency, and a view of their community. However, our model is that people go back and check with others and report back to the council or workgroup which helps provide more representation. We also work to bring in a diversity of views, and many people know others with a different perspective. A key element of the vision process is developing diversity of opinion within the leadership group.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams

A: We have a single patient stakeholder on our executive committee, although other executive committee members have children with chronic health conditions. For the primary question that "Cognitive AED Outcomes in Pediatric Localization Related Epilepsy (COPE)"[5] is addressing, there is little concern that other patients or parents of children with epilepsy would consider cognitive side effects of long-term treatment to be an unimportant concern.

Answer provided by David Loring

[5] Available at pcori.org/pfaawards/cognitive-aed-outcomes-in-pediatric-localization-related-epilepsy-cope/.

Q: How do you engage with community stakeholders who are busy? How do you help people understand the value in participating in meetings and discussions?

A: We try to make the meetings engaging and include information of value to them or their agency or community. For this reason, we sometimes have guest speakers on key topics of importance to the community or provide readings or other materials of use. We allow people to go "on and off the bus" as they need to and remain a part of the group. We ask them to help us make the meetings important and interesting. For this reason, there is always a community or patient co-lead for each meeting of the council, executive committee, and work groups, and the agenda is developed by the academic and community co-leads. We use meeting reflection sheets to determine what worked and what didn't work, and we review those in our leadership meetings and make course corrections. We also work to find meeting times that are convenient for people, which can sometimes mean evening meetings. People can participate by phone. Sometimes, we use webinars.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams.

A: Our ongoing engagement is through regular teleconferences. We hope that, as we continue to develop our research partnership, greater description of both our project and the importance of research participation will be incorporated into stakeholder websites in the form of both web page content and podcasts.

Answer provided by David Loring.

Q: How is overhead handled on both the academic and community sides?

A: We use whatever overhead applies to a particular agency; typically, overhead is somewhat lower for community agencies. Some patient representatives participate as individual consultants without overhead.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams.

Q: I'd love to hear more about the practicalities and documentation for engaging with patients and stakeholders.

A: The initial phase of our engagement in work concerning depression occurred in the Witness for Wellness initiative, which is described in a series of articles in *Ethnicity & Disease* and also posted on the website of the Community Health Improvement Collaborative.[6]

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams.

[6] Available at communitytrials.org.

A: Our stakeholder engagement was initiated from two directions. During study preparation, we surveyed physicians on their treatment preferences and relied on existing relationships with the Epilepsy Foundation. However, Brandy Parker independently introduced herself to me as the founder of the online forum My Epilepsy Story, asked about research activities, and volunteered to participate in any way she could with clinical epilepsy research.

Answer provided by David Loring.

Q: Is $25 for a two-hour meeting adequate reimbursement for a stakeholder's participation?

A: It depends on the context. Most of the participants are part of an agency and on company time and do not need additional reimbursement. For unaffiliated community members or patients who are not part of regular leadership, such as part of a working group, $25 seems to be sufficient pay as a thank-you. Many workgroups have fairly large numbers of community members or patients—perhaps as many as 15 to 30.

We also have special positions, called Community Scholars, in which a community member works with us, say, a half-day a week, to develop a concept or proposal. In those cases, we try to pay perhaps $5,000 for several months or $10,000 for a full year. For main leaders, we develop consulting arrangements. Main agencies have subcontracts that are substantial.

Answer provided by Ken Wells, Loretta Jones, and Pluscedia Williams.