Report on Community Partner Input
Regarding Partnerships with the Collaborative Center for Health Equity

FALL 2014

Introduction & Background

What some have called a “significant renaissance of community engagement in research” (Ahmed & Palermo, 2010, p. 1380) has been nurtured by numerous funders of health research in recent years, including many of the 27 Institutes that comprise the National Institutes of Health (NIH). The Clinical and Translational Science Awards (CTSA) program, funded by the NIH’s National Center for Advancing Translational Sciences (NCATS) identifies community engagement as a key function for a CTSA which is concordant with the suggestion by the Institute of Medicine that the “ultimate goal of translational research—to improve human health—requires meaningful community engagement across the entire spectrum of research” (Institute of Medicine [IOM], 2013, p. 10). Indeed, an evaluation by the IOM of the CTSA program commissioned in 2012 by NCATS included among its seven recommendations for the program the need to “Ensure community engagement in all phases of research” (IOM, 2013, p. 13).

The CTSA program from its inception was intended to “not only translate basic discoveries into the clinic, but also further translate and disseminate new findings into real-world practice” (Zerhouni, 2007, p. 127). Furthermore, the possible benefits to communities are well stated by Ahmed & Palermo (2010) in their observation that “Community engagement in research may enhance a community’s ability to address its own health needs and health disparities issues while ensuring that researchers understand community priorities” (p. 1380). The importance of community engagement is further underscored in a report by the CTSA’s Community Engagement Key Function Committee, which includes a set of four best practices, one being Community First, which the authors explicate by stating that “Too often researchers turn to the community when they find they are having difficulty recruiting people for a trial. Community engagement is the opposite of this approach – it puts the community and its priorities first, not last” (The Clinical and Translational Science Award Consortium’s Community Engagement Key Function Committee, 2008, p. 8).

The Collaborative Center for Health Equity (CCHE) resides in the Institute for Clinical and Translational Research, the CTSA housed within the University of Wisconsin School of Medicine and Public Health (SMPH). The CCHE’s mission is to improve health outcomes in underserved communities in Wisconsin by promoting community engagement through collaborations between campus- and community-based partners in education, research and initiatives focused on improving health equity. The CCHE connects partners from Wisconsin’s rural, urban, tribal and other diverse communities with university faculty, research staff and trainees so that together they can use or develop educational, training and research resources aimed at improving the health and wellness of Wisconsin’s underserved, minority and immigrant populations. The CCHE strives to sustain long-term, mutually respectful, and trusting partnerships with their community partners around the state.

Project

A plan to interview community partners was developed for the purpose of investigating in more depth the characteristics of the multiple community partnerships established by the CCHE. The interviews were intended to obtain the perspective of community-based collaborators who have worked with CCHE regarding various aspects of their partnerships with CCHE investigators. By eliciting the views of community partners the CCHE staff hoped to identify approaches for strengthening community engagement efforts.
Methods

Based on prior knowledge of CCHE-community partner initiatives, the CCHE staff identified seven community partner sites, and two individuals from each of these sites, for face-to-face interviews. Partner sites and individuals were chosen based on length and scope of involvement in CCHE partnership initiatives and represented projects in urban, rural, tribal and non-tribal communities. Community partner sites and major CCHE community initiatives are listed in Appendix B. Institutional Review Board (IRB) approval for the study was obtained through the University of Wisconsin Health Sciences IRB.

The CCHE engaged an independent evaluator, Dr. Candace Peterson, from the UW Population Health Institute (UW PHI) Evaluation Group to design and conduct the interviews, and analyze interview data. Dr. Peterson and the CCHE team jointly developed open-ended, semi-structured interview questions, which included:

1. In general, what makes community/academic partnerships work well?
2. What types of projects have CCHE staff worked with you/your community on?
3. In what ways do you think partnerships with CCHE work well? Why?
4. Are there things CCHE staff could do to improve, grow or strengthen partnerships with you?
5. How do you/your larger community benefit from your partnerships with CCHE?
6. How do you think CCHE benefits from partnering with you?
7. What things do you think your community does well in terms of being a partner to CCHE?
8. Are there things you think your community could do to grow, strengthen, or improve your partnership with CCHE?
9. Is there anything that we haven’t covered that you think is important to add?
10. If you are interested in seeing a summary of the feedback our partners provide to us, what is the best way to get that information to you?

Initial contact was made by CCHE staff with each interviewee to provide information about the study and to request an interview. Subsequently, Dr. Peterson contacted each potential interviewee via email, inviting them to participate in a confidential, face-to-face, one hour interview at a location of their choice and at a mutually convenient time. The interview questions were included in the email. Thirteen of the fourteen invited interviewees agreed to participate, with one individual declining, citing limited time in partnership on projects with the CCHE. This individual suggested two other staff from his site, who were both contacted and agreed to participate. While one-on-one interviews were suggested in the invitational email from Dr. Peterson, three community partner sites preferred that all interviewees from that site be present at the interview at the same time.

Fifteen interviews were conducted with staff from seven community partners. To ensure the accuracy of the data, within two days of each interview, Dr. Peterson sent a typed summary of the interview to the interviewee for review and comment, and necessary edits were made from those comments.

Analysis

Dr. Peterson and an evaluation researcher from UW ICTR (who is familiar with CCHE and its initiatives) reviewed the interview data and conducted thematic analysis of interview content to identify themes. The three emergent themes identified in the interview data are presented next with selected interview quotes that represent the overall theme. A summarization of the actual interview data organized by interview question is included in Appendix A.
Results by Theme

Theme 1: Transparency, authenticity and equality in relationships.

Two questions asked what makes community/academic partnerships work well, both in general and specifically in terms of working with CCHE. The words and ideas used to describe what makes partnerships work in general, and with CCHE in particular, included language suggesting that the community partners value a respectful relationship that acknowledges special skills on both “sides” of the partnership, along with genuine cultural sensitivity. Some of the respondents felt these skills had already been achieved.

“We are no longer separate and working together, but one. It is important to sustain this.”

Most comments about CCHE were extremely positive and reflect long-term relationships with many of the respondents’ organizations. Complimentary comments were made specifically about several CCHE staff. The respondents recognize the complexity of their relationship with university-based academic partners, in that there are usually many people with whom they interact, and that having a single contact person helps to coordinate communication and reduce redundancy. The word “communication” was often used, indicating a high value on open, frequent, honest and face-to-face interaction. Many comments were made about the need for academic researchers to physically come to the communities with whom they’re collaborating, attend meetings, get to know people, and to be sincere and committed over the long term. High quality communication is important in order to build trusting relationships and establish the sincerity of intent to maintain long-term collaborative partnerships. Time for reflection is also important in order to be able to identify changes that might be needed in implementing research plans.

Respondents recognized that difficulties will come up, but stated that compromises can and do emerge when everyone involved is able to respectfully work through the issues and come to consensus about solutions. One potential problem mentioned concerned the issue of “who owns the data.” The respondent who mentioned this stated that “when working with Tribal community partners, make sure the academic partner knows that the Tribe owns the data.”

Respondents also noted that video-conferencing and email only work well as communication technologies with community-based collaborators when supplemented by a considerable amount of in person face time. Several respondents commented that academics need to understand that community collaborators may be less “tech-savvy” as people from the University. Spending time traveling out to collaborating communities, meeting them on their own terms, will likely result in better working relationships over the long term. Academics try to manage their time by using technological supports, truncating interactions, or speeding up meetings, but these coping strategies are not always perceived in favorable ways by community-based partners. The descriptions of what makes partnerships work involve basic human interaction characteristics of equality, respect, trust, flexibility, and sensitivity, as well as negotiation on key issues such as data ownership.

Several respondents mentioned the need to agree about a variety of issues confronting research partners, including the priority goals and objectives of the undertaking, along with having a specific scope of work. Some respondents specifically mentioned areas of need for technical assistance including several references to program evaluation, help with media, graphic arts, technical skills, and a videographer.
Theme 2: “Make Time for Us” – Timely interaction and dissemination of information

Respondents were asked if there were things CCHE staff could do to improve, grow or strengthen the partnership. An additional question asked if the respondent thought there were things the community organization could do to strengthen collaboration. Tying in with Theme 1, some respondents mentioned wanting to see community-academic partners as equals and the need for academic partners to appreciate the levels of sophistication of their collaborators. These comments suggest that perhaps the respondents felt that some of their University collaborators did not yet completely view their community-based colleagues as equal partners in the research process, or in some cases the academics were surprised at the level of sophistication among community staff.

Several comments were made about a variety of human resources available to community projects, including:

- Maintain consistency and continuity of staff and commitment in time and effort;
- Improve project management with appropriate staff;
- Clarify roles of ambassadors;
- When staff have to change, be vigilant about transitions and communication;
- Get deans to come to communities;
- Show us an organizational chart to describe the relationship between CCHE, ICTR, SMPH, and other UW schools/colleges
- Recognize necessary skill levels required for studies and get the right people;
- Important to train academics before they try to engage a community partner; needs to be action learning; “culture is how we live, learn and communicate” not just language or dress; they [academics] have “culture” too.

Since these comments appear under a question about ways to improve, one might assume that the respondents felt that sometimes their interactions with their academic colleagues were not ideal. The need for consistency, clarity, communication, commitment, continuity, vigilance, and treating collaborators as equals emerged in the discourse in response to this question. The reference to wanting to see an organizational chart for university programs, institutes and schools suggests that the complexity of the University environment is recognized by community-based collaborators and clarity about these relationships would be appreciated. Respondents mentioned cultural differences, the need to bridge them, to appreciate what culture really means, and to recognize that everyone (including academic partners and the UW) “has culture.”

Several respondents mentioned a need to do more “showcasing” to communities and other entities about research partnerships, accomplishments, and findings – to share with others who are not directly part of the projects, what the partnership is doing in the community, and to market UW initiatives in the region via showcasing efforts. In line with dissemination of findings, is the critique from one respondent that there was too much lag time between data collection and dissemination, and from another, that it was important to work together to develop outcomes. Another participant mentioned that there needed to be more timely reimbursement when costs associated with a project were expensed by the community. The success of partnerships occurs on a continuum, so that many of the positive characteristics identified by the respondents were in fact goals that had not been completely met by the academic research partners.

Respondents talked very specifically about things that they themselves could do to strengthen partnerships. They spoke about program evaluation – learning how to do process evaluation and to articulate more clearly their strategy, priorities and direction. They felt they could do a better job connecting students, faculty and staff with Native American
Indian (NAI) students, and in bringing the “right people” to the table. One respondent recognized the danger in depending too much on the skills of a single person who functions well as an organizer, and another lamented the turnover in staff, and a lack of thorough transition between staff. Respondents also mentioned many organizational management skills for implementing effective community-academic partnerships in answer to these questions, seeming to demonstrate a fair degree of sophistication around issues related to development of effective partnerships.

Theme 3: Strength and power in unity: Partnerships with CCHE “give us clout”

Two questions focused on bi-directional benefits from the perspective of the community-based partners: how does the community benefit from the partnerships with CCHE and how does the community think that CCHE benefits from the community partnership? Mutual benefit might be summed up by the idea of “helping the academics do their jobs well” along with capacity-building in the community, and in general, mutual learning. There seemed to be an astute recognition of the skills that academic researchers can bring to communities, including helping to sort out data, find information, generate scientific information that supports anecdotal data, develop effective interventions, and understand health status data and how to use that data to address issues. Community collaborators felt that there had already been actual direct health benefits from interactions with their academic partners in the process of determining ways to intervene to improve health.

Community perceptions of benefits from academic partnerships were very specific about actual health benefits from mobilizing communities around health issues; help with specific needed skills in data management and how to run studies; training in time management, communications and how to set priorities; simply bringing people together around health issues; mentoring opportunities for NAI students going to Madison. Many mentioned the value of the Community Advisory Board (CAB) in terms of bringing people together and getting people involved in brainstorming health-related problems and solutions. Another respondent said that partnering with CCHE “gives us clout” in the sense of helping to attract resources/funding, and prioritizing how to allocate resources.

Although one respondent said, “We have a very good partnership; they are good people” another one mentioned that “some learned, some did not” when the opportunity arose for academic researchers to work with and learn from other cultures. Specific benefits of partnering with CCHE (from the perspective of community partners) included helping CCHE implement the annual Health Equity Leadership Institute; helping them fulfill their role of training scholars; building their reputations for working in Indian Country; and making additional connections by providing entrée to new communities.

Additionally, respondents proudly spoke of what they feel they do well within the context of their partnership with CCHE and their brokering role between the University and communities in need.

• “We are straightforward in our communication with them.”
• “We communicate consistently and clearly... we are clear on roles and responsibilities.”
• “We help the academic partner look good.”
• “We are a patient, friendly environment for an academic partner to learn in.”
• “We work for a purpose, not just a paycheck.”
• “We are a positive, moving force.”

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1 Weeklong ‘research bootcamp’ for health equity scholars (post doctoral and MDs) from across the country who come to Madison and Milwaukee to learn about CCHE and UW health equity research and career development infrastructure operates
Believing that “the community owns the project”, the respondents feel they are flexible in finding ways to meet objectives; that they understand the larger context within which research is conducted, that they are able to provide good information, identify good staff, be accountable, and help with subject recruitment. Respondents seem to perceive that many of the characteristics of good partnerships are the things they are already doing well in working with CCHE staff.

Discussion

For the Collaborative Center for Health Equity (CCHE) to meet its stated mission to be an organization that builds lasting partnerships and engages university and community partners in collaborative teaching, research, and service initiatives to improve health equity in underserved communities of Wisconsin, outreach efforts such as those described in this paper to clearly elucidate the “voice” of community partners are essential. Indeed, as a “core center” within the larger Institute for Clinical and Translational Research here at the University of Wisconsin and the national network of Clinical and Translational Sciences Award programs, CCHE should be mindful of the recommendations of the IOM to “Ensure community engagement in all phases of research” and to the CTSA’s Community Engagement Committee’s identification of a best practice that “puts the community and its priorities first, not last.”

Understanding the perspective of community partners is vital for those engaged in growing strong, sustained, and mutually beneficial community-academic partnerships and the efforts described here should constitute only the first of an ongoing program of dialogue with community partners. While every partnership that CCHE is involved in is unique, the key themes identified here should be carefully considered and strategies based on the themes and the underlying data should be crafted to strengthen current and future CCHE-community partnerships.

The fact that interviewees expressed appreciation that the CCHE initiated this effort to gather input on the functioning of the partnerships along with the many positive comments regarding their experience should be encouraging to the CCHE staff and should act as a catalyst to even greater efforts to assure open, honest and consistent communication and renewed commitment to dissemination of information to partners.
## Appendix A

### Table 1: Summaries of responses by question

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<th>Question</th>
<th>Responses</th>
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<tr>
<td><strong>1. In general, what makes community/academic partnerships work well?</strong></td>
<td>• build trust through long term commitment and investment in working together as partners for effecting change&lt;br&gt;• the academic partner evidences a sincere interest and concern about the community and their needs&lt;br&gt;• academic partner has a physical presence and “face time” in the community&lt;br&gt;• the partnership accomplishes what they set out to do&lt;br&gt;• each partner brings their unique skills, strengths and resources to the table&lt;br&gt;• clear and common understanding of expectations, roles and responsibilities&lt;br&gt;• clear and consistent communication&lt;br&gt;• each partner demonstrates flexibility, willingness to compromise adapt, and a commitment to work through and resolve differences as partners&lt;br&gt;• the academic partner sees the community partner as an equal and acts accordingly&lt;br&gt;• establish mutual benefit; the efforts have to be a win-win for the academic partner and the community partner&lt;br&gt;• continuous reflection and learning, making changes as needed and learning together</td>
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<td><strong>2. What types of projects have CCHE staff worked with you/your community on?</strong></td>
<td>• Healthy Activities Partnership Program for Youth (HAPPY) research project&lt;br&gt;• cervical and breast cancer screenings&lt;br&gt;• men’s wellness council&lt;br&gt;• community research council&lt;br&gt;• wellness commons&lt;br&gt;• research ambassadors as part of NIMHD P60 Center of Excellence infrastructure&lt;br&gt;• RC4 application to NIH&lt;br&gt;• shared knowledge, and sharing knowledge in an intentional way&lt;br&gt;• CCHE Advisory Board&lt;br&gt;• Native American Research Centers for Health and internships for Native American Indian (NAI) students&lt;br&gt;• UW Indigenous Health and Wellness Day&lt;br&gt;• Healthy Children, Strong Families research project&lt;br&gt;• WPP Medical Education and Research Committee (MERC) grant, focused on children’s nutrition and physical activity&lt;br&gt;• WI Nutrition and Growth Study&lt;br&gt;• SUNWEAVERS/Vitamin D and cardiac health research study</td>
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<td><strong>3. In what ways do you think partnerships with CCHE work well? Why?</strong></td>
<td>CCHE: &lt;br&gt;• demonstrates commitment and investment in relationship with our community and needs&lt;br&gt;• demonstrates understanding of community issues&lt;br&gt;• demonstrates trustworthiness&lt;br&gt;• demonstrates mutual respect&lt;br&gt;• communicates and organizes effectively, using a point of contact person&lt;br&gt;• demonstrates cultural sensitivity&lt;br&gt;• offers support in locating needed resources&lt;br&gt;• shares our vision and values&lt;br&gt;• demonstrates flexibility, and ability to work together constructively to resolve problems</td>
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<td><strong>4. Are there things CCHE staff</strong></td>
<td>• increase face time in the community&lt;br&gt;• consistency and continuity of staff working with the community</td>
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| could do to improve, grow or strengthen partnerships with you?          | • anticipate and communicate about transitions  
• continue building community capacity so efforts can be sustained  
• increase amount and scope of involvement in the community  
• clarify roles of staff working on-site in the community  
• increase attention on showcasing our joint efforts  
• increase effort to manage timely communication to larger community about efforts and results  
• increase efforts to aid in securing resources or access to resources for the community                                                                                                                   |

| 6. How do you/your larger community benefit from your partnerships with CCHE? | Our community:  
• gets data and information that help direct and prioritize our health efforts  
• gets opportunities to build skills and knowledge in evidence-based practices, and in project planning, project management and evaluation  
• has a more positive perception about being involved in academic efforts  
• has become more engaged and invested in community health efforts  
• has built connections both within the community and between our community and those outside of the community  
• has increased visibility, credibility and clout  
• is better able to attract needed resources  
• receives important health information and services resulting in health benefits                                                                                     |

| 6. How do you think CCHE benefits from partnering with you?               | CCHE:  
• gains access to our community residents for study participation and resultant data  
• gains experience with communities and cultures  
• gains experience in being a good academic partner to a community with its layered complexity  
• gains increased visibility, credibility, clout and connections  
• accomplishes their objectives when working with a strong community partner                                                                                           |

| 7. What things do you think your community does well in terms of being a partner to CCHE | • demonstrate commitment and accountability to our partnership and to learning together  
• provide/allocate resources to joint projects, including our resources, time and expertise  
• fulfill our work tasks and responsibilities  
• promote connections, and help them gain access to community  
• promote and encourage community interest and involvement with them and with our joint projects  
• provide a patient, friendly environment in which to help them learn about our community and how to successfully work in it  
• practice good partnering skills, including initiative, communication and flexibility                                                                                                         |

| 8. Are there things you think your community could do to grow, strengthen, or improve your partnership with CCHE? | • learn more about CCHE and their needs and expectations  
• gain more clarity about our own needs, direction and priorities  
• continue to encourage the involvement of the community members for needed input and support  
• help them showcase our joint efforts                                                                                                                                      |

| 9. Is there anything that we | • we’ve been pleased.  
• I consider them partners and friends. We have a very good relationship, they are good people                                                                 |
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| haven’t covered that you think is important to add? | • I cherish working with three specific CCHE staff. We’ve reached a tipping point where partnership moves to oneness...we are no longer separate and working together, but one. It is important to sustain this  
• We are grateful we are able to work together; we need the experience and expertise that scientists have so we can develop good intervention projects/programs.  
• Thank you for undertaking the interviews to get feedback from community partners, doing this kind of a check-in.  
• This interview exercise stimulates thoughts and may give our collaboration/partnership new ideas or directions.  
• It’s important to provide more education/training to researchers on community/academic partnerships, before they try to engage in one, and during; they need to become more aware of what partnership really means. I know there are books, conferences, etc. on community/academic partnerships...but it is the “choir” who are usually the ones taking advantage of these, and the others who really need to be schooled. And, learning about communities and being an academic partner with a community needs to be action learning, not just modules taken in a classroom.  
• Academics need to learn more about what “culture” entails (including their own), that it is not just language or dress; culture is how we live, learn, and communicate.  
• It would be useful to see an organizational chart that shows the relationship between ICTR, CCHE, UW School of Medicine and Public Health, and the School of Human Ecology.  
• The role that specific CCHE staff member plays (investing a lot of time, on the ground, physical presence, resource finder and connector) is critical.  
• It would be very helpful if CCHE could offer resources to help us with very specific skill sets, like evaluation, media, graphic arts, technical skills, videographer, etc.  
• Showcase our partnership and accomplishments more, both in Indian Country and at UW Madison and other academic settings, e.g., publications, presentations.  
• if specific CCHE staff person is interested in talking with the Tribal Health Director’s Association about expanding relationships with other tribes, specific Tribal Health Director Association member would be willing to help her get on their agenda.  
• CAB has been very good and very effective, a tool to get people involved in a way that is now specific to just one concern or another. It’s sad to say, but I truly believe that if specific person wasn’t facilitating, the CAB would not continue to keep going. |

References


