Keeping the Promise of Community-Based Participatory Research: Integrating Applied Critical Rhetorical Methods to Amplify the Community's Voice for Trial Development

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Abstract

Community-based participatory research (CBPR) represents an important improvement in the integration of marginalized voices into research programs by including community members in the designs, conduct, and dissemination of studies. CBPR often features a social justice component, generating studies designed to reduce societal disparities and improve outcomes for disenfranchised groups. However, the practical implementation of CBPR usually fails to capitalize on this promise, using the same traditional research methodologies, leadership structures, trial designs, and research questions that inculcate researcher bias. In response to the problem, we propose a new solution: Applied critical rhetorical research (ACRR) integrated into the CBPR approach to clinical health research. ACRR research combines critical/cultural studies and rhetorical methods to amplify the figurative voice of marginalized populations. ACRR can expose how majority power (i.e., hegemony) manifests in social institutions like healthcare and government, where its meanings and subjectivities are absorbed. ACRR analyses enhance CBPR by shaping research in directions that reduce stigma, unintended disenfranchisement, and culturally bound bias, increasing the yield from CBPR for researchers and the community.

Introduction

"…health education must start where the people are…" (SOPHE Annual Report, 2016, p. 2).

The shift from work *on* communities to work *with* communities is a critical move in modern research, and a deep integration of community members in the research enterprise has emerged as a central component of ethical research. At the core of health promotion is the ideal that communities guide what work is conducted on their behalf. This belief has long been a part of health promotion's culture and assists in producing greater health equity by augmenting the voice of the disempowered (LeBonte, 1994; Syme, 2004; Ubbes, Black, & Ausherman, 1999). This ideal is also a core value of community-based participatory research (CBPR), which is popular in health promotion because it requires deep engagement with the community (Minkler, Vasquez, Warner, Steussey, & Facente, 2006; Wallerstein & Duran, 2006). CBPR has proliferated across academic disciplines and takes many forms across those domains. Specific to health fields, CBPR often leads to randomized controlled trials (RCTs), which can be more compelling than other studies by virtue of rigorous comparisons that manage random error. However, RCTs have limitations that can cause them to be incompatible with CBPR

principles. We propose applied critical rhetoric as an additional level of analysis to make the process and results of RCTs more compatible with CBPR work and consistent with the ideals of health promotion, health equity, and education practice. ACRR combines critical/cultural studies and rhetorical methods to hear, record, and amplify the figurative voice of the marginalized (Riffin, Kenien, Ghesquiere, Dorime, Villaneuva, Gardner, Callihan, Capezuti, & Reid, 2016). For example, an ACRR analysis of a healthcare provider's office accessibility for transgender persons would seek to understand physical barriers to care (e.g., gendered bathrooms), historical issues and their manifestations (e.g., intake forms requiring a binary sex choice and legal names), influence of hegemonic orderings of normalcy (e.g., attitudes of personnel that are stigmatizing that could manifest in deadnaming, misgendering, etc.), or performative rituals creating discord (e.g., check in, biometric data collection, etc.). Additionally, ACRR analysis links outward to cultural understandings of the constructs of study, which, as described below, are generated by the community and then analyzed to demonstrate the impact of how these cultural understandings shape social realities. As a result, ACRR offers a promising method for capitalizing better on the engagement

of the community and improving the results from health-based CBPR research programs due to the additional understandings of potential pitfalls that can then be accounted for in the trial results.

RCTs persist as the gold standard in health research, yet it is a culturally bound tool that is prone to vulnerabilities, particularly the subjectivities of researchers (Christ, 2014). Although changing, most research is conducted from a narrow perspective—that of the researchers—disproportionately representing coastal urban centers and economically advantaged white men. The negative impacts of this bias are seen in low minority representation in trial research that restricts the benefits of findings. Moreover, the U.S. research enterprise has been exported to the rest of the world and is now the predominant cross-cultural approach to conducting human research. Efforts to reduce the negative impacts of this homogenous viewpoint target systems (e.g., the compulsory inclusion of women, children, etc.), methodologies (e.g., a trend toward mixed methods designs), and both (e.g., the push for patient-centered outcomes research). CBPR approaches leading to RCTs have emerged as one of these efforts, integrating community members into the research process. However, nominal CBPR research often fails the test of CBPR, attaining only community engagement, which can reduce the community to half-partners in service to the investigators' agenda. Consequently, most health research maintains the status quo, filtering the voices of the marginalized and maintaining their disempowerment and distance from the cultural products and benefits of research.

Bridging this communication divide necessitates the deliberate inclusion of the empowered voice of the community. Previously, we demonstrated how ACRR can lead to concrete public health communication recommendations. In Mocarski and Bissell (2016), the popular television program "The Biggest Loser" was analyzed through an ACRR method that utilized the lens of social cognitive theory. This analysis demonstrated the ways in which the program relied on hegemonic and stereotypical understandings of obesity and weight loss. The researchers demonstrated that ACRR analysis offered multiple pathways to incorporate the show into health education programs. This critical reading helped practitioners avoid reinforcing the stereotypes the show relies on, instead utilizing these understandings as opportunities for client education. By incorporating popular culture into

health education work, we argued, practitioners risk perpetuating stigmatizing stereotypes. In contrast, we contended that rhetorical analysis allows the use of popular culture in programs while guiding the generation of pragmatic health messaging recommendations. As we will present here, a compelling application of ACRR arises with transgender and gender diverse (TGD) people, whose experiences vary tremendously from urban coastal centers like San Francisco, where they have free full-service care centers, to rural towns in Middle America, where the most basic care may be hours away. This cultural variation carries significant consequences for TGD people seeking healthcare, where patient-provider communication is critical to effective care (Beach, Sugarman, Johnson, Arbelaez, Duggan, & Cooper, 2005). To address this problem directly and to demonstrate how it might be extended to similar populations, we describe how CBPR may be elaborated through the integration of ACRR into clinical health research and how this positions RCTs to be community guided and responsive.

CBPR Foundations

Arising from an international movement for greater attentiveness to patients in health research, CBPR is a growing research approach in health disciplines, which increasingly value and emphasize patient centeredness in the design of RCTs (Locklear, Flynn, & Weinfurt, 2016; Wallerstein & Duran, 2006). When used as a framework, it often features patient-centered outcomes research (Las Nueces, Hacker, DiGirolamo, & Hicks, 2012). Together, these approaches provide a coherent, multifaceted methodology for refocusing traditional research by integrating community members into the design, conduct, and dissemination of studies (Las Nueces et al., 2012). CBPR grounds research in communities by including community members on the research team at every stage of the project and by employing qualitative or mixed methods approaches to integrate the community's voice (Israel, Schulz, Parker, & Becker, 1998). Broadly, the core principles of CBPR cast community as a unique identity with distinct strengths and resources that can contribute meaningfully to collaborative partnerships across the research enterprise; view the process as cyclical and iterative, integrating knowledge and action to address health from both positive and ecological perspectives for the mutual benefit of partners at all phases, including dissemination; and describes partnering as a co-learning and empowering process that

attends to social inequalities (for a good example, see detroiturc.org.) Products of this partnership are shown in Table 1 and include greater research relevance and applicability to the community, higher quality results and interpretations, and better understanding of the community being studied (Viswanathan, Ammerman, Eng, Garlehner, Lohr, Griffith, Rhodes, Samuel-Hodge, Maty, Lux, Webb, Sutton, Swinson, Jackman, & Whitener, 2004).

However, most CBPR-aimed research falls substantively short of full community integration and utilizes many of the same traditional elements that infuse trials with the unconscious biases of researchers (Rucinski, Davis, Gomez, Flores, Perez, & Zanoni, 2011). Principal among these are its habitual reliance on enfranchised researchers to operate as de facto leaders of research teams who operate without real checks on their biases in the design and implementation of the study or interpretation of the results. Such failings are often side effects of the power given to academic leads by society and their lack of true connection to the communities, such as the limited engagement with community partners, the value of academic leads

due to research expertise, and results reported primarily to satisfy academic expectations. Similarly, although CBPR often features a social justice component and may produce studies designed to reduce societal disparities and improve outcomes for disenfranchised groups, CBPR rarely integrates the methodologies of critical analysis beyond the reflexivity inherent to qualitative approaches. As a result, the implementation of CBPR usually fails to address social justice concerns directly, focusing instead on generalizable results of interest to external researchers and natural to controlled research designs. Thus, although CBPR presents a number of strengths, it also carries noteworthy limitations, and large deficits remain in the ability of CBPR to achieve its promise.

ACRR Foundations

The adoption ACRR as another level of analysis in project design is a response to some of the caution toward CBPR approaches expressed by health promotion researchers (Robertson & Minkler, 1994). ACRR directly responds to Minkler's call for trust and reflection (Minkler, Vasquez, Tajik, & Peterson, 2008) and harkens to calls for greater interdisciplinary integration in health research. The cultural, critical, and rhetorical (CCR) tradition sits at the intersection of Rhetorical Studies and Cultural Studies (Rosteck, 1999a). ACRR represents a pragmatic CCR approach useful for integration into studies with human subjects to analyze how discourse influences and creates shared meaning. Discourse is defined as any communication available for analysis— from qualitative interviews, to institutional documents, to television shows, to performances (both formal, such as a play, and informal, such as the embodiment of gender), to social media,

Table 1. Areas of CBPR enhancement through the integration of ACRR

Problems in Clinical Trials	CBPR Solutions	ACR Solutions
Lack of external and ecological validity (Persons & Silberschatz, 1998)	Engages stakeholders like community providers and clinics to enrich pragmatic value of trials	Engages referent discourses linking data from participants to larger contextual and societal inputs
Strict and narrow inclusion criteria (Silva et al., 2011)	Works alongside the community to establish who is in the most need and what characteristics are most important in setting selection criteria	Identifies who is silenced or left-out given the research questions and design
Lack of trust (Swartz et al., 2004)	Creates a Community Advisory Board (CAB) to integrate the community into the research at all phases	Invokes reflexivity in analyses to identify, reveal, and address biases from the researchers
Recruitment and retention (Magruder et al., 2009)	Integrates community gatekeepers into the research, facilitating recruitment, maximizing visibility, and integrating participants as equal collaborators	Records and amplifies the community's voice, uncovering elements that distance participants from engagement
Masking of clinical decision-making (Persons & Silberschatz, 1998)	Integrates providers on the team and collects provider data about clinical judgments and decision making	Engages in deep analysis of routines and processes to expose potential and actual biases

to cultural norms (Rosteck, 1999b). Discourses are dynamic, temporal, and grounded in context (Marks, Reed, Colby, & Ibrahim, 2004). The choice of discourses studied and methods of study are entwined with the analysis and argument (McKerrow, 1989). This core reflexivity makes ACRR a powerful tool for CBPR-based research, especially in studies of disenfranchised groups. The use of ACRR allows for an examination of the ways that cultural norms operate in relation to the disenfranchisement and to study the impacts of study construction.

A primary assumption of ACRR is that hegemony is an important force when it comes to the crafting and sustaining of meaning. Here, hegemony is understood to be the willing submission of society to dominant meanings and subjectivities (Zompetti, 1997). This is not done through coercion or overt force, but rather, power is enacted through inculcation into culture, which leaves the subjects of power not only under the control of power, but also desiring the codes and rules of power that keep them under its rules (Smart, 1986). That is, power manifests in social and cultural institutions (e.g., family, healthcare, capitalism, religion, gender relations) and their rules that perpetuate the dominant way of thinking as the standard (Cloud, 1996). We learn these rules as we grow, both implicitly through cultural norms and explicitly through educational institutions (Cloud, 1996). Thus, because we implicitly and explicitly desire the rewards of these systems, we abide by their rules and discipline those who break them (Cloud, 1996). As opposed to traditional health research, the means by which hegemonic forces are perpetuated, propagated, and wielded are central targets of ACRR. Thus, ACRR analysis offers a method to identify and reveal areas where hegemonic power acts in and on the community and clinical trial. The analysis seeks to answer questions such as why the stakeholders are who they are, what voices have been silenced, what the contextual factors are that present problems for the community, and what factors drove the choice of research questions (see Table 1).

Integration of ACRR and CBPR

As described above, engagement with the community is the central element of CBPR. Often, CBPR incorporates the use of mixed methods research, including both quantitative and qualitative components, in the development of RCTs. As opposed to quantitative research that employs closed-ended questions, qualitative research features open-ended questions to capitalize on the experience of participants. However, the products of most mixed methods qualitative processes are still instrumental by design, focused on arriving at answers to specific research questions derived from the particular viewpoint of the researcher (e.g., short-answer and structured interviews).

ACRR offers an innovative avenue for expanding the benefits from CBPR. Using techniques that render the implicit explicit, ACRR analyses can enhance the products of CBPR with in-depth data on cultural phenomenon acting on the research, the development of a trial, and wider culture. It can recast research in ways that reduce stigma, unintended disenfranchisement, and culturally bound bias, whatever the source. In addition, through the integration of ACRR to CBPR, researchers and health professionals will be empowered to check and reduce their own biases. This shift alone should improve the internal and external validity, participant retention, and community member engagement with a trial, among other benefits. To illustrate the value of combining ACRR methods into CBPR research with disenfranchised communities, we will briefly outline the role of ACRR in one of our current projects.

Trans Collaborations (TC). In partnership with the Central Great Plains TGD community and TGD-friendly mental health practitioner community, we are conducting a multi-site mixed methods study to develop principles of TGD-affirming mental health care. TC was founded in late 2014 by Debra Hope, professor of clinical psychology, Richard Mocarski, assistant professor of communication studies, and Nathan Woodruff, community TGD advocate. The overarching and generative goal of TC is to reduce the health and social disparities facing the TGD population. Societal stigma against TGD people exerts marginalization stress that may have significant physical and mental health consequences, especially if social support, coping, and other resiliency buffers are unavailable. Although many TGD people live healthy and productive lives, TGD communities nevertheless experience elevated rates of anxiety, depression, and suicidality; elevated rates of drug and alcohol abuse; and societal threats including homelessness, refusal of healthcare, and violence (Bockting, Minor, Swinburne Romine, Hamilton, & Coleman, 2013; Haas, Eliason, Mays, Mathy, Cochrane,

D'Augelli, Silverman, Fisher, Hughes, Rosario, Russell, Malley, Reed, Litts, Haller, Sell, Remasedi, Bradford, Beautrais, Brown, Diamond, Friedman, Garofalo, Turner, Hollibaugh, & Clayton, 2011; Lombarid, 2001).

CBPR foundation and research trajectory. The founding members first established a working relationship over several meetings, where common goals and the structure for TC were agreed upon. Then the group recruited a local board made up of five TGD community members and a national board made up of six academic researchers who had experience working with the TGD community or had methodological expertise (both of which have increased their numbers to six and seven, respectively). The local board is run by the founding community partner and meets at least quarterly. This board sets the research agenda for TC and screens all materials generated by the academic side, including measures, manuscripts, grants, and potential collaborators. The national board meets annually in conjunction with one of the community board meetings and contributes expertise to all products and future research plans.

With the overarching goal in mind, the local board and core investigators met in early 2015 to set the research trajectory. This initial meeting set the course for the first prong of research: To create evidence-based guidelines for TGD-affirming behavioral healthcare professionals. The goal was to train providers "with good hearts but no brains," as eloquently stated by our community co-founder. Our board echoed this sentiment with stories of their own healthcare where, in order to gain adequate care, they provided their healthcare professionals with books and other resources about TGD medical care. These experiences, where the patient trains the provider, were refreshing in juxtaposition to the many stories about being denied care from other providers. Two later prongs of this research feature strong community engagement, the backbone of TC. The second prong focuses on the community, developing workshops to increase patient self-efficacy through narrative medicine and leadership techniques. The third prong aims at promoting evidence-based policy, investigating current policies of the region and mechanisms whereby they impact training in healthcare, cultural acceptance in the region, and available services. The outreach agenda now includes an annual, grant-funded (participant costs covered) camp for TGD youth and their families, community talk-backs, involvement in community

fundraisers, and more. In short, the CBPR program described here has led to multiple prongs of research ready for trials as the community and our community board continue to steer TC toward impactful, highly salient efforts to improve the lives of the TGD community in our region.

Evidence-based principles of care project design. To create evidence-based guidelines for TGD-affirming behavioral healthcare, TC designed an iterative multi-step mixed methods community-based project. First, 27 regional TGD community members and 10 TGD-affirming behavioral health providers (as identified by our community) were interviewed. These interviews were then transcribed and analyzed utilizing a parallel process that featured a traditional qualitative analysis from a grounded-theory perspective and the ACRR analysis. Two senior research team members analyzed the interview data following a grounded-theory methodology, but stopped short of select coding. In other words, first and axial-level coding were completed and reported to key constituents with the select coding process postponed due to the pragmatic nature of the study. Results from these analyses had significant overlap. Interviews and transcription were conducted by other members of the team, but the researcher who analyzed the data was instrumental in the design of the interviews. Thematic saturation was reached after the full coding of 16 interviews utilizing a constant comparison technique; however, all 27 were coded. The co-founding community partner reviewed and discussed all transcripts and analyses with the research team. An executive summary was then produced and presented to the community board for comment. The board helped to flesh out codes and situate the findings to the realities of the region. This process was conducted at both the first and axial coding levels.

Results from the qualitative analysis included findings that demonstrated TGD patients have unmet expectations in healthcare situations (Meyer, Mocarski, Holt, Hope, King, & Woodruff 2019), that cultural milieu creates both barriers to fair treatment and a shared language to create fair treatment in the community that provider training is lacking even in those providers who are allies of the community (Holt, Hope, Mocarski, Meyer, King, and Woodruff, 2018), and that the process of gender confirmation is varied and unique to the individual and can often include choices that reify societal expectations (Hope, Mocarski, Bautista, & Holt, 2016). Furthermore, the results led to a

number of products for the community, including a progress monitoring clinical scale for behavioral healthcare specific to gender comfort (Holt, Huit, Shulman, Meza, Smyth, Woodruff, Mocarski, Puckett, & Hope, 2019), the development of an advocacy workshop for the community, and the principles of TGD-affirming care we aim to test in RCTs.

Applied critical rhetoric research. The second level of analysis engaged ACRR to illuminate cultural influences on the project. Participants in the study referred to cultural artifacts for a number of reasons, including as examples of their own lives, as sources of frustration, and as sources of joy and connection. These referenced discourses were then subjected to a critical rhetorical analysis following McKerrow's (1989) methodology. Critical rhetoric is generally conducted on static artifacts, such as television shows, presidential speeches, and memorials, within a static temporal frame. By incorporating this type of analysis into a qualitative inquiry, we applied critical rhetoric to a pragmatic use, branding the process as Applied Critical Rhetoric Research (ACRR). ACRR analysis was conducted by Mocarski, who also conducted the qualitative analysis. The ACRR analysis blended qualitative data with referent cultural artifacts, both those emerging from the interview and related to these initial discourses. Relevant referred to discourses for inclusion and analysis in this project included movies, television shows, articles, cultural norms, celebrities, and local policies. The ACRR analysis produced a context-based taxonomy of stigma. The taxonomy consisted of a rhetorical genealogy, or web of words, images, constructs, and descriptions that came from the data and linked outward to referenced cultural discourses. It catalogued stigmatizing and destigmatizing language as it existed around TGD healthcare, grounding the specific lived experience of study patients, providers, and advocates in a greater cultural context.

The results of the ACRR analysis highlight the unseen aspects of the lives of TGD people that contribute to barriers to treatment, such as the pervasive stereotypes crafted and reinforced through media and the array of microaggressions experienced in the behavioral healthcare environment (Galupo, Henise, & Davis, 2014). Furthermore, the ACRR analysis exposed the chasm between the cultural gender norms of rural TGD people in the Central Great Plains and the expected norms held by board members and collaborators from urban, coastal centers, where

most of the nation's transgender surgical services are provided. Thus, ACRR informed our practice guidelines by amplifying the voice of TGD people to shape the mental health services they receive and by pushing back against the hegemony of society in defining to them what is appropriate care. Results from this analysis are reported elsewhere (as noted previously), but following we demonstrate how these findings have informed the trial that we are currently conducting, making our trial more relevant and responsive to the community.

Trial preparation and ACRR influence. At the current stage, TC is finalizing the development of an RCTs to demonstrate the value of integrating our principles of TGD-affirming care into standard behavioral healthcare treatment. Specifically, we are applying our principles to transdiagnostic evidence-based treatment for anxiety and depression (Norton, 2012). The ACRR analysis has served as a critical guide to shape an affirming trial design in three areas: the use of audiovisual exemplars of affirming versus stigmatizing behavioral healthcare to reduce potential risk to participants, the protection against creative misappropriation of the TGD experience, and education to disentangle sex, gender, and sexual orientation.

In the preparation of this trial, we are first measuring the impact of the principles of care through the creation of three sets of staged videos representing segments of Norton's treatment approach. Each set will include five key segments from the treatment with either adaptations based on our Principles of Care, treatment as usual with no adaptations, and treatment that includes common stigmatizing experiences arising from our qualitative interviews with the TGD communities. Given the difficulty in evaluating complex behaviors, this approach will facilitate an explicit test to demonstrate that there is a difference between "neutral" treatment and TGD-affirming care. The stigmatizing experimental condition is included to ensure that our "treatment as usual" condition is not explicitly stigmatizing. Members of the TGD community will view the videos and provide qualitative and quantitative feedback on the appropriateness of our adapted treatment approach. This is a key step to amplify community voices about whether the treatment is logical, acceptable, and affirming. After review, these videos will serve as potent training materials that model the complex task of maximizing positive and minimizing negative phenomena associated with behavioral healthcare with TGD people.

The ACRR analysis informed this process in critical ways. First, it described the problematic media pattern of appropriation of the marginalized TGD position in that it uses cisgender perspectives and persons to tell TGD stories instead of TGD actors playing the TGD characters in television and movie productions. In response to this issue, our hired actors for the client role are from the TGD community. Second, the decision to use videos rather than having participants engage with providers in an actual or mock session responds to both scientific and ethical concerns, the latter of which also has some roots in the ACRR analysis. Scientifically, the videos will allow greater experimental control by presenting a standard stimulus across participants. In addition, we determined that it is not justifiable to subject TGD participants to an intentionally stigmatizing experience, even in a mock session, given that it could remind participants of actual experiences and could reduce the likelihood they would seek needed services in the future. The ACRR analysis demonstrated that TGD persons are subjected to repeated exposures to microaggressions in mediated messages. These messages, coupled with the qualitative data that demonstrated the prevalence of this type of treatment in TGD persons' everyday life, made a live experiment unnecessarily stressful for participants. Although we are aware that the videos with negative or neutral portrayals mirror such mediated content and present risks of negative reactions, the ability to stop the videos during the process should a participant's distress become too high is a protection against this risk. Furthermore, our debriefing plan includes viewing the affirming video segments to help reinforce the need for the guidelines and, thus, the trial.

One other significant finding from the ACRR was that mediated messages reify the conflation of sex, gender, and sexual orientation. This reification is often also propagated and implemented by health providers. We have incorporated this finding into the principles by specifically addressing the distinctions between these constructs. Furthermore, our principles clarify sexuality dimensions and specifically correct false assumptions about sexuality and the TGD community. In our RCTs, we have measures that deal with culture and its impacts, as well as the impact of cultural understandings of sex, gender, and sexual orientation. While it is not possible to parse out every way that the ACRR influenced the RCTs design, these examples demonstrate the reflexive value of adding this type of analysis to any project through concrete implementations of its results.

Conclusion

Many social injustices within the current healthcare system are well-documented, from hospitals that refuse care to individuals with insufficient financial resources to emergency rooms that serve as primary care for large swaths of the population. These widely acknowledged problems produce an unequal burden of clear negative consequences for many marginalized groups based on gender, race, sexuality, and socioeconomic status. This is known in part because of community-engaged research approaches, such as community-based participatory research, that amplify the influence of marginalized population on research. However, current implementations of community-engaged research—particularly clinical trials—often fail to counteract this marginalization effectively due to pragmatic influences that reestablish traditional power structures. Furthermore, healthcare research has been largely isolated from the scrutiny of critical theory approaches that could highlight the cultural factors driving and expressing this systemic marginalization. This lack of scrutiny is largely responsible for the perpetuation and continued codification of systematic injustices in healthcare that persist despite intentional efforts to reduce them. Although many healthcare researchers actively engage in personal and study-focused self-reflection aimed to circumvent or even fight against these injustices in their research, such efforts are unable to fundamentally change the larger system. Until a time when reflexivity is codified as a fundamental value of all healthcare research, ACRR methods are uniquely poised to fill the gap in RCTs by capitalizing fully on the promise of CBPR to identify, highlight, and address the systemic biases that underlie the pervasive and deadly disparities (e.g., 40% suicidality rate vs. 2–4% for the general population—James, Herman, Rankin, Keisling, Mottet, & Anafi, 2016).

Note from Community Lead

The CBPR framework of trans collaboration offers an opportunity to have meaningful input on the research projects and the outcomes, emphasizing tools and products that benefit the community. I value the participation

and genuine interest in how the community sees the projects. It is unlike any community advisory work I have participated in before because it is not just one-shot involvement. It is ongoing, which is a different model than I am used to. One important role is for us to hold the researchers accountable to the community. One challenge is that it can take more time for the researchers; they cannot just run off and collect data. The community board recognizes the need for research, especially the graduate students' need for research for their own careers, and the graduate students and faculty appreciate the role of the community board. This makes for a good partnership.

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