Sociology Faculty Research   Department of Sociology

2-7-2020

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Abstract

Community Advisory Boards (CABs) are used in efforts to reduce health disparities; however, there is little documentation in the literature regarding their use in precision medicine research. In this case study, an academic-CAB partnership developed a questionnaire and patient educational materials for two precision smoking cessation interventions that involved use of genetic or genetically-informed information. The community-engaged research (CEnR) literature provided a framework for enhancing benefits to CAB members involved in developing research documents for use with a low-income, ethnically diverse population of smokers.The academic partners integrated three CEnR strategies: 1) in-meeting statements acknowledging their desire to learn from community partners, 2) in-meeting written feedback to and from community partners, and 3) a survey to obtain CAB member feedback post-meetings. Strategies 1 and 2 yielded modifications to pertinent study materials, as well as suggestions for improving meeting operations that were then adopted, as appropriate, by the academic partners. The survey indicated that CAB members valued the meeting procedure changes which appeared to have contributed to improvements in attendance and satisfaction with the meetings. Further operationalization of relevant partnership constructs and development of tools for measuring these aspects of community-academic partnerships is warranted to support community engagement in precision medicine research studies.

Keywords

community-engaged research; community advisory board; health disparities; precision medicine

INTRODUCTION

Advantages of citizen participation in health disparities-related research have been described as early as the 1970s (Ahmed, Neu Young, DeFino, Franco, & Nelson, 2017; Lawrence & Stewart, 2016; Buchanon, Reddy, Sifunda, James, & Naidoo, 2010). These include community members having access to research tools and results that empower them to address concerns about their community's health, build their capacity to deliver important services in their community, and develop research questions of importance to them (Cheney et al., 2016; Coffey et al., 2017; Halbert et al., 2016; Cunningham et al., 2015; Simonds, Wallerstein, Duran, & Villegas, 2013). Researchers learn from community members who share about their culture and social networks, and in turn, gain valuable insight in identifying research topics and methods that are salient to and informed by members of marginalized communities. Furthermore, they obtain involvement and support from more diverse research participants, richer interpretation of results, and improved implementation of research-based interventions (Cargo & Mercer, 2008; Bowers, Jacobson, & Krupp, 2017; Kaiser, Thomas, & Bowers, 2017; Rhodes et al., 2018; Simonds et al., 2013).

The importance of community-engaged research (CEnR) for academic investigators in the expanding fields of genomics (Ginsburg & Willard, 2009) and, more broadly, precision

medicine (Schleidgen, Klingler, Bertram, Rogowski, &Marckmann, 2013; de Grandis &Halgunset, 2016) has been emphasized as a means of accruing these benefits in these new areas of health services. Successful partnerships between university-based researchers and community advisory boards (CABs) offer the potential to accelerate the application of precision medicine to minority communities, and reduce the risk of widening disparities in access to quality care (Graves &Tercyak, 2015; Halbert, McDonald, Vadaparampil, Rice, & Jefferson, 2016; Halbert et al., 2016; Kaphingst et al., 2015; Kaplan et al., 2017; Kimball, Nowakowski, Maschke, & McCormick, 2014; Korngiebel, Thummel, & Burke, 2017; Ma, Rosas, &Lv, 2016). The appropriate implementation and use of genomic tests is influenced by several system and patient variables, such as use of cultural diversity of research participants, level of patient health literacy, and the context in which patients are provided with information about reasons for testing and the implications of test results (Korngiebel et al., 2017).

Potential barriers to addressing disparities in development and application of precision medicine tools can be addressed by including more minority participants in precision medicine research. In addition, engaged community partners can assist researchers by addressing health literacy related to genomic and precision medicine, and considering the context in which research participants will be asked for, and informed about, use of their biological samples for genetic testing. Communicating the benefits of precision medicine to minority patients poses a challenge that requires additional investigation (National Academies of Sciences, Engineering, and Medicine, 2016a). Williams et al. (2018) and others (National Academies of Sciences, Engineering, and Medicine, 2016b) noted that advisors from minority and underserved communities can provide critical advice to academic researchers that is useful for translating precision medicine concepts for audiences that may be unfamiliar with terms associated with genomic technologies used in intervention research. This article is a case study of the process in working with a CAB to develop a questionnaire and patient educational materials for two precision smoking cessation interventions that involved the use of genetic information.

METHODS

Context of the Academic-Community Partnership

The Meharry-Vanderbilt-Tennessee State University Cancer Partnership (MVTCP) Cancer Outreach Core (COC) CAB is an academic-community partnership that was established in 2006. The CAB, which meets quarterly, includes over 20 community members from diverse racial and ethnic backgrounds who are cancer survivors, caregivers, representatives of cancer-related organizations, and other community members with an interest in cancer. CAB members have provided feedback on numerous studies including three projects that involve precision medicine in the last year. Members of the CAB, especially current and former smokers, were invited to join a CAB Tobacco Cessation Subcommittee for this research project.

Precision Interventions for Smoking (PRISM) in the Southern Community Cohort Study (SCCS) was designed to reduce the disproportionate burden of smoking-related mortality affecting racial and ethnic minorities (Shields et al., 2008). The SCCS is a longitudinal

cohort study in the Southeastern U.S. that includes 86,000 low income adults recruited between 2002–2009 to study health disparities prospectively (Signorello, Hargreaves, & Blot, 2010). Most participants were recruited through federally qualified health centers (FQHCs) and are predominantly African-American and low-income. PRISM goals included surveying SCCS participants about their willingness to participate in genetically-informed smoking cessation treatments. Members of the PRISM academic team, referred to in this paper as academic partners, asked the CAB Subcommittee members to provide feedback regarding the survey, as well as the design of educational materials for two precision care (PC) interventions for smoking cessation. One uses genetic information to enhance the accuracy of estimating lung cancer risk (Young, 2012), and the other assesses speed of nicotine metabolism to inform pharmacotherapy choice (Lerman et al., 2015).

Identification of Relevant Community Engagement Strategies

To guide planning for CAB Subcommittee meetings, academic partners reviewed literature related to training of community-engaged researchers to identify best practices for enhancing engagement and expanding benefits for CAB members. Discipline-specific training for academic researchers does not always provide a good foundation for collaborative learning with researchers in other disciplines, or community members whose skills reflect other training and experiences(Cornell et al., 2013). In our review of team science literature (Selker& Wilkins, 2017; Bennett &Gadlin, 2012; Selker& Wilkins, 2017), we noted the recommendation for "broadly-engaged team science" in which researchers commit to co-learning with community members to advance the quality and beneficial impacts of research. We operationalized co-learning, a feature of community-engaged participatory research (Braun et al., 2012), as identifying ways academic and community partners learned from each other during each Subcommittee meeting.

Partnership, engagement, and collaboration (PEC) research is a related field of study that focuses on the need for greater understanding of communication skills necessary to successfully bridge research and community perspectives (Leeman, Birken, Powell, Rohweder, & Shea, 2017; Powell et al., 2017). This literature reminded academic researchers to consider verbal and nonverbal messages that would be congruent with their intention to learn from community members. Precision medicine research requires a particular style of sensitive listening and speaking because the vocabulary is so specialized. Laypersons tend to be less familiar with treatments employing the use of molecular biology to predict treatment outcomes – making community engagement all the more crucial (Halbert et al., 2016; Kaplan et al., 2017). The co-learning approach requires researchers to explain genomic-informed tests and treatments, while learning what might be confusing about their approach to describing these activities. They then collaborate with community members in revising language and graphics to more effectively communicate concepts important for informed consent and delivering the interventions.

Two systematic reviews of literature describing community-researcher partnerships noted that among the most common barriers to successful community-academic collaborations are a lack of clarity and insufficient communication about roles (Drahota et al., 2016; Huang et al., 2018). In addition, the importance of academic partners' listening and self-reflection

skills has been emphasized by a number of CEnR scholars (Arora, Krumholz, Guerra, &Leff, 2015; Coffey et al., 2017; Kaplan et al., 2017; Oswald, 2016). They also noted the importance of establishing trust in the community-academic partner relationship; clearly articulating roles of participants in the conversation; bi-directional communication with community members getting feedback about the process and content of meetings; and evaluation of what transpired. These aspects of effective CEnR are also emphasized in team science and PEC.

While many measures relevant to community-academic partnerships are described in the literature (Arora et al., 2015; Eder, Tobin, Proser, & Shin, 2012; Kagan et al., 2012; Marek, Brock, &Savla, 2015; Meza, Drahota, & Spurgeon, 2016; Newman et al., 2011; Oetzel et al., 2015; Salsberg et al., 2015; Sandoval et al., 2012; Simonds et al., 2013), a number of investigators have noted the need for more precise, reliable, and valid measures of constructs relevant to the work of such partnerships (Bowen et al., 2017; Drahota et al., 2016; Halladay et al., 2017; Huang et al., 2018; Marek et al., 2015; Sandoval et al., 2012). Evaluation of the community-academic meeting process is essential to understanding the types of interactions that either enhance or diminish health outcomes in the community by allowing partners to identify and adapt strategies to improve their ability to reach long-term dissemination and implementation goals (Schulz, Israel, & Lantz, 2003). In addition, metrics provide another focus for researchers as does self-reflection and tracking progress (Oetzel et al., 2015). Bowen et al. (2017) suggested that community and academic partners choose several measures according to the desired outcomes of their project, and that was the path taken for this PRISM study.

Process of Conducting CAB Meetings

Four members of the academic team met four times with the CAB Subcommittee to review study documents. During the first two CAB Subcommittee meetings, the focus was on designing a questionnaire to assess PRISM participants' attitudes and beliefs about smoking and health, opinions about genetically personalized smoking treatment, and willingness to join a trial of two genetically personalized treatments for quitting smoking. During the third and fourth meetings, community and academic partners discussed health education materials for use in the two smoking cessation interventions. Prior to each CAB Subcommittee meeting, drafts of materials previously developed by the academic team were provided for discussion.

Researchers in the PRISM study acknowledged that the use of genetic and biomarker information to personalize smoking cessation treatments has ethical and social ramifications beyond those encountered in more traditional health interventions (International HapMap Consortium, 2003; Korngiebel et al., 2017; Terry, Horn, Scott, & Terry, 2011). Therefore, the research team planned for the involvement of the MVTCP CAB Subcommittee in developing research materials that clearly communicated the study's purpose, the types of testing to which participants might be randomly assigned, and the interventions that would follow from those results. The research team wanted to learn about CAB Subcommittee members' preferences and needs regarding the way genetic information and testing was defined, and the design of informational materials for genetically-informed interventions.

In addition to achieving the study goals, the academic partners realized that the CAB members were helping expand awareness of sometimes subtle elements of the structure and process of the meetings, which had the potential to affect the range of their contributions to the project. Subsequently, academic partners committed to taking steps to identify strategies that might further empower the community advisors (Kimball et al., 2014; Korngiebel et al., 2017). As part of an ongoing quality improvement process, academic partners took detailed written notes during each meeting. The research team discussed and reflected on them in order to identify opportunities for strategic changes that could be implemented during future meetings.

The four CAB Subcommittee meetings were facilitated by an academic partner. Each meeting began with a round-robin sharing of names and purpose for attending, giving everyone an opportunity to learn something about other attendees. Some Subcommittee members and academic partners shared their experiences as current or past smokers. The conversation among Subcommittee members and academic partners generated a number of suggestions for changes to the draft participant questionnaire.

Few community members attended the second Subcommittee meeting. Those who came described difficulty finding a parking area on the crowded university campus. During the meeting, CAB Subcommittee members and academic partners brainstormed about meeting locations that would be more convenient for community members and decided to hold future meetings at a centrally located local health department, with more accessible parking. Those attending the meeting also reflected on the format of the meetings, and what elements made the meetings more interesting for community members. They agreed to seek additional community members to participate in the CAB Subcommittee meetings.

Subsequently, the academic partners identified three evidence-based CEnR techniques to enhance meeting dynamics during the third and fourth CAB Subcommittee meetings. Specifically, academic partners addressed ways in which some communication approaches may lead to disempowerment of CAB members (Safo, Cunningham, Beckman, Haughton, &Starrels, 2016), and used empowering strategies outlined by Kaiser et al. (2017) as follows: Although academic partners were facilitating the meeting, they announced at the outset that they were present to hear CAB Subcommittee members' feedback about the materials being developed for the PRISM project. This contrasted with the previous two meetings during which academic team members expressed their opinions about the material being reviewed, rather than explicitly focusing on listening to and understanding community members' perspectives. This change in role expectations reflected a CEnR principle that researchers encourage community members to express their opinions and concerns, rather than expecting them to defer to academic partners because of perceived differences in expertise and authority.

The second CEnR strategy was for academic partners to take detailed notes on a large flipchart while CAB Subcommittee members commented on materials being revised. The written comments were displayed prominently to acknowledge the value of each person's contribution to the discussion. Third, we adapted a sixteen-question meeting evaluation survey designed by Giachello (2007) to gather anonymous feedback from Subcommittee

members regarding meeting productivity and the overall effectiveness facilitation. The CAB subcommittee members completed this survey at the end of the last two of our four meetings.

Analysis

The documented input from community members during each CAB Subcommittee meeting regarding the questionnaire, study materials, and patient education materials was organized and summarized. Meeting attendance and the responses of the meeting evaluation surveys were tabulated using descriptive analysis.

RESULTS

The number of community members attending each CAB Subcommittee meeting was greater in the last two meetings compared to the first two (Table 1). The following sections are organized to highlight the input that academic members of the partnership received from community members for the PRISM study, followed by highlights reported by community members regarding the benefits they obtained from participating in CAB Subcommittee meetings.

PRISM Study Input from CAB Members

In the first Subcommittee meeting, CAB members and academic partners focused on the PRISM study participant questionnaire. CAB members were asked to consider the questions as if they were a study participant, and to report where they had confusion or unease. The discussion included reviewing an explanation of genes that had been piloted in a previous study, which CAB members deemed to be adequate for the PRISM population. The group discussed placement in the questionnaire of the explanation of genes and testing for nicotine metabolite ratio (NMR) to improve study participants' preparation for the brief explanatory statements in the context of questionnaire items.

During the second CAB Subcommittee, community members reviewed the informed consent document, and the context in which it would be presented to individuals who had indicated in the PRISM questionnaire that they were willing to participate in a "research study that uses information about your genes to help you quit smoking." Changes were recommended to simplify language for scripts used to describe the precision medicine interventions to which study participants might be randomly assigned. Examples included, "research appointment" instead of "encounter," and "confirm" referring to a cotinine test to assess quit status, rather than "validate," which some CAB Subcommittee members perceived as implying a study participant was lying. Subcommittee members described aspects of the text and graphics in these documents that they found difficult or disturbing, with some saying graphics regarding lung cancer susceptibility were "confusing" and "stressful."

The third and fourth CAB Subcommittee meetings continued the focus on the appearance and text in study materials. CAB Subcommittee members asked academic partners for more information about the standard of care that would be provided to all PRISM study participants. Academic partners explained that study participants would be referred to the designated QuitLine in the state in which the participant resides. During the fourth meeting

CAB Subcommittee members discussed the medications that healthcare providers would recommend to study participants based on genetic information about nicotine metabolism. The community members provided input regarding the language that described potential benefits and side effects of these medications.

CAB Subcommittee members asked if the study materials they were seeing in color might be reproduced in black and white. Academic partners clarified that the materials would be mailed to study participants and would be in color. Other Subcommittee members' suggestions included wording to describe the test that determines the risk for lung cancer. They helped develop phrases to describe genetic information, family history, smoking history, and other factors, along with how test results would be presented to study participants. Several Subcommittee members expressed appreciation for the work of a professional graphic designer who integrated their suggestions regarding color, size, and placement of graphics in modified versions of the educational materials. The graphic designer also eliminated some elements of early drafts that CAB Subcommittee members thought would be more confusing than helpful for potential study participants.

Over the course of the four Subcommittee meetings, CAB members recommended changes to educational materials to strengthen both ethical and clinical execution of the intervention. Subcommittee members also identified ambiguities and complicated phrasing of certain statements, and suggested modifications that would help avoid misinterpretations. For example, one of the original questionnaire items asked, "*Did you use any of the listed quit aids during your last quit attempt?*", and several CAB members thought the word "attempt" implied failure.Discussion of this question led to rewording of the question to, "*Did you ever use any of the following to try to quit smoking?*" Overall, CAB member feedback provided the academic investigators with insights regarding potential hopes and concerns study participants may have regarding genomic-based medicine. Overall, subcommittee meetings produced insightful discussions resulting in several modifications of text, graphics, and approaches to message delivery. Specifically, community members provided suggestions for clarifying aspects of clinical trials research, being transparent about side effects of genomic-based medication treatment, and specifying the method for obtaining blood samples in this study.

Some CAB Subcommittee members emphasized that the research team needed to make sure study participants understood that individuals enrolled in one intervention arm would have different medical treatment than those enrolled in the other intervention arms. CAB Subcommittee members felt strongly about listing the side effects and costs associated with medication in the informed consent documents. CAB Subcommittee members acknowledged that receiving study information prior to consenting to participate might influence an individual's decision to enroll in the study. In addition, several CAB Subcommittee members said that despite efforts to improve and simplify study documents, participants would likely have questions and areas of concern. Thus, they felt it would be critical to have follow-up contact and an opportunity to ask questions, preferably a call from study staff.

What CAB Members Valued About Subcommittee Meetings

The meeting evaluation survey was distributed at the end of the third and fourth Subcommittee meetings to obtain feedback from community members on the content and process of the meeting. The results of these surveys are displayed in Table 2. After Meeting #3, three items were unanimously rated as Excellent (location, information shared, and opportunities for participating and sharing). A majority of participants rated the other items as Excellent, and some rated them as good. The items with the lowest number of Excellent responses were clear agenda, appropriate objectives, action plan or strategies developed, and assignments or follow-up tasks. After Meeting #4, all but one item (appropriate objectives) received unanimous Excellent ratings, demonstrating a pattern of improvement over the previous meeting.

The evaluation survey included three open-ended questions: Was this meeting worth your time? What did you learn today? What went well in this meeting? All CAB members responded affirmatively to the first question. Responses to the second question included learning more about the study procedures, about the precision medicine tools (lung cancer risk assessment, and NMR), as well as linking NMR to specific medication recommendations. Members also commented about elements of design for educational materials, and the importance of community input. Regarding what went well, written comments referred to the opportunity to network, discuss, and "opportunity for everyone to share."

The PRISM study's principal investigator attended the fourth CAB Subcommittee meeting and responded to many CAB Subcommittee member questions about the precision medicine elements of the study. Subcommittee members commented that they learned more during the meeting about risk factors for lung cancer and reasons certain smoking cessation medications work better for some smokers than others.

DISCUSSION

Academic researchers collaborated with an existing CAB to form a CAB Subcommittee for PRISM, an investigation involving two precision medicine tests to inform smoking cessation treatment. The community-academic partnership developed a questionnaire to assess smokers' attitudes about two precision medicine smoking cessation interventions and their willingness to participate in a study of the intervention impact. In addition, the CAB Subcommittee participated in the development of educational materials about each intervention to be used in the next phase of the PRISM study.

During the first two Subcommittee CAB meetings, academic team members sought guidance for modifying meeting formats in CEnR and related literature. Three relatively small changes were instituted in the CAB Subcommittee meeting procedures in the final two of four meetings: the use of empowerment strategies to communicate the value of community expertise, the display of detailed notes on member's suggestions in real time, and the evaluation of meeting processes via anonymous assessment. These changes appeared to have contributed to improvements in Subcommittee meeting attendance and satisfaction with the meetings. CAB participants indicated that they appreciated the structure that

supported more active CAB members' participation. One individual who was recruited for the CAB Subcommittee subsequently asked to join the larger CAB, indicating that the meetings had been informative and enjoyable for her.

Researchers have begun to explore what people in the community know about precision medicine, their attitudes and beliefs about it, and what they want to know to make informed decisions about its application. Evidence suggests that some community members support genomic-based medicine, although nearly a third of volunteers in a New Jersey precision medicine study were confused about some aspects of its use (Gollust et al., 2012). In conducting focus groups with members of the Mayo Clinic Biobank CAB who were invited to provide feedback regarding a specific genomic research protocol, Kimball et al. (2014) found that CAB members saw potential benefits in having genomic information in medical records, and using genomic information to prescribe medication. The investigators' initial objective for the focus groups was to obtain feedback about a specific research protocol. However, as investigators reflected on what they were hearing, they appreciated the insights their CAB members were offering which addressed broader questions based on their perspectives of precision medicine. The focus group feedback regarding the collection, storage, and use of genomic information provided researchers relevant lessons beyond the scope of the study for which the CAB was consulted.

Our feedback from the MVTCP subcommittee was similar in a variety of ways. For instance, subcommittee members emphasized clarity of both language and visual aids in the description of precision medicine concepts to participants of the PRISM project. This supports the idea of presenting information in a manner that allows community members to make autonomous and informed decisions about the application of precision medicine. Similar to Gollust et al. (2012), MVTCP's subcommittee brought to light the potential for community members to be confused by genetic jargon and/or ambiguities in the phrasing of various statements. Lastly, surveys reflected excitement from members who described learning more about using genomic information to individualize treatment. Academic researchers benefited from suggestions for enhancing the design of questionnaires and educational materials.

The CAB Subcommittee meetings provided meaningful engagement opportunities for members and reinforced the idea that the persons who will be involved in the PRISM study are valued partners as well. CAB Subcommittee members were sensitive to the potential for study participants to perceive precision medicine interventions as experimental, and potentially harmful. Input from the community members of the subcommittee enhanced the design of the study questionnaire and educational materials in a culturally sensitive manner. Members of the CAB Subcommittee were invited to participate in development of this manuscript, and those who accepted are identified as co-authors.

CABs bring the voices and perspectives of diverse populations to bear on improving process and health outcomes (Holt, Hussain, Wachbroit, & Scott, 2017). The academic partners of MVTCP's CAB aimed to create a mutually supportive space that facilitated learning on both the part of researchers and community members. Although several measures were found for assessing CAB effectiveness as construed in CEnR, the variation across partnerships and

definitions of success is problematic when applied to a precision medicine research project involving minority communities (Abelson & Gauvin, 2006; Braun et al., 2012; Esmail, Moore, & Rein, 2015; Rowe &Frewer, 2005).

In line with the academic team's review of the literature, Esmail et al. (2015) concluded that process measures of engagement are found more often than outcome measures. The goals of this project involve assessing both process and impact. The academic team aimed to understand what aspects of the community-academic partnership contribute to community member involvement in health promotion among their families and neighbors. What constitutes *best* processes are further complicated when the intended purpose of CEnR strategies involves community empowerment and education in the evolving and highly specialized field of precision medicine. This requires researchers to identify and suspend implicit assumptions about precision medicine so that a sense of respect and cultural sensitivity can be conveyed through skillful listening and meeting facilitation.

CONCLUSION

Engaging community members in the context of precision medicine research provided academic partners with additional perspectives regarding the language and images used in the PRISM questionnaire and educational materials. Community members had opportunities to learn more about precision medicine applications to smoking cessation. By implementing three CEnR-informed strategies in our CAB Subcommittee meetings, we hope we have taken steps to improve our work with community-academic partnerships for future research projects. The process used and lessons learned can be useful to inform other community-academic partnerships about effective strategies for involving CABs in precision medicine research.

ACKNOWLEDGEMENTS

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Table 1.

Attendance at CAB Subcommittee meetings

	Community members	Academic partners
Meeting #1	4	5
Meeting #2	2	5
Meeting #3	6	4
Meeting #4	8	5

Table 2.

Responses to CAB Subcommittee Meeting Evaluation Form

How would you rate each of the following:	Poor	Fair	Good	Excellent	Poor	Fair	Good	Excellent
		CAB Meeting #3 (n=6)				**CAB Meeting #4 (n=7)**		
The agenda (clear) [*]			2	3				7
The objectives (appropriate)			2	4			1	6
The location of the meeting				6				7
Quality of the facilitators/presenters			1	5				7
Information shared at this meeting				6				7
The way decisions were made			1	5				7
The handouts (appropriate, useful)			1	5				7
Opportunities for participation and sharing				6				7
The action plan or strategies developed		1	1	4				7
Assignments or follow-up tasks [*]			2	4				6

[*] One person did not provide a rating for this item.