Community Strategies to Enhance Culturally Responsive Research

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Abstract

Background
Under-representation of minorities in research hinders the ability to address persistent health disparities. In 2016, Community-Campus Partnerships for Health engaged diverse individuals to understand factors that impede engagement of communities of color in research. Individuals spoke to the importance of accounting for historic mistrust in and broken promises with research and healthcare, highlighting a need to better understand communities' visions of culturally responsive research.

Objectives
The objectives were to elicit diverse communities' ideas regarding culturally responsive research in order to develop responsive strategies for research engagement.

Methods
Three community organizations and one university partnered together to engage four communities (African American, Native Hawaiian, Hmong, Latino) in listening sessions to explore what culturally responsive research looks like. The partnership completed community-specific and cross-community participatory analysis. Provisional findings from the analysis were shared at community forums for further refinement.

Results
Analysis yielded six recommendations: 1) Learn about community/research and deepen self-awareness; 2) Build trust and relationship; 3) Collaborate to choose a topic that matters to community; 4) Plan and do research in equitable partnership; 5) Respectfully engage community members; 6) Understand results together and share them in ways that strengthen community. Each recommendation built off of community concerns and desires regarding research.

Conclusion
The results align with core principles of community-based participatory research, underscoring the importance of building equitable research partnerships that honor cultural practices and account for the socio-political context. Results are formatted as tools for community and academic researchers to enhance culturally responsive research practices.

Introduction

Although the 1993 NIH Revitalization Act mandated increased representation of minorities in research, underrepresentation in clinical research remains a problem[1,2]. With an increasingly diverse society and persistent health disparities, a pressing question is: how can researchers better engage culturally diverse patient populations? To do so, a need exists to learn what culturally responsive research means to individuals from diverse communities, particularly underserved communities. In 2016, Community-Campus Partnerships for Health (CCPH) hosted three regional conferences and a pre-conference session where diverse individuals spoke to the importance of accounting for the historic mistrust in and broken promises with both research and healthcare. Across each of these four gatherings, attended by 150 participants, the themes of trust, transparency, and partnership emerged. The shared stories broadened the focus of research ethics and practices to include an awareness of the existence and impact of social exclusion, which includes a critical understanding of the community and cultural context. This approach addresses factors that often impede engagement of communities of color in research. This includes, but is not limited to, the importance of 1) honoring cultural differences regarding what constitutes respect, beneficence, and justice, 2) accounting for individual and cultural differences in how trust is earned and sustained, 3) recognizing the existence and impact of institutional racism, 4) accounting for linguistic differences, and 5) addressing potential explicit and implicit biases perpetuated by researchers and research institutions throughout the research process[3-6].

To gain greater understanding of how diverse communities perceive and experience culturally responsive research, a community-academic partnership was formed for this project, which was comprised of representatives from 3 community organizations working with 4 ethnic communities: Community-Campus Partnerships for Health (CCPH), Ahahui Malama I Ka Lokahi (AML), SoLaHmo Partnership for Health & Wellness (SoLaHmo); and 1 academic institution, the University of New England's School of Social Work (UNE SSW). For the purpose of this paper, our partnership is referred to as "team".

- CCPH's (Raleigh, NC) mission is to promote health equity and social justice through partnerships between communities and academic institutions.

- AML's (Kailua, HI) mission is to practice, promote, and perpetuate a modern native Hawaiian conservation ethic that provides for a healthy Hawaiian ecosystem nurtured by human communities and serving as a model for local and global resource management.

- SoLaHmo's (St.Paul, MN) mission is to promote the health of diverse communities by maximizing cultural strengths, practicing social justice, and addressing racism through Community-Based Participatory Action Research (CBPAR), education, and policy.

- UNE SSW's (Portland, ME) mission is to provide transformative and collaborative learning that embraces the values of social inclusion and promotes enhanced quality of life for individuals and communities.

The project's objectives and the overall approach were identified in bi-monthly partnership meetings that served to plan, implement, and evaluate listening sessions and community forums that would:

- Elicit diverse communities' visions of culturally responsive research.

- Develop guidelines for engagement of diverse communities in research, based on analysis of community members' experiences and perspectives.

Methods

At the project's start, the team convened in-person to finalize the methods and overall approach utilizing SoLaHmo's existing Research Partnership Checklist,[4] a tool developed in collaboration between members of SoLaHmo and the University of Minnesota's Program in Health Disparities Research and School of Public Health, to develop: 1) a common vision of the project goals and values, 2) key partnership processes, including decision making, conflict resolution, and communication styles, and 3) approach to data access, use, and ownership. University of New England's IRB reviewed the proposal and determined it was exempt. The project was funded by a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award (EA #6177). The methods consisted of two phases.

Phase 1: Community Listening Sessions

In Phase 1, the three community partners facilitated listening sessions at their respective sites. These partners recruited participants based upon existing relationships enhanced by snowball recruitment. Each session lasted 60-90 minutes and was recorded with participants' permission. Specifically, AML hosted two sessions with Native Hawaiian participants (17 participants total); CCPH hosted three sessions with African American participants (15 participants total); and SoLaHmo hosted two sessions with Latino members (one in English, one in Spanish, 16 participants total) and two with Hmong participants (both in English with some Hmong words, 11 participants total).

The listening sessions focused on participants' experiences with research. Questions were informed by a review of the literature and built off the team's previous work. The questions reflect core concepts informed by the Research Partnership Checklist[4], the Healing by Heart Model for Culturally Responsive Health Care[5] and the National Collaborative Study Team's proposed core competencies for researchers[6].

Examples of questions include:

1. What needs to happen for you to feel TRUST in the research process?

2. What are some of the challenges people may experience with researchers based upon differences in CULTURAL BELIEFS or PRACTICES?
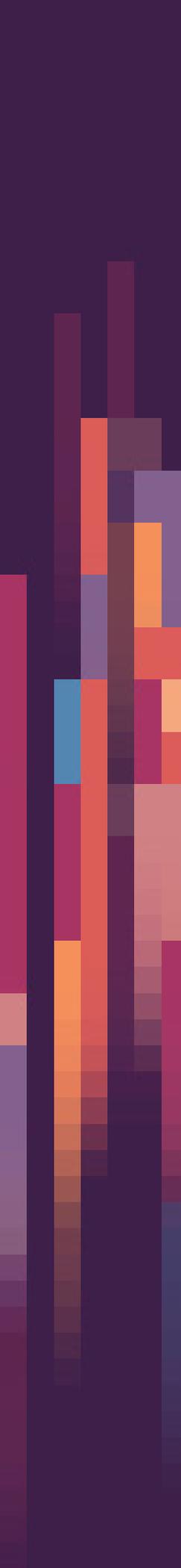
Each listening session recording was transcribed, translated where necessary, and then uploaded into Dedoose[7] for thematic analysis. This entailed line-by-line coding by sub-teams composed of members at each site. This participatory analysis yielded community specific reports. Each member of the whole team reviewed these reports and engaged in a cross-community analysis during several team phone calls.

This process resulted in a Community Research Recommendation table (CRRT) that outlined community concerns, desires, and recommendations about research, as well as a graphic that summarized key points and visually represented the relationships between each of the different components.

Phase 2: Community Forums

Each community partner hosted community forums with 16-21 participants at each location, some of whom had participated in the listening sessions. Similar to the listening sessions, partners recruited participants based upon existing relationships and through snowball sampling.

At the 2.5 hour forum, participants were divided into small groups and asked to reflect upon the CRRT and graphic developed from the Listening Sessions.

Examples of questions include:

> 1. What part or parts of these guidelines are the most/least important to you or your community?

> 2. What other recommendations do you have to ensure your cultural beliefs and practices are honored?

Adhering to the analysis approach used in Phase 1, the whole team analyzed the transcribed community forum recordings using Dedoose and Microsoft Word to conduct thematic analysis. The analysis yielded a forum report for each of the four engaged communities, which the team discussed to generate a cross-community forum report. This entailed further revisions to the CRRT plus a second graphic that incorporates the participants' input.
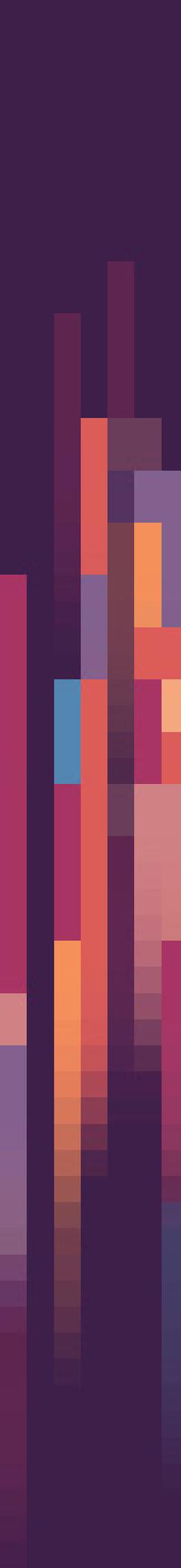
Results

Community Research Recommendations Table

The CRRT for both academics and community researchers consisted of six community-identified recommendations to make research more culturally responsive.

These recommendations are:

- Learn about community/research and deepen self-awareness.

- Build trust and relationship with community and researcher.

- Collaborate to choose a topic that matters to community.

- Plan and do research in equitable community-academic partnership.

- Respectfully engage community members.

- Understand results together and share them in ways that strengthen community.

Associated with each of these recommendations are community concerns and desires regarding research, as well as strategies for implementation. This Results section highlights strategies for communities, researchers, and partnerships to consider as they work towards enhancing culturally responsive research practices. (See Full Community Research Recommendations Table in Appendix.)

RECOMMENDATION 1:
LEARN ABOUT COMMUNITY/RESEARCH AND DEEPEN SELF-AWARENESS

Community concerns:	Community desires:	Strategies:
Researchers do not understand communities (i.e., historic trauma, geo-political context, socio-economics, institutional racism, history research abuse). Researchers treat people and communities as homogenous.	Researchers understand cultural and community practices, and not stereotype, dismiss, or misrepresent communities. Researchers critically understand the broader context and how that impacts communities' experiences both within and beyond research. Researchers act with humility.	Communities -Realize diversity in the community. -Expand connections with diverse community members. Researchers -Gain awareness of the community's desires and concerns for research. -Recognize communities are heterogeneous and work to reach diverse people. -Raise own awareness and consciousness of self, biases, and assumptions. Partnership -Recognize and build upon community assets. -Offer training within the partnership to support co-learning including "ism" training sessions. -Listen to community members' experiences and stories, especially those who have been harmed by research.

Strategies

In general, participants across the four community forums agreed upon the specific steps that researchers must take to understand cultural and community practices to avoid stereotyping, dismissing, or misrepresenting communities. This included understanding the historical, political, and socio-economic context of each community. These experiences are not confined to what has transpired with research, but represent lived experiences overall. As discussed extensively within the Native Hawaiian forum, for example, researchers must understand historic and ongoing exploitation of Native Hawaiians, which includes pervasive institutional racism across multiple systems including, educational and justice systems. In the Hmong forum, people spoke to the importance of taking into consideration the Hmong community's lived experiences, which includes understanding the impact of the historical trauma as refugees from the Vietnam War/Secret War in Laos.

Several considerations emerged as well in the Latino forum, including the need to be sensitive to diversity within the Latino community that includes differences by country of origin, language groups, generational differences, immigration experiences, and the need to be critically aware of the risks related to immigration status/climate, as well as understanding how some people are scared to participate in research. As part of the discussion during the African American forum, participants spoke about unjust and harmful research practices within their community, such as the U.S. Public Health sponsored syphilis study in Tuskegee and how these traumas carry over across generations, which require researchers and research to be sensitive to historical traumas.

As part of the discussion, a participant in the Hmong community forum cautioned that to effectively engage in culturally responsive research, the community needs to be supported in deconstructing their own biases about research and to construct a positive relationship with community-based participatory research (CBPR or CBPAR, where "A" refers to action). This ties into the recommendation identified in the Latino community forum regarding the importance of educating the community about what research is and how it can be relevant and beneficial to the community. Another participant in the Hmong community forum also posed the following questions for researchers to consider as part of their self-reflection process: "Are you ready to be changed? Derailed by what you have learned, engaged in, and uncovered? And then, how are you going to be accountable to the community?"

"The research team has to prepare itself because if they don't know the culture, the language, the community they will be working with, then the study is lost because the information will be poor, and then they stigmatize the community being studied."

-Latino participant

"What I would say is if researchers plan to research a community, I know we've mentioned going out and talking with folks, but actually going out and trying to understand the culture for yourself in the area in which you plan to research. Cause you know we are different pockets. Saint Louis African American is completely different than rural African Americans in South Carolina. Understanding that the culture will differ from pocket to pocket (area) and going out and embracing that. "

-African American participant

RECOMMENDATION 2:
BUILD TRUST AND RELATIONSHIP WITH COMMUNITY & RESEARCHER

Community concerns:	Community desires:	Strategies:
Researchers use communities for their own benefits.	Community and researchers be partners. Researcher -Treat community with respect and fairness. -Be truthful, transparent, and accountable.	Communities -Learn 1) about research ethics, methods, and analysis; 2) how research can identify community strengths and challenges; and 3) how to employ approaches that benefit the community. -Specify what culturally responsive partnership processes look like that meet community interests and desires. -Express what has caused mistrust in research and more generally, and what researchers need to do to earn trust. Researchers -Act according to community's desires. -Do not just show up to do research and then leave. -Listen to community to understand their desired level of engagement, and what respectful engagement means to them. Partnership -Create partnerships that honor co-learning, collaboration, accountability, transparent agendas, trust, and actionable results. -Be attentive to and knowledgeable of community considerations. -Start partnership work before grant is written. -Continue engagement after the project. -Conduct activities at trusted locations. -Address power differentials transparently. -Ensure team members represent different aspects of the community. -Deconstruct biases about research in the broader community to raise awareness about the potential for research to be culturally responsive and beneficial.

Strategies

Across all four community forums, participants spoke to the importance of building nurturing and genuine partnerships. While participants were not asked specifically about CBPR, several participants named CBPR as a preferred research approach. Others shared desires for research that align with CBPR, such as recognizing that building trust takes time, honoring co-learning, and ensuring actionable results.
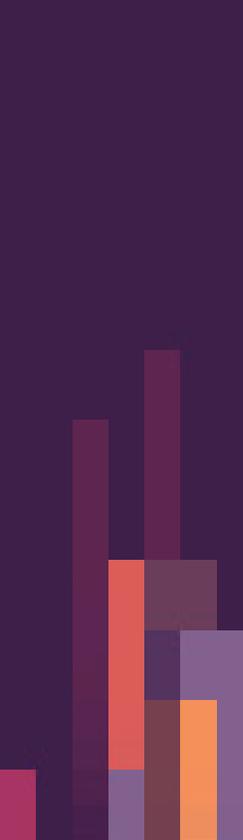
Several words of caution emerged, however, regarding the concern that researchers too often use communities for their own benefits and are not fully committed to equitable partnerships. In the Hmong community forum, participants spoke to how partnerships cannot be built around token participation, where communities don't have decision-making power or researchers don't act with cultural humility (i.e., trustworthy, accountable, responsive to community, acknowledge positional power and work to counter inherent power imbalance, be present without having to be transactional).

As part of this discussion, one person raised the question as to whether partnership building is realistic, recognizing how partnership building in general may not be suitable for all researchers and may not be a community's preferred approach. The value of working with researchers from one's own community was also discussed. As shared within the Native Hawaiian forum, participants pointed out how a growing number of Native Hawaiian researchers exist and may be more suited to working with Native Hawaiian communities given their understanding of cultural values, language, the historical and socio-political context that includes a critical awareness of exploitation and oppression, and the relevance and importance of decolonizing methodologies.

"When you go into a community, you had better have community people there who understand all of this. Even if you are Native Hawaiian, you are going to be seen as an outsider to that community if you are not from that community. A lot of times connections are critical and if you want people to participate and be fully involved, then you have to have people with you that have connections. Otherwise, you are going to be seen as an outsider."

-Native Hawaiian participant

"People always think back to the Tuskegee experiment and not having all of the information. So, the trust factor is definitely, I would think, probably the highest ranking reason why people don't wanna [participate in research]. And also, because when you think of the word "research" alone, a lot of us look at it as us being guinea pigs as if we're being tested for the benefit of some-body else. So, we don't think about it necessarily benefiting us. We think about it benefiting other people. You know, whether that be another culture or whether that's our culture, but later on down the line."

-African American participant

RECOMMENDATION 3:
COLLABORATE TO CHOOSE A TOPIC THAT MATTERS TO COMMUNITY

Community concerns:	Community desires:	Strategies:
Researchers do not focus on topics important to communities.	Explore topics that benefit communities. Ensure relevancy of the topic to the community. Develop/co-develop research processes that address community concerns.	Communities -Specify topics that matter to one's community. Researchers -Listen to what matters to the community. Partnership -Choose topics that are relevant and can benefit community. -Use shared decision-making methods to build capacity that identify shared prioritization and goal setting.

Strategies

The importance of ensuring a research topic that matters to community resonated with participants across all four community forums. For example, people at the Native Hawaiian forum discussed the importance of focusing on topics that bother the community, what the community is experiencing that is painful, and what is felt to be impacting the community rather than researchers arriving with a topic that is not addressing a condition that the community has prioritized.

Participants in the Hmong forum stressed that it is important for the community, not the academic researcher, to define what "responsive collaboration and transparency" means based in the community's context and from the community's cultural standpoint. In addition to choosing a topic that matters, it is also important how measurements are determined and that they are culturally responsive rather than imposing white dominant standards on diverse communities.

"[CBPR] is looking to ask people what is it that they need help with, as opposed to telling them what they need help with. As an adult, if I think that my conversation with you is going to help me, then I might be willing to have that conversation. But I'm not just doing this for the 50 bucks. I'm doing it because 'Gee, I'd really like to get some answers to this issue that I'm dealing with that I can't get an answer to.' "

-Latino participant

"[Researchers] hear from the existing community about what its needs are versus somebody else coming in and saying,'You need this so we are going to do this when it's not what we want or what we need.' "

-Native Hawaiian participant

"Because a lot of times, things that you are evaluating are standards set by white culture. So, when you're looking at evaluating a community of color, you're not looking at what they think is important. So, if you're evaluating the success of youth graduating high school in this youth program, how many people are actually graduating high school? The numbers are low but when you're actually asking the youth, to them it's like oh they're now happier, but that's not being evaluated because that's not what the standard is. So, looking at what is important, what is considered effective in the community that you're researching."

-Hmong participant

"I know for our community, because we have a very high prevalence of chronic diseases, some of the people feel like we are forever stigmatized or we are always being looked at as a community that has so many issues in a negative way. And so, we want to be perceived as a positive community or something. And so, research just magnifies our issues to a certain degree. You know we're first in chronic disease, we're first in stroke, we're first in you know, so that's one of the things and one of the perceptions we have in our community, is that the research just magnifies what we already know is wrong. So, when will we have research that magnifies some of the good qualities that we have?"

-African American participant

RECOMMENDATION 4:
PLAN AND DO RESEARCH IN EQUITABLE COMMUNITY-ACADEMIC PARTNERSHIP

Community concerns:	Community desires:	Strategies:
Researchers create processes that make sense to them not for communities.	Create more equitable research processes. Understand community and geo-political context, and develop/co-develop processes that address contextual injustices/factors. Engage in research that supports community ownership. Develop/co-develop research that accounts for cultural considerations. Embrace the values and principles of CBPR.	Communities -Recruit researchers who understand community's vision and desires, and have the experience in partnering in a culturally responsive manner. -Grow and nurture researchers from within one's community. -Ask researchers and/or their institutions what they can do to help enhance life for the community in a meaningful way. Researchers -Be present in the community. -Value people and their experiences. -Use clear and accessible language. Partnership -Co-create research design accounting for cultural context. -Host activities in community settings. -Train researchers to be culturally responsive -Be transparent and accountable to each other. -Address power imbalances and identify. strategies to ensure shared power and decision-making. -Be inclusive of older and younger generations. -Ensure all partners have support and resources to engage in partnership processes.

Strategies

The importance and value of developing equitable community-academic partnerships resonated across the community forums. Community participants want to see research moving away from being researcher-driven and devoid of community relevance, towards research that honors partnership commitments such as equity, community ownership, and co-development of the research and partnership processes. This requires researchers to understand the community and geo-political context, and be committed to addressing community-identified injustices.

Other desires that surfaced in both the African American and Hmong forums was the importance of connecting to community leaders/gatekeepers and ensuring a diverse research team that includes members from the community. Other themes that emerged were comprised of the importance of being inclusive, eliminating barriers to participation, and being accountable to the community.

"I think that is what we do consider when we do CBPAR and when you involve community partners as partners, so they have a say in the whole process, from the recruitment to the methods that you use for data collection... to incorporate the community voice in each of those steps, I think it's fundamental. "

- *Latino participant*

"There's not intentionality, there's not that, 'Hey let's plan this out and make sure that the intention is the same from day one. If we got this money and let's figure this out and bring people to the table in order to have voices and to let the community participants be empowered somehow and to be informed.'"

- *Hmong participant*

RECOMMENDATION 5:
RESPECTFULLY ENGAGE COMMUNITY MEMBERS

Community concerns:	Community desires:	Strategies:
Researchers build processes that don't account for cultural context and/or assume homogeneity.	*Each of these desires refers to engagement as study participants, study advisors, and/or decision makers:* -Ensure potential participants understand what is being asked -Reduce barriers to participation -Understand reasons why. communities/individuals may want to participate or not. -Address reasons why communities/individuals may want or not to participate to eliminate coercion. -Recognize negative experiences, but don't assume communities won't participate.	Communities -Identify gatekeepers or trustworthy individuals who can ensure engagement happens respectfully, on community's terms and according to their preferences. Researchers -Act with cultural humility. Partnership -Respectfully recruit by considering people's motivations for and concerns about being involved in research. -Use approaches that are outside of the box that meet people/communities where they are at. -Tailor research engagement to truly hear and center community experiences and stories. -Tailor data collection methods to ensure cultural relevance.

Strategies

Participants emphasized the need for respectful engagement of community members as study participants, gatekeepers or liaisons, advisors, and/or other decision-makers.

These recommendations build off of community concerns (i.e., researchers do not account for the cultural context and/or assume their community is homogenous) and desires (i.e., researchers recognizing a community's negative experience with research but not assuming communities will not participate). To respectfully engage people from the community, participants in the African American forum spoke to the importance of researchers talking to people who feel harmed by research and to really listen to their experiences and stories.

Additional recommendations for researchers were to recognize that African Americans may choose to participate in research for a variety of reasons and that money is not the sole incentive. In the Hmong forum, people spoke about the need to reach out and recruit participants from diverse aspects of the community. This recommendation ties directly into the concern expressed across the forums regarding the tendency for researchers to view community as homogenous.

"For me, you can ask me to do something, but if I don't know you and I don't know what you are about then it's hard for me; a lot of time I would just say no. If there's that relationship there already that I do trust that you do have respect for me, because sometimes when you do things you can already tell the person by the way they talk to you, the way the person treats you, sometimes they are condescending. And if that's the case, then I will pull back. But when there is that trust and there is that respect, then I am going to listen more. Is the other person listening to what I have to say as well? Without all of that, I wouldn't have participated. "

- Native Hawaiian participant

"There is a really genuine investment in valuing participants' time and knowledge, and then we go through so much to find an Uber or a taxi to get a participant to come here for a focus group, and then once they get here, providing food and thanking them, always acknowledging their opinions after a question is asked, has been a really successful interaction that I've seen, that I think is something really nice. "

- Hmong participant

RECOMMENDATION 6:
UNDERSTAND RESULTS TOGETHER AND SHARE THEM IN WAYS THAT STRENGTHEN COMMUNITY

Community concerns:	Community desires:	Strategies:
Researchers' negative representation of results perpetuate stereotypes. Researchers lack effective community dissemination.	Ensure findings are shared with the community. Develop ways to celebrate with the community to honor their time. Ensure community benefit. Advocate for increased funding to support CBPR.	Partnership* -Interpret results together, accounting for community and academic perspectives. -Ensure community is aware of findings and their rights regarding research engagement. -Encourage participants to share results (word of mouth is frequently relied upon means of sharing information). -Disseminate results in meaningful ways. -Highlight "bright spots" to counter effects that highlight negative/stigmatizing results. -Share results to multiple audiences, including other organizations and/or communities that might benefit, and community members who live in other places. -Ensure results lead to actions that benefit the community. -Evaluate effects/impact of research findings over time.

* Strategies associated with the sixth recommendation are categorized under partnerships only given the listening session and community forum participants' recommendations emphasized the importance of partners working together to address identified concerns and actualize community desires.

Strategies

All strategies for this section were considered strategies for the research partnerships. Forum participants spoke strongly to the importance of sharing results with participating communities. Too often researchers gather information and neither share the findings nor help with translating findings into beneficial action steps. In the Native Hawaiian community forum, participants spoke extensively about how findings should be shared, which included use of social media, community celebrations, and word of mouth. The importance of sharing findings was emphasized, with one participant speaking to how this was their kuleana (responsibility).

"The results and data should be somewhere the Hmong people could access. Somewhere they feel like it's their own, maybe the Hmong Cultural Center. They're like, 'Hey, that's the community and like we can always go there.'"

- Hmong participant

"No one ever told us, every time we do something for research, no one ever told us what happened to that information. Then we see something published that totally shines a different light on Native Hawaiians because we are talking about Native Hawaiians, how we are lazy, no education or anything like that."

- Native Hawaiian participant

"Something that I have heard is people asking, 'I'm going to give my time, I'm going to be like a guinea pig, and what is the result? They come, they lure me in, and then leave. And later they forget about me.' That is not good. "

- Latino participant

"How is the conclusion of the story? For me, that debriefing is important. Once you have analyzed the data or do the publication, can you come back and present to us, in layman's terms, so that we can understand what we were a part of? I have never heard the outcome of a study. No one is going to understand that peer review or journal article that you wrote."

- African American participant

Recommendations Graphics

The team synthesized the CRRT into two graphics, given community feedback that included preferences for a less text-heavy visual representation. Graphic #1 highlights five core ideas shared during the listening sessions, while Graphic #2 incorporates additional ideas shared during the community forums, including six core ideas that aim the messages at community members, researchers, and academic research partnerships. Of note, the participants at the Native Hawaiian forum felt the first graphic strongly resonated with their experiences and requested no additional changes. Both graphics have two outer circles: Community Concerns and Community Desires for Research. The dotted line between the concerns and desires indicates that the concerns and desires are fluid and feed into one another.

For communities that cultivate academic researchers from within their own communities, Graphic #1 may speak more to their experiences, whereas for communities that seek to partner with external academic researchers, Graphic #2 might be more applicable.

Community Concerns occupy the outer ring of both graphics to reflect that when participants spoke about research, they emphasized the need to understand the historical experiences of research exploitation as well as societal exploitation (i.e., colonization). The inner ring of the circle, where the recommendations live, contains the Community's Desires for research, which correspond to each of the recommendations discussed above.

Examples of specific ideas that were shared include:

- It's really not just going out and building relationships, it's actually going backwards and de-constructing all other preconceived notions and biases around research... And it's really deep rooted, it could be traumatic things that you are trying to root out. (Hmong participant)

- Talk to the person who feels like they've been harmed. Don't just kind of ignore it, sweep it under the carpet. Bring that person to the forefront so they can be heard. Put their voice in the room. (African American participant)

- [Researchers can] treat people and communities as homogenous: culture, generations, gender, and immigration. An example of this say, Hawaiian people. The people who live in Waimano are different than the people in Waianae and different from the people in Hilo. So, when you come in as researchers and you understand how families work, the dynamics; what happens in Waianae may not be the same thing that happens in Kona, or wherever. So, as a researcher coming in, you have to understand that, that we are different. (Native Hawaiian participant)

- …The comunidad and the feeling of family because that's a very important value among Latinos and that's also something we use to engage with our community as well.... Personal relationships, which you cannot do until you start rubbing shoulders with people. Unless you get together and actually have encounters, you will not be able to develop that trust. (Latino participant)

GRAPHIC 1

**Recommendations for Academic Researchers Partnering with Communities**

Graphic #1 has, at its center, "nurture genuine research partnerships with communities" as a means to do research in a culturally responsive way. The five white boxes are five key recommendations. The topics start at the top of the circle and are arranged clockwise as a continuum of the research process. The dotted lines that connect the recommendations also indicate the fluidity between the desires and the central goal of nurturing genuine research partnership with communities. The connections between each of the five recommendation boxes illustrate that partnerships should be able to move back and forth between recommendations depending on what is needed in the research project. For instance, if a partnership arrives at the third recommendation of "plan and do research in partnership with community," but realize that they need to learn more about the community and deepen self-awareness, then they should be able to return to the first recommendation. Lastly, the ultimate goal of this work is to nurture genuine research partnerships with communities.
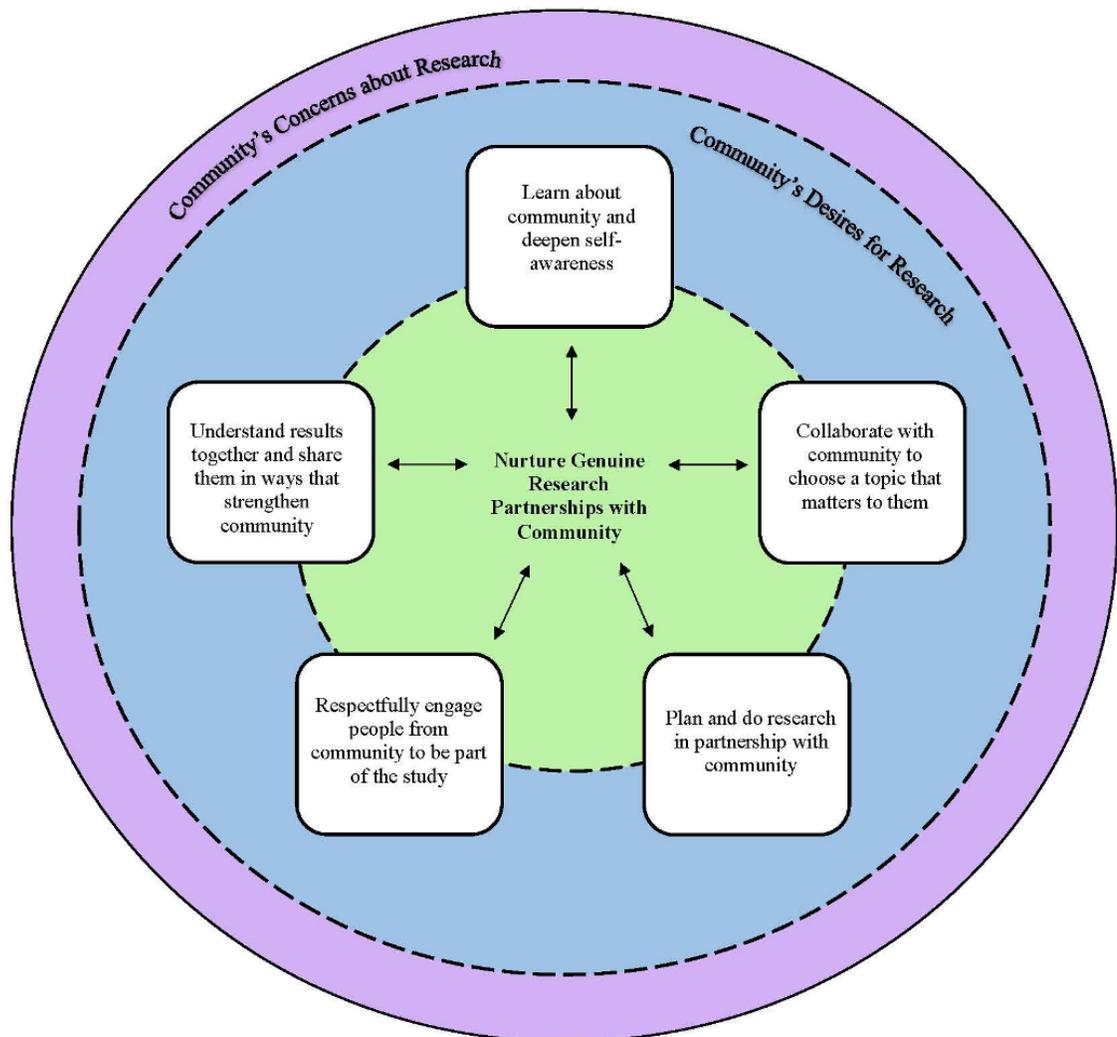
GRAPHIC 2

Recommendations for Community-Academic Researcher Partnerships

Graphic #2 is a variation of Graphic #1 which incorporates the feedback from community participants during the community forums. A key change in the second graphic is that community health and well-being is placed at the center, thus reflecting the main goal of health and wellness as a result of culturally responsive research. Partnerships represent the supporting framework that create equitable research relationships, which ideally lead to community health and well-being. A second change was the inclusion of trust and relationship as a central part of developing a culturally responsive partnership, thus adding a sixth recommendation to the graphic. A third change was broadening the language to reflect how the tool should speak to both academic and community researchers. For example, the second graphic states "learn about community/research and deepen self-awareness" for both academicians and community members. The outer circles of Community Concerns and Desires for Research remain the same.
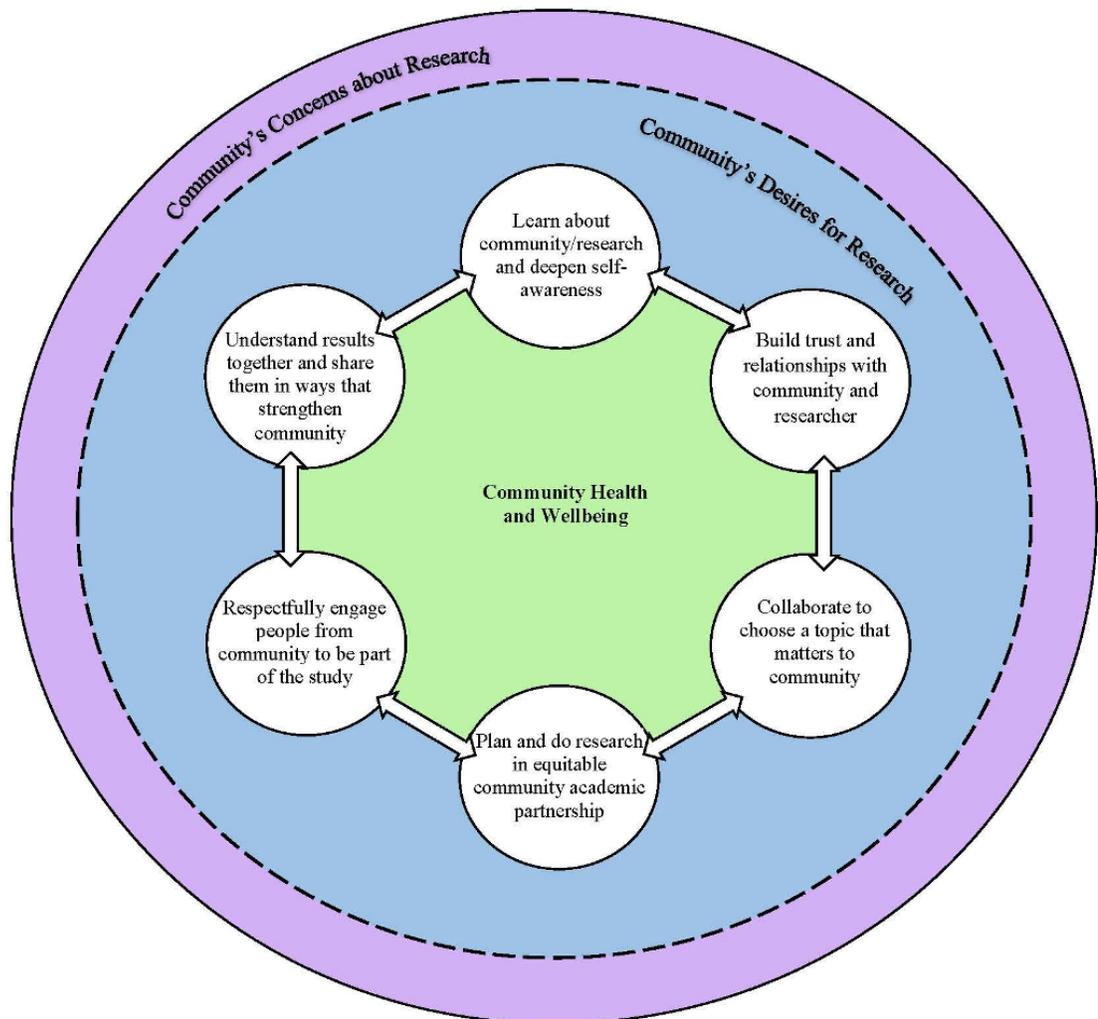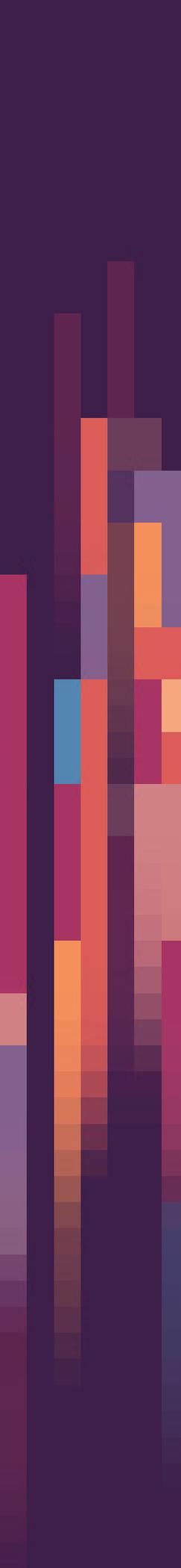
Disscussion

The ideas and concepts that emerged from the listening sessions and community forums are organized and formatted in such a way as to create a tool, which community members, researchers, and academic-community research partnerships could use. The recommendations from the CRRT and graphics align with core approaches in CBPR. [9,10, 11] The fact that these community participants from across all 4 ethnic groups voiced recommendations that align with a CBPR approach has two possible interpretations. One, these results re-affirm that CBPR is a research approach that resonates with ethnic communities. Two, these results indicate the gap between the ideal and the real. While CBPR has been proposed and utilized for over two decades, it has not replaced non-community-friendly research practices, so there is more work to do in changing research practices and supporting research partnerships. These findings could be a tool aimed at lessening the gap between ideal research partnerships and current practices. Given this gap, future work needs to be done specifically on how to identify and address structural issues that impede culturally responsive research. Issues that could be explored include how to hold institutions accountable by advocating for changes in promotion and tenure processes that honor equitable research partnerships or funders accountable for supporting community-driven research practices. Being structurally responsive, furthermore, requires explicit attention to addressing conditions that continue to impact communities, such as acknowledging the historic context that shapes how research is perceived and experienced.

Lessons Learned

Without the guidance and expertise of our community partners, we could not have effectively engaged the four communities within our project. We began our project focused on our existing connections and/or partnerships and knew that the success of this project relied on our ability to support and center the voices of our community partners. All partners were actively involved in bi-monthly team meetings to determine all aspects of the project design. The team was comprised of individuals from each of the engaged communities, which helped to keep the project accountable to the engaged communities.

The methods used of listening sessions and community forums, coupled with participatory analysis conducted by the team helped ensure that community voices remained centered throughout the project and yielded rich insights into how research is experienced and strategies to enhance culturally responsive research practices.

Limitations

These results reflect the experiences of a small group of participants that may not be generalizable to all African American, Hmong, Latino, and Native Hawaiian individuals. Similarly, these ideas may not be applicable to other diverse community groups because others were not involved. However, because the results resonate with CBPR literature, the general framework may be helpful with each community using the general framework to insert their community specific concerns, needs, and strategies. Future projects may engage other diverse communities to more fully understand experiences with research and what culturally responsive research requires for them.

Implications

The CRRT and accompanying graphics complement each other and could be used in tandem by community members, researchers, and academic-community partnerships. The graphics provide a visual representation of how the different recommendations and pieces interact in relation to one another and may represent a stand-alone tool. For example, a participant in the Native Hawaiian forum stated that she envisioned posting just the graphic on her wall to guide her research.

Community groups can use this tool to help determine how they want to partner with researchers, what to expect from academic researchers, how to ensure the work is done equitably and respectfully, and how to advocate for their specific community's desires. For academic researchers, this can serve as a guide to help them be accountable to the partnership and to build strong, respectful, and authentic relationships with community partners. Community-academic research partnerships may use this tool as a standard to hold partnerships accountable and be transparent. Indeed, the tool could be a living document that serves as a meaningful starting point for efforts geared towards enhancing culturally responsive research.

Part of the dissemination effort includes requests for feedback aimed at further refining the tools and assessing impact of tools towards enhancing the cultural responsiveness of research practices, including fostering equitable community-academic research partnerships.

References

1. Dovido JF, Fiske ST. Under the radar: How unexamined biases in decision-making processes in clinical interactions can contribute to healthcare disparities. *American Journal of Public Health*. 2012; 102(5): 945-952.

2. University of Minnesota Program in Health Disparities Research, PHDR Resources for Community-based Research, PHDR Resources Co-developed with SoLaHmo. Accessible at: https://www.healthdisparities.umn.edu/about/resources-community-based-research. Accessed 3/25/17.

3. Allen ML, Svetaz MV, Hurtado GA, Linares R, Garcia-Huidobro D, Hurtado M. The Developmental Stages of a Community-University Partnership: The Experience of Padres Informados/Jovenes Preparados. *Progress in Community Health Partnerships*. 2013;7(3):271-279.

4. University of Minnesota CTSI Resources for Community-Engaged Research. Accessible at: https://www.ctsi.umn.edu/sites/ctsi.umn.edu/files/research_partnership_checklist.pdf. Accessed 3/25/17.

5. Vawter DE, Culhane-Pera KA, Babbitt B, Xiong P, Solberg MM. (2003). A model for culturally responsive health care. In Culhane-Pera KA, Vawter DE, Xiong P, Babbitt B, & Solberg MM, eds. *Healing by Heart: Clinical and Ethical Case Stories of Hmong Families and Western Providers*. Nashville, TN: Vanderbilt University Press, pages 297-356.

6. National Collaborative Study Team (2015). Research Ethics Reconsidered in the Context of Community-Engaged Research. Accessible at: https://ccph.memberclicks.net/assets/Documents/PapersReports/research_ethics_reconsidered_final.pdf. Accessed 3/25/17.

7. Dedoose; Great Research made easy. https://www.dedoose.com/

8. Jackson SF. A participatory group process to analyze qualitative data. *Progress in Community Health Partnerships*. Summer 2008; 2(2):161-170.

9. Cashman SB, Adeky S, Allen AJ, 3rd, et al. The power and the promise: Working with communities to analyze data, interpret findings, and get to outcomes. *American Journal of Public Health*. 2008; 98(8):1407-1417.

10. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. Annual Review of Public Health. 1998;19: 173–202.

11. Wallerstein N & Duran B. Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*. 2010; 100(Suppl 1):S40-S46.

Appendix: Full Community Research Recommendations Table

I. LEARN ABOUT COMMUNITY/RESEARCH AND DEEPEN SELF-AWARENESS

Community concerns:	Community desires:	Strategies:
Researchers do not understand communities (i.e., historic trauma, geo-political context, socio-economics, institutional racism, history research abuse). Researchers treat people and communities as homogenous.	Researchers understand cultural and community practices, and not stereotype, dismiss, or misrepresent communities. Researchers critically understand the broader context and how that impacts communities' experiences both within and beyond research. Researchers act with humility.	Communities -Realize diversity in the community. -Expand connections with diverse community members. Researchers -Gain awareness of the community's desires and concerns for research. -Recognize communities are heterogeneous and work to reach diverse people. -Raise own awareness and consciousness of self, biases, and assumptions. Partnership -Recognize and build upon community assets. -Offer training within the partnership to support co-learning, including "ism" training sessions. -Listen to community members' experiences and stories, especially those who have been harmed by research.

2. BUILD TRUST AND RELATIONSHIP WITH COMMUNITY & RESEARCHER

Community concerns:	Community desires:	Strategies:
Researchers use communities for their own benefits.	Community and researchers be partners. Researcher -Treat community with respect and fairness. -Be truthful, transparent, and accountable.	Communities -Learn 1) about research ethics, methods, and analysis; 2) how research can identify community strengths and challenges; and 3) how to employ approaches that benefit the community . -Specify what culturally responsive partnership processes look like that meet community interests and desires. -Express what has caused mistrust in research and, more generally, what researchers need to do to earn trust. Researchers -Act according to community's desires. -Do not just show up to do research and then leave. -Listen to community to understand their desired level of engagement and what respectful engagement means to them. Partnership -Create partnerships that honor co-learning, collaboration, accountability, transparent agendas, trust, and actionable results. -Be attentive to and knowledgeable of community considerations. -Start partnership work before grant is written. -Continue engagement after the project. -Conduct activities at trusted locations. -Address power differentials transparently . -Ensure team members represent different aspects of the community. -Deconstruct biases about research in the broader community to raise awareness about the potential for research to be culturally responsive and beneficial.

3. COLLABORATE TO CHOOSE A TOPIC THAT MATTERS TO COMMUNITY

Community concerns:	Community desires:	Strategies:
Researchers do not focus on topics important to communities.	Explore topics that benefit communities. Ensure relevancy of the topic to the community. Develop/co-develop research processes that address community concerns.	<u>Communities</u> -Specify topics that matter to one's community. <u>Researchers</u> -Listen to what matters to the community. <u>Partnership</u> -Choose topics that are relevant and can benefit community. -Use shared decision-making methods to build capacity that identify shared prioritization and goal setting.

4. CONDUCT RESEARCH IN EQUITABLE COMMUNITY-ACADEMIC PARTNERSHIP

Community concerns:	Community desires:	Strategies:
Researchers create processes that make sense to them not for communities.	Create more equitable research processes. Understand community and geo-political context, and develop/co-develop processes that address contextual injustices/factors. Engage in research that supports community ownership. Develop/co-develop research that accounts for cultural considerations. Embrace the values and principles of CBPR.	<u>Communities</u> -Recruit researchers who understand community's vision and desires, and have the experience in partnering in a culturally responsive manner. -Grow and nurture researchers from within one's community. -Ask researchers and/or their institutions what they can do to help enhance life for the community in a meaningful way. <u>Researchers</u> -Be present in the community. -Value people and their experiences. -Use clear and accessible language. <u>Partnership</u> -Co-create research design accounting for cultural context. -Host activities in community settings. -Train researchers to be culturally responsive. -Be transparent and accountable to each other. -Address power imbalances, and identify strategies to ensure shared power and decision-making. -Be inclusive of older and younger generations. -Ensure all partners have support and resources to engage in partnership processes.

5. RESPECTFULLY ENGAGE COMMUNITY MEMBERS

Community concerns:	Community desires:	Strategies:
Researchers build processes that don't account for cultural context and/or assume homogeneity.	*Each of these desires refers to engagement as study participants, study advisors, and/or decision makers:* -Ensure potential participants understand what is being asked. -Reduce barriers to participation. -Understand reasons why. communities/ individuals may want to participate or not. -Address reasons why communities/ individuals may want or not to participate to eliminate coercion. -Recognize negative experiences, but don't assume communities won't participate.	Communities -Identify gatekeepers or trustworthy individuals who can ensure engagement happens respectfully and on community's terms and according to their preferences. Researchers -Act with cultural humility. Partnership -Respectfully recruit by considering people's motivations for and concerns about being involved in research. -Use approaches that are outside of the box that meet people/communities where they are at. -Tailor research engagement to truly hear and center community experiences and stories. -Tailor data collection methods to ensure cultural relevance.

6. UNDERSTAND RESULTS TOGETHER AND SHARE THEM IN WAYS THAT STRENGTHEN COMMUNITY

Community concerns:	Community desires:	Strategies:
Researchers' negative representation of results perpetuate stereotypes. Researchers lack effective community dissemination.	Ensure findings are shared with the community. Develop ways to celebrate with the community to honor their time. Ensure community benefit. Advocate for increased funding to support CBPR.	Partnership* -Interpret results together, accounting for community and academic perspectives. -Ensure community is aware of findings and their rights regarding research engagement. -Encourage participants to share results (word of mouth is frequently relied upon means of sharing information). -Disseminate results in meaningful ways. -Highlight "bright spots" to counter effects that highlight negative/stigmatizing results. -Share results to multiple audiences, including other organizations and/or communities that might benefit, and community members who live in other places. -Ensure results lead to actions that benefit the community. -Evaluate effects/impact of research findings over time.

* Strategies associated with the sixth recommendation are categorized under partnerships only given the listening session and community forum participants' recommendations emphasized the importance of partners working together to address identified concerns and actualize community desires.