Best Practices for CEnR Partnerships for Health Equity

Patrice Forrester, PhD, MSW[1], Abdou Simon Senghor, PhD[1], C. Daniel Mullins, PhD[1], Michelle Medeiros, MS, MA[1], Claudia Baquet, MD, MPH, PhD[1], Pastor Donald L. Wright, EMBA, MDiv [2], T. Joseph Mattingly II, PharmD, MBA, PhD[3]

(1) University of Maryland School of Pharmacy, Baltimore, MD. USA; (2) Mount Lebanon Baptist Church, Baltimore, MD. USA; (3) University of Utah College of Pharmacy, Salt Lake City, Utah. USA

Abdou Senghor: 0000-0001-9353-5482

T. Joseph Mattingly II: 0000-0001-7786-5780

Claudia Baquet: 0000-0002-7914-1871

C. Daniel Mullins: 0000-0003-4322-2490

Patrice Forrester: 0000-0002-8180-454**X**

ABSTRACT

Background: Best practices for community-engaged research (CEnR) partnerships to promote health equity can mitigate barriers to health care, especially during public health crises. They also establish value congruence specific to the promotion of health equity for underserved communities.

Objectives: Our goal was to co-develop best practices for CEnR partnerships promoting health equity.

Methods: A purposeful sample of 9 researchers and 13 community members with experience in CEnR participated in the study. A first version of the best practices document was developed based on feedback from community members during pre-engagement activities that sought to co-design a sustainable model for trustworthy CEnR partnerships. The best practices document was further developed from compilation and categorization of comments from study participants in virtual meetings.

Results: The best practices document included general guiding principles for CEnR partnerships promoting health equity and specific guidelines for partnerships relevant to COVID-19 testing. Foundational practices for all CEnR partnerships include the development of shared goals, accountability, and transparency. Guidelines specific to the social, ethical, and behavioral implications (SEBI) of COVID-19 testing include identifying community resources and challenges, identifying and communicating the value and risks associated with COVID-19 and COVID-19 testing, and minimizing risks and hardships relevant to COVID-19 testing.

Conclusions: Best practices for CEnR partnerships promoting health equity should be tailored to the specific CEnR partnership. Future research could explore how community members and researchers implement CEnR partnership best practices to promote health equity for underserved communities.

KEYWORDS: Community-Based Participatory Research, Community health partnerships, Community health research, Health disparities, Process issues, Community-engaged research, COVID-19

In the U.S., underserved communities (e.g., low-income, racial/ethnic minorities) have limited access to resources to cope with COVID-19.[1] Even with the Families First Coronavirus Response Act (FFCRA) allowing all individuals access to COVID-19 testing in the U.S., underserved communities of color (e.g., African Americans) continued to not access COVID-19 testing.[2] Lack of awareness of policies that provide access to COVID-19 testing among low-income or uninsured populations, inclusive of people of color, may have led many to the belief that they cannot obtain COVID-19 testing because of the cost.[3] It is paramount to overcome barriers to testing, especially as many patients were never tested who died as a result of COVID-19 infection.[4] One method to mitigate the barriers to testing has been to form partnerships between communities and academic researchers.[2,4] These community-engaged research (CEnR) partnerships have played a significant role in increasing COVID-19 testing among underrepresented groups.[5] There is a need to continue developing these CEnR partnerships to prevent and respond to future public health crises and empower marginalized communities during these crises.

Best practices for CEnR partnerships to promote better health equity for underserved communities can be a means of mitigating barriers to COVID-19 testing and other health equity issues. The development of best practices for CEnR partnerships promoting health equity, based on a multi-stakeholder approach, aims to produce positive change in order to enable better consideration of the community's needs.[6] Fostering engagement in a CEnR partnership can be characterized by reciprocal relationships, co-learning, partnerships, transparency, honesty, trustworthiness, continuous community engagement, and trust.[7,8] Thus, shared values such as common best practices that serve to strengthen trust between partners can serve as a foundation

from which a CEnR partnership can operate. Examining efforts to address and understand the impact of the co-learning process when co-developing CEnR partnership best practices is needed to establish value congruence specific to public health crises such as the SARS-CoV-2 public health pandemic and to identify organizational-level best practices from community representatives and academic members with experience in CEnR partnerships. From this perspective, a CEnR partnership between a trusted messenger and expert in an underserved West Baltimore community, Mount Lebanon Baptist Church (MLBC), the academic partner, the PATIENTS Program at University of Maryland Baltimore (UMB), and a community health partner who wishes to remain anonymous, is essential to support uptake of COVID-19 testing to underserved communities in West Baltimore. The foundation of the partnership between the PATIENTS Program and MLBC was initially developed in November 2011 when they received a contract from the Patient-Centered Outcomes Research Institute (PCORI) to conduct a study to identify methods for including hard-to-reach patients throughout research continuum from design and conduct, through to dissemination of results. It was found that establishing and maintaining mutual trust between researchers and patients are methods that should be used to engage patients and ensure representation of hard-to-reach populations as they foster open and sustained engagement and produce valid and reliable results.[9] A trusting relationship between the MLBC and PATIENTS Program has developed in a context where underserved communities of color in West Baltimore have had historic mistrust of academic researchers and health systems.[10] Here within we describe how community members, researchers and stakeholders co-develop best practices for CEnR partnerships to reduce health disparities and increase trust between community and academic partners.

Methods

This study was funded by the National Institute on Minority Health and Disparities (NIMHD). MLBC pastor reviewed and provided feedback on the manuscript in preparation for submission. Before engaging in study procedures, community and academic partners participated in the Institutional Review Board (IRB) process. The MLBC and PATIENTS Program researchers reviewed and discussed study information, such as the recruitment flyer and research plan. Study materials were revised as needed based upon comments from the MLBC, to better engage prospective study participants from the community. The study was then reviewed and approved by the UMB Institutional Review Board (IRB).

The MLBC and PATIENTS Program also worked together on research design. To co-develop best practices, MLBC and researchers from UMB engaged community members in a process previously used by Armstrong et al. as a model for patient and public involvement in clinical practice guideline development.[11] We adapted this process to achieve our study objective and incorporated key stakeholders such as community members, CEnR researchers, and the research team.

Recruitment

MLBC and UMB's PATIENTS Program researchers co-developed the recruitment plan. MLBC Pastor recruited community members using flyers, while the PATIENTS Program's Executive Director recruited CEnR researchers by email to participate in this project.

Participants

Community members and researchers were purposefully sampled based on their prior experience with CEnR. Community members were representatives of community-based or

faith-based organizations in Baltimore. Researchers were employed by an academic institution

and had familiarity with Baltimore. In all, four virtual meetings were organized. The meetings

were virtual as MLBC was undergoing renovation.

[Insert Figure 1 here]

Analytic Approach

Study participants were invited to a total of four (4) virtual retreats - one for academic

members only, one for community representatives only, and two joint virtual retreats that

brought all participants together. The two joint virtual meetings were designed to facilitate

community representatives and academic members reaching a consensus on best practices. The

discussions focused on the best practices document subdivided into two sections: (1) Section 1:

Foundational practices for all CEnR partnerships, and (2) Section 2: Practices for Social,

Ethical, and Behavioral Implications (SEBI) for COVID-19 testing. Additionally, as the study

was conducted under the NIH RADx®–Underserved Populations (RADx-UP) Consortium,

participants were asked to complete the Common Data Element (CDE) questionnaire. The

CDE questionnaire was implemented in order to collect uniform aggregate data to assess the

impacts "on COVID-19 disparities in specific populations, facilitate analysis of research

questions and possibly inform policy at the local, community, and/or Tribal levels." (RFA-OD-

21-009) The questionnaire was lengthy and could be perceived as personal and sensitive in

nature. Therefore six research team members completed the questionnaire to test the survey

and further build trust by demonstrating their willingness to engage in study procedures they

asked study participants to complete. Participants were offered the option to select "prefer not

to answer" for each question. None of the researchers' data was used specifically for the focus of the paper and were not used to develop best practices.

Results

Of 12 researchers and 16 community members with experience in CEnR who were recruited, 9 researchers and 13 community members attended the initial meetings, where researchers and community members met separately with the intent to subsequently co-develop a CEnR best practices document in a joint meeting. Virtual retreats (Figure 1) included academic researchers only (n=9) on October 5, 2022, community representatives only (n=13) on October 6, 2022. We then organized two joint meetings. A first group of researchers and community members (n=11) attended the first joint meeting on October 14th; the other group of researchers and community members (n=11) attended the second joint meeting on October 20th . One researcher that was present during the initial virtual meeting was absent during subsequent joint meetings. Another researcher was absent during one of the joint meetings but participated in the other joint meeting. Otherwise, all researchers and community representatives participated in both the initial meeting with their group and one of the two combined meetings aimed at co-developing the final set of best practices. A majority of those who completed the RADx-UP questionnaire as part of this study identified as Black or female and ranged in age from 18 – 74 (Table 1). The demographics table includes PATIENTS Program research team members, n = 6, who completed the RADx-UP questionnaire.

[Insert Table 1 here]

CEnR Partnership Best Practices Document

The final best practices document was created based on an iterative approach as described in Figure 1. We identified and evaluated best practices for CEnR partnerships promoting health equity in virtual meetings with community members and academic researchers with CEnR experience. Having separate virtual retreats to initiate the best practices development process helped to minimize unequal power dynamics that may occur due to the higher status and assumption of expertise that is often attached to researchers in contrast to those who are not researchers. In addition, community members' comments were maintained during each iteration of the best practices document to ensure we formulated best practices that addressed health equity issues relevant to our community partners. The research team member who moderated meetings also ensured that at least half of the time at joint meetings was used to get feedback from community members.

At the beginning of each meeting, a research team member gave a summary of the study including the topics to be discussed. A first version of the best practices document was developed based on feedback from community members in a prior study funded by NIMHD (grant number 1U01MD017437-01) that sought to co-design a sustainable model for trustworthy CEnR partnerships addressing SEBI and COVID-19 testing. The best practices document was revised based on feedback collected during virtual meetings. In addition to the meeting being recorded, two research team members took notes on significant points of agreement, disagreement, and non-verbal cues. A research team member edited the document with stakeholders and researchers in real time at virtual meetings. After each virtual meeting, the research team member who facilitated the virtual meeting and the two team members who wrote notes at meetings, reviewed participants' suggestions and integrated omissions based on

the notes taken. The edits were left in track-changes mode to allow visibility on the evolution of the development process. There were two successive versions of the best practices document based on community member and researcher feedback. Everyone who participated in virtual meetings, whether they attended the follow-up joint meetings or not, were sent a final best practices document for their review.

Based on the discussion at meetings, the document that was developed included two sections. The first section entailed general guiding principles for CEnR partnerships and the second section included guiding principles for CEnR partnerships specific to COVID-19 testing. While both researchers and community members had common views regarding the general principles for CEnR partnerships (Section 1 Best Practices Document) such as the need for transparency and accountability, there were some differences in where each group focused during the development process. In both separate and joint meetings, researchers spent significant time wordsmithing or changing words in the best practices document so that it was more precise or relevant to health equity and community concerns. Researchers emphasized how words could best convey the community's interests and health concerns in a partnership. This ensured that researchers in the partnership had a clear responsibility to be transparent and work to minimize hardships and risks on the communities with whom they were in partnership in response to concerns regarding research harms raised by community members and researchers in meetings. Community members focused more on practical actions to address health equity in their community, such as empowering community members through health education and removing economic factors that prevent community members from accessing healthcare. Community members also discussed ways to address challenges of the community and engage in advocacy activities to promote health equity (e.g., public counsel hearing). Some also wanted to

address mental health issues caused by COVID-19. The community's general concerns around addressing health equity in their community were affirmed by researchers, leading to the development of principles that supported actions that could lead to equitable health care outcomes in COVID-19 testing (e.g., Best Practice #2.3 and #2.6 in Section 2 of the Best Practices Document). The final best practices document reflected themes relating to SEBI (Social, Ethical, and Behavioral Implications) factors, trust, accountability, commitment, and transparency. An overview of representative elements of the best practices document is provided below.

Preamble

The community members felt strongly that a preamble was needed to provide justification for the use of best practices in a CEnR partnership. The preamble acknowledged the harms committed by health care and academic institutions. It also detailed SEBI factors (e.g., lack of transportation) that posed barriers to equitable health care access and services. For example, the preamble starts by saying: "We acknowledge the root causes of COVID-19 disparities and mistrust include structural racism in health care delivery and research, low health literacy, lack of access to information and awareness of health services, lack of transportation, and other social determinants of health." The words of the preamble firmly planted the responsibility to remediate these barriers to health care on institutions such as research and health care organizations

Section 1: Foundational Practices for all CEnR Partnerships

The first section noted the importance of committing to respecting and valuing each partners' contributions, committing to being held accountable through a memorandum of commitment, and committing to be transparent about what is needed and clearly communicating

relevant information. As an example, Best Practice #1.3 stated the following: "Partners commit to transparency around contributions and recognizing how the CEnR partnership activities and research outcomes benefit each organization, the community, and community members." Section 1 also built upon the preamble's focus on institutional transformation and initiative as a first step in ameliorating wrongs by noting that partners needed to identify, understand, and address any actions that could cause mistrust such as power dynamics. This was shown in Best Practice #1.4: "Partners commit to identifying, understanding, and addressing any actions that can cause mistrust for each organization, the community, and community members." Partners also needed to commit to actively participating in the dissemination of what is learned from the research and other activities that emerge from the partnership to promote health equity: "Partners commit to actively participating in the dissemination of what is learned from the research and other activities that emerge from the CEnR partnership" (Best Practice #1.7).

Section 2: Practices for Social, Ethical, and Behavioral Implications (SEBI) of COVID-19 Testing

The second section of the best practices document focused more specifically on the practices relevant for a CEnR partnership for COVID-19 testing. There was an emphasis on identifying local leadership and organizations to support partnership goals before a health crisis: "Identify and outreach to local community-based organizations to build champions or coalitions in proximity of these entities to leverage existing relationships (Best Practice #2.1)."Study participants also reported that it was necessary to elicit the perspectives and experiences of community members and leaders to identify community challenges and concerns relevant to COVID-19, a necessary practice to address the concerns raised by community members in meetings. All COVID-19 testing related activities, including research or training, needed to be

tailored to the specific needs of the local community: "Ensure all research, health education, provider training, and other COVID-19 testing related activities are designed to meet the needs of local community and key community stakeholders (Best Practice #2.3). Related to this, it was important for the partnership to use various communication channels to communicate the potential impact of COVID-19 testing, including risks or benefits, to the local community. Like the first section, there was a focus on the partnership working to mitigate risks that could impact the local community and its members: "Acknowledge the historical hardships; all financial and non-financial costs of COVID-19 as well as commit to minimizing them" (Best Practice #2.6). Participants defined financial risks as monetary costs associated with COVID-19 testing, whereas non-financial risks tended to refer to physical side effects of testing and struggles with deciding whether to take the test or not. Acknowledgement was the basis for minimizing hardships on the community that were within partnership members' control. To make the partnership activities more relevant to the community, new knowledge learned was to be translated for clinical practice. An example best practice of this was: "Commit to a Learning Health Care Community and going beyond the transactional health care model to an investment in a long-term continuum of care for optimal health outcomes" (Best Practice #2.7). Community members particularly talked about the importance of application of partnership practices to the community. From participant feedback, a glossary was added to the document to help define some terms for greater clarity.

Discussion

A best practices document for CEnR partnerships was co-developed between our research team, researchers and community members with CEnR experience. There is limited research on the process of developing best practices for CEnR partnerships; more research has

explored principles (e.g., values to abide by in CEnR) or outcomes of CEnR partnerships.[12,13] Though we focus on the process of developing best practices with a specific CEnR partnership that may not be transferable to all CEnR partnerships, future research can build upon our research by examining different CEnR partnerships for better understanding and application of our results. It was important for us to explore the process of co-developing best practices with our community partners to better understand ways partnerships can be more effective in promoting greater health equity for underserved communities.[13] Organizing a retreat such as we did with participants, has been shown to have a positive impact in that it promotes active engagement of participants and helps stakeholders better understand their role in a participatory project.[14] Despite a common goal to engage the community to consider their needs regarding health equity and COVID-19 testing, there were important differences in perspectives between community members and researchers. Researchers generally were more focused on the process of creating a best practices document that would be responsive and respectful of the community, whereas community members tended to be more interested in the application of best practices in promoting the health of their community. Differences between the community and academic partners regarding best practices also arise in other partnerships such as in CEnR partnerships promoting early childhood development in underserved communities.[15] Although academic and community partners in a partnership created best practices that sought to guide them in addressing educational issues impacting young children, they had divergent definitions regarding the nature of research and actions needed to resolve educational issues in the community.[15] We asked community members for feedback on the best practices document, including researchers' wordsmithing, to reconcile differences. Community members' ideas regarding actions to address health equity in their community and researchers'

revision of words to provide direction for addressing health equity were combined in the final best practices document. We co-developed best practices in Section 2 of the document that provided for identification and addressing of specific issues relevant to community members (e.g., Best Practice #2.2 and #2.3).

Community members in our study focused on what was needed to address health equity in their community, such as empowering community members through education and addressing economic factors that prevent community members from accessing healthcare. They were also interested in addressing common barriers to accessing COVID-19 testing, such as financial cost that has been found to be a barrier to underserved populations in other studies examining COVID-19 health dispairities.[13] In particular, one California-based CEnR partnership addressed community concerns regarding barriers to COVID-19 testing during the pandemic by co-developing best practices for COVID-19 vaccine equity.[16] Best practices included reducing financial burdens through no-cost vaccines for all regardless of immigration or insurance status.[16] Unlike our study, Washburn et al.[16] examined best practices to address a specific issue in their community rather than evaluate their process of engagement in the partnership. Best practices for the process of engaging in CEnR partnerships, inclusive of community member feedback, may allow for more equitable research practices and may be a useful tool for community members to advocate for research practices that are not harmful to their communities (e.g., Guidelines for Community Partnership Research: Executive Summary, 2014, https://csch.uconn.edu/wp-content/uploads/sites/2206/2017/03/Guidelines-for-Community-Partnership-Research.pdf.). Some community members also wanted to address mental health issues caused by COVID-19, which was not mentioned by the researchers. A CEnR partnership in England also found that community members were more motivated in

comparison to researchers to be involved in the partnership to promote social change in addressing mental health challenges for the underserved in their community.[13] We did not specifically address mental health concerns, but co-developed best practices, particularly in Section 2 of the document, that would allow for this issue and other community concerns to be identified and addressed.

Institutional bureaucracy and funding constraints make it difficult for researchers to have availability to support the wellbeing of communities over time through their research.[17,18] This may be a possible explanation for researchers in our study spending less time on discussing how to address community issues in comparison to community members. Researchers attempted to minimize the harm researchers could cause and to address the historic mistrust that underserved communities have had of researchers and health institutions through the editing process.[10] Researchers may also have wanted to make it clear that they have a responsibility to leverage their privilege through specific actions that build trust, balance power dynamics, and minimize hardships and risks on communities in the partnership. These responsibilities have been similarly suggested by Mullins et al[6] and Sheridan et al[8] when engaging communities in research. Overall, community members and researchers had similar perspectives regarding general best practices for CEnR partnerships, including the need for transparency and accountability. These best practices have also been identified as key ingredients for effective CEnR partnerships addressing social and health inequities in communities.[6,15,19]

Conclusions

Best practices were co-developed for CEnR partnerships promoting health equity. Community members and researchers had shared values regarding transparency and

accountability. Both groups had a strong desire to make sure that the partnership was responsive to the needs of the community. Where community members and researchers differed was on the focus of their concern regarding the best practices document. Researchers primarily were interested in defining the terms of the best practices document to guide researchers in being responsive and ethical in relationships with community members. Community members were largely concerned about the impact of COVID-19 on their communities and how that could be addressed through the partnership. These differences were reconciled through inclusion of both suggested researcher language promoting health equity and best practices that would allow for addressing community concerns regarding COVID-19 in the final document. Although factors of trust such as accountability and transparency were included in best practices, there was no focused assessment of trust between the parties involved in the process of co-developing the best practices document. Evaluation of trust building and maintaining trust in CEnR partnerships has not been explored widely in the literature.[20] Future research should assess the level of trust building and trust maintenance in CEnR partnerships, particularly those involving community members living in underserved communities. In addition, researchers could explore how community members and researchers implement CEnR and tailor CEnR partnership best practices to promote health equity for underserved communities. It would be particularly important to examine how researchers and community members with often differing perspectives and concerns maintain a CEnR partnership. The best practices document can be utilized as a template for CEnR partnerships that promote health equity for underserved communities. As we did in this study, researchers and community members with experience in CEnR can provide their views on best practices for promoting health equity, using our best practices document as a

basis for discussions. Best practices developed by other CEnR partnerships promoting health equity should be tailored to the specific community and partnership.

Figure 1: Co-development process of best practices by community members representatives, researchers, and research team.
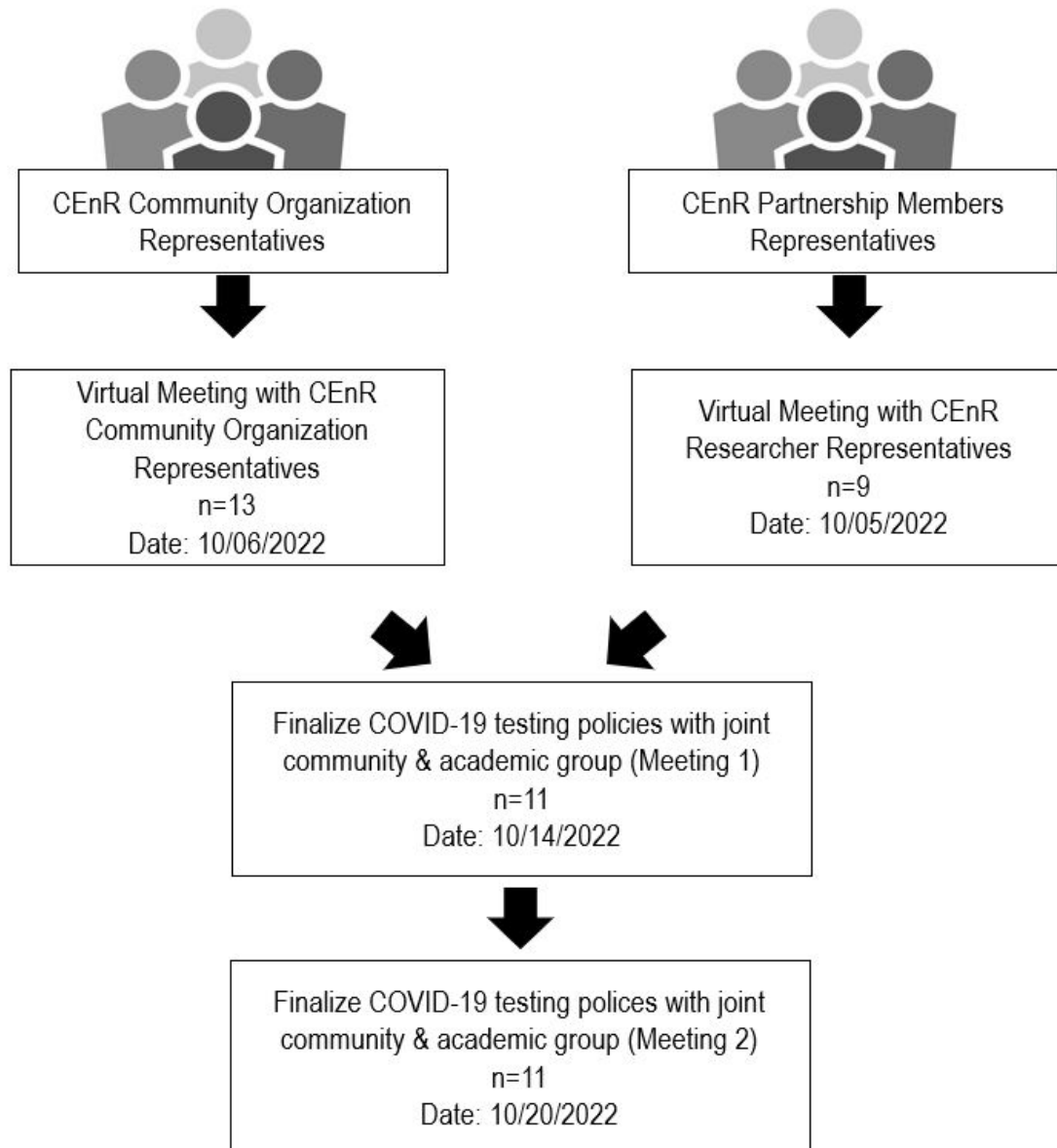
Table 1: Demographics

Race	Ethnicity	Age in Years	Gender
Black	Not Hispanic or Latino	48	Male
Not disclosed	Not disclosed	Not disclosed	Not disclosed
White	Not Hispanic or Latino	44	Female
White	Not Hispanic or Latino	46	Male
Black	Not Hispanic or Latino	38	Female
Black	Not Hispanic or Latino	35	Female
Black	Not Hispanic or Latino	Not disclosed	Female
Asian	Not Hispanic or Latino	52	Male
More than one race	Hispanic or Latino	63	Male
Not disclosed	Not Hispanic or Latino	Not disclosed	Not disclosed
Black	Not disclosed	55	Female
Black	Hispanic or Latino	56	Female
Black	Not Hispanic or Latino	49	Female
Black	Hispanic or Latino	18	Female
Not disclosed	Not disclosed	Not disclosed	Not disclosed
Black	Not Hispanic or Latino	66	Male
Black	Not Hispanic or Latino	45	Female
Black	Not Hispanic or Latino	62	Female
Black	Not Hispanic or Latino	73	Female
Black	Not Hispanic or Latino	38	Female
Black	Not Hispanic or Latino	74	Female
Black	Not Hispanic or Latino	65	Female
Not disclosed	Not disclosed	Not disclosed	Not disclosed
Black	Hispanic or Latino	42	Female
Black	Not Hispanic or Latino	71	Female
Black	Not Hispanic or Latino	71	Male
Black	Not Hispanic or Latino	58	Male

REFERENCES

1. Nana-Sinkam P, Kraschnewski J, Sacco R, Chavez J, Fouad M, Gal T, et al. Health disparities and equity in the era of COVID-19. J Clin Transl Sci . 2021;5(1): e99.

2. Louis-JeanJ, Cenat K, Njoku CV. Coronavirus (COVID-19) and racial disparities: a perspective analysis. J Racial and Ethn Health Disparities. 2020;**7**:1039–45.

3. Ali SH, Tozan Y, Jones AM, Foreman J, Capasso A, DiClemente RJ. Regional and socioeconomic predictors of perceived ability to access coronavirus testing in the United States: results from a nationwide online COVID-19 survey. Ann Epidemiol. 2021 Jun;58:7-14.

4. Beaney T, Clarke JM, Jain V, et al. Excess mortality: the gold standard in measuring the impact of COVID-19 worldwide? Royal Society of Medicine. 2020;113(9):329-34.

5. Dada D, Djiometio JN, McFadden SM, Demeke J, Vlahov D, Wilton L, et al. Strategies that promote equity in COVID-19 vaccine uptake for Black communities: a review. J Urban Health. 2022;99(1):15–27.

6. Mullins CD, Tanveer S, Graham G, Baquet CR. Advancing community-engaged research: increasing trustworthiness within community-academic partnerships. J Comp Eff Res. 2020;9(11):751–53.

7. Mullins CD, Wingate LT, Edwards HA, Tofade T, Wutoh A. Transitioning from learning healthcare systems to learning health care communities. J Comp Eff Res. 2018;7(6):603–14.

8. Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA, Advisory Panel on Patient Engagement (2013 inaugural panel). The PCORI engagement rubric: promising practices for partnering in research. Ann Fam Med. 2017;15(2):165–70.

9. Kauffman KS, Dosreis S, Ross M, Barnet B, Onukwugha E, Mullins CD. Engaging hard-to-reach patients in patient-centered outcomes research. J Comp Eff Res. 2013 May;2(3):313-24.

10. Natafgi N, Ladeji O, Hong YD, Caldwell J, Mullins CD. Are communities willing to transition into learning health care communities? a community-based participatory evaluation of stakeholders' receptivity. Qual Health Res. 2021;31(8):1412–22.

11. Armstrong MJ, Rueda J-D, Gronseth GS, Mullins CD. Framework for enhancing clinical practice guidelines through continuous patient engagement. Health Expect. 2017;20(1):3-10.

12. Sanchez-Youngman S, Prajakta A, Gonzales A, Dickson E, Myers K, Alaniz C, et al. Transforming the field: the role of academic health centers in promoting and sustaining equity based community engaged research. Front Public Health. 2023;11:1111779.

13. Wallerstein N, Oetzel JG, Sanchez-Youngman S, Boursaw B, Dickson E, Kastelic S, Koegel, P., Lucero, et al. Engage for equity: a long-term study of community-based participatory research and community-engaged research practices and outcomes. Health Educ Behav. 2020;47(3):380–90.

14. Thomas F, Hansford L, Wyatt K, Byng R, Coombes K, Finch J, et al. An engaged approach to exploring issues around poverty and mental health: A reflective evaluation of the research process from researchers and community partners involved in the DeStress study. Health Expect. 2021;24(Suppl 1):113–21.

15. Walsh ME, Adams SM, Ferguson S, Hearst, MO, Jones J-V, Wall S, et al. Inquiry in action: reflections on the implementation of best practices in child- and family-focused university–community partnerships. J Educ. 2021;201(1): 42–53.

16. Washburn KJ, LeBrón AMW, Reyes AS, Becerra, I, Bracho, A, Ahn, E, et al. Orange County, California COVID-19 vaccine equity best practices checklist: a community-centered call to action for equitable vaccination practices. Health Equity. 2022;6(1), 3–12.

17. Irby MB, Moore KR, Mann-Jackson L, Hamlin D, Randall I, Summers P, Skelton JA, et al. Community-engaged research: common themes and needs identified by investigators and research teams at an emerging academic learning health system. Int J Environ Res Public Health. 2021 Apr 8;18(8):3893.

18. Wang KH, Ray NJ, Berg DN, Greene AT, Lucas G, Harris K, et al. Using community-based participatory research and organizational diagnosis to characterize relationships between community leaders and academic researchers. Prev Med Rep. 2017 Sep 1;7:180-6.

19. Reich, SM, Kay JS, Lin, GC. Nourishing a partnership to improve middle school lunch options. Fam Community Health. 2015:38(1): 77-86.

20. Kim MM, Cheney A, Black A, Thorpe RJ, Cene CW, Dave GJ, et al. Trust in community-engaged research partnerships: a methodological overview of designing a multisite Clinical and Translational Science Awards (CTSA) initiative. Eval Health Prof. 2020;43(3):180–92.

Appendix

COmmunity Mistrust and Measures of Institutional Trustworthiness (COMMIT)

Best Practices of Trustworthy Community Engaged Research (CEnR) Partnerships to Address Social, Ethical, and Behavioral Implications of COVID-19 Testing

Preamble: We acknowledge the root causes of COVID-19 disparities and mistrust include structural racism in health care delivery and research, low health literacy, lack of access to information and awareness of health services, lack of transportation, and other social determinants of health. To address these root causes in Baltimore; structural barriers to trust, testing, treatment, and prevention of COVID-19, we must change processes, procedures, policies, and practices among health care and research institutions. Institutional transformation to advance trustworthiness is needed prior to asking patients and community members to trust in research and health care delivery to improve health outcomes and wellbeing among community members.

SECTION 1: FOUNDATIONAL PRACTICES FOR ALL CEnR PARTNERSHIPS

Best Practice #1.1 – *The goal*
Each organization commits to partnering in the development of a shared mission, vision, goals, and memorandum of commitment of the newly established CEnR partnership. The CEnR partnership should provide long-term value and align with the needs and core values of participating institutions.

Best Practice #1.2 – *Value and accountability*

Partners commit to respecting and valuing each organization's contribution to the CEnR partnership's mission. Partners will hold themselves accountable and each other accountable to the memorandum of commitment.[1]

Best Practice #1.3 – *Commitment to the community*
Partners commit to transparency around contributions and recognizing how the CEnR partnership activities and research outcomes benefit each organization, the community, and community members.

Best Practice #1.4 – *Acknowledge our past mistakes*
Partners commit to identifying, understanding, and addressing any actions[2] that can cause mistrust for each organization, the community, and community members.

Best Practice #1.5 – *Commit to transparency*
Partners commit to fully disclosing what is needed and clearly communicating all information relevant to the CEnR partnership and each organization, the community, and community members.

Best Practice #1.6– *Mutual benefits*
Partners commit to disclosing any conflicts of interests or power dynamics that foster mistrust. Partners will work toward a common goal and honor integrity.

Best Practice #1.7 – *Takeaways to promote health equity*
Partners commit to actively participating in the dissemination of what is learned from the research and other activities that emerge from the CEnR partnership.

SECTION 2: PRACTICES FOR SOCIAL, ETHICAL, AND BEHAVIORAL IMPLICATIONS (SEBI) OF COVID-19 TESTING

Best Practice #2.1 – *Local leadership communication*
Identify and outreach to local community-based organizations[3] to build champions or coalitions in proximity of these entities to leverage existing relationships. Ideally, there would be prior engagement to be proactive before a crisis.

Best Practice #2.2 – *Identify community challenges*
Engage community members and leaders for their perspectives and insights into community challenges and concerns related to COVID-19 testing.

---

[1] Memorandum of commitment refers to the expectations of each partner in a partnership. The memorandum of commitment to be developed will consist of terms of agreement for community members and researchers in a CEnR partnership for COVID-19 testing that is acceptable to both the community and academic organizations.

[2] Actions that may cause mistrust may be intentional or unintentional.

[3] Community-based organizations such as business owners, faith-based institutions, health service providers, colleges, student groups, and government officials.

Best Practice #2.3 – *Tailor key COVID-19 activities*
Ensure all research, health education, provider training, and other COVID-19 testing related activities are designed to meet the needs of local community and key community stakeholders[4].

Best Practice #2.4 – *Communication of community value*
Clearly communicate the value and potential impact of COVID-19 testing to the local community and key community stakeholders[4] and use various communication channels.

Best Practice #2.5 – *Risks and uncertainty: Honesty*
Clearly and honestly communicate any risks to COVID-19 testing individual community members or the community at large and work to mitigate risks.

Best Practice #2.6 – *Acknowledge and address the burden on the community*
Acknowledge the historical hardships; all financial and non-financial costs of COVID-19 as well as commit to minimizing them.

Best Practice #2.7 – *Share learnings and translate into clinical practice*
Commit to a Learning Health Care Community[5] and going beyond the transactional health care model to an investment in a long-term continuum of care for optimal health outcomes.

Best Practice #2.8 – *Long-term consequences of COVID-19*
Identify and address the potential socioeconomic, psychosocial, and physiological implications of COVID-19. Elicit community concerns related to the health disparities that may arise as we learn more about the disease.

---

[4] Key community stakeholders such as seniors, youth, homeless, racial and ethnic minorities, individuals with disabilities, veterans, immigrants and refugees, faith-based organizations, persons with substance use disorders, and non-English speaking individuals.

[5] Learning Health Care Community expands on the National Academy of Medicine's learning health care system model to include active and continuous stakeholder and community engagement (Mullins et al. 2018)

SECTION 3: GLOSSARY OF TERMS

Accountability – Hold each other responsible for successfully accomplishing objectives of the partnership in order to achieve the mission of the partnership (according to the National Institutes of Health, Office of Management). https://hr.nih.gov/working-nih/competencies/competencies-dictionary/accountability

Burden – The term burden encompasses health, social, political, environmental, and economic factors that impact the individual and society (according to the Centers for Disease Control and Prevention)

COVID-19 – Disease caused by a naturally arising virus—the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) (according to National Institutes of Health). https://covid19.nih.gov/sites/default/files/2021-05/NIH-Wide-COVID-19-StratPlan_2021_508_1.pdf

COVID-19 Testing - test looking for the virus that causes COVID-19, by testing specimens from your nose or mouth (according to Centers for Disease Control and Prevention). https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/testing.html

Cost – combined costs, in dollars and other impacts, as the result of a disease such as COVID-19. This includes pain, lost wages, caretaker costs, mental health effects (according to National Health Council). https://nationalhealthcouncil.org/additional-resources/glossary-of-value-assessment-terms/

Health Equity – the opportunity for everyone to attain their full potential for health and well-being and to be as healthy as possible (according to World Health Organization and Centers for Disease Control and Prevention). https://www.who.int/health-topics/health-equity#tab=tab_1 & https://www.cdc.gov/healthliteracy/learn/index.html

Health Literacy – degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others; and the degree to which organizations equitably empower individuals to find, understand and use information and services to inform health related decisions and actions for themselves and others. (according to Centers for Disease Control and Prevention). https://www.cdc.gov/healthliteracy/learn/index.html

Learning Health Care Community – partnership among health care providers, researchers, and administrators engaging area residents in on-going communication to establish trust, remain healthy, and improve health literacy before treatment is needed (according to The PATIENTS Program, University of Maryland School of Pharmacy). https://www.pharmacy.umaryland.edu/programs/the-patients-program/what-we-do/learning-health-care-community/

Misconduct – intentional, knowing, or reckless behavior in the research partnership that is viewed by members of the partnership and community stakeholders as highly unethical and illegal (according to National Institute of Environmental Health Science).https://www.niehs.nih.gov/research/resources/bioethics/glossary/index.cfm#research-misconduct

Provider – Any organization, institution, or individual that provides health care services to individuals or groups impacted by medical conditions (according to Centers for Medicare and Medicaid Services). https://www.cms.gov/glossary?term=provider&items_per_page=10&viewmode=grid&page=1

Risk – the product of the probability and magnitude (or severity) of a potential harm from COVID-19 testing or other testing for medical related conditions (according to National Institute of Environmental Health Sciences). https://www.niehs.nih.gov/research/resources/bioethics/glossary/index.cfm#a750753

Social Determinants of Health – conditions in the places where people live, learn, work, and play that affect health risks and outcomes; they are non-medical factors that influence health outcomes such as economic policies, housing, social systems (according to Centers for Disease Control and Prevention & World Health Organization) https://www.cdc.gov/socialdeterminants/about.html & https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1

Stakeholder – broad range of communities that have a stake in generating useful and relevant healthcare research evidence. These include, but are not limited to: patients, families and caregivers; patient advocacy groups; clinicians; researchers; purchasers of health benefits for employees and their dependents; payers (public and private medical health insurers); industry; hospital and health systems; policy makers; and training institutions (health and medical professional educators) (according to National Center for Advancing Translational Sciences). https://toolkit.ncats.nih.gov/glossary/stakeholder/

Structural Racism – embedded in societal, institutional, organizational, and governmental systems through formal and informal processes, procedures, and practices, limiting opportunities, resources, power, and wellbeing to marginalized racial and ethnic communities (according to National Institutes of Health) https://grants.nih.gov/grants/guide/rfa-files/RFA-DK-22-014.html & https://www.nimhd.nih.gov/resources/understanding-health-disparities/srd.html

Transparency – openly disclosing information that members of the partnership and community stakeholders would want to know, such as financial interests or risks to the community (according to National Institute of Environmental Health Sciences). https://www.niehs.nih.gov/research/resources/bioethics/glossary/index.cfm#a750754

Value – something that is worth having or desiring, such as happiness, knowledge, justice, or virtue (according to National Institute of Environmental Health Sciences).https://www.niehs.nih.gov/research/resources/bioethics/glossary/index.cfm#a750762