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Examining community-engaged and participatory research programs and projects

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Examining community-engaged and participatory research programs and projects

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Editorial: Examining community-engaged and participatory research programs and projects

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Editorial on the Research Topic
Examining community-engaged and participatory research programs and projects

The number of community-engaged and participatory research projects has greatly increased over the past few decades, contributing to both additions and refinements in methods and to statistics and stories about research studies and their outcomes. By integrating community expertise and experience, community-engaged and participatory research projects have increased knowledge and applied that knowledge to create social, environmental and political interventions and programs to benefit communities (1, 2). While a clearly recognized canon and discipline has yet to emerge, we have a sufficient foundation for dialogue that is so essential for advancing science (3–6). We assume dialogue will help establish a consistent use of terminology. However, inconsistencies in using terms about community engagement reflect inherent challenges in building evidence from descriptions of local contexts that appear to and that may lack empirical sameness (7, 8). The importance of recognizing local contexts for how we understand and talk about the integration of theory and practice for community engagement in research and for partnership and interpersonal dynamics has been elevated by the attention to middle range theory in Realist Evaluation (9–14). Understanding the local as more than merely a physical space takes on an added significance given the international and national contexts included within this Research Topic. Inconsistencies in the use of terminology is further confounded by the diversity of disciplines, by community histories and personal experiences, and by the different approaches to conducting research and creating knowledge that inform the research and author teams.

We selected the following keywords to indicate the scope of the Research Topic: Community-engaged research, participatory research, community involvement, research implementation. Additionally, and not surprisingly, this Research Topic includes reports that utilize the following terms: Community-based participatory research (Ramji et al.), community-engaged research (Hallmark et al.), both community-based participatory research and community-engaged research (Sanchez-Youngman et al.), community-academic engagement (Chinekezi et al.), community-academic partnership (Chak and Carminati), and participatory health research (Gilfoyle, Salsberg, et al.). Further, the varied forms of and terms for community engagement also allows researchers and community partners to utilize different study designs. The methodologies in this Research Topic include a mixed methods qualitative study (Sanchez-Youngman et al.), a social network analysis (Gilfoyle, Salsberg, et al.), a randomized control trial (Sinclair et al.), a historical or retrospective review (Wieland et al.), a deliberative democracy approach (Guan et al.), and a longitudinal cohort study (Mau et al.). As different as each is one from another, each design reflects an overarching commitment to the science of community engagement. The variation in terminology and differences in research methods challenges scholars internationally to integrate and synthesize not only study designs and methods but also research data.

The essays in this Research Topic are informed by a history of scholarship about engaged and participatory research and their record of achievement in improving community health outcomes. Our editorial team sought to make a unique contribution to the literature by encouraging each manuscript to demonstrate methodological rigor and self-reflectivity. From problem development through outcome assessment, implementation and dissemination, self-reflection in the form of critical consciousness can assume many forms. Our editorial intention to critical reflection in the assessment of context and strategies for overcoming bias is evident in a study that reviews and reflects on discourses about public and patient research engagement within global and national contexts, recommending public and patient leadership of health research and the development of effective partnerships for co-learning that could then drive policy (Gilfoyle, Macfarlane, et al.). Another study, references Leadership Complexity Theory, exploring effective leadership amidst complexities within community-academic partnerships in Germany (Chak and Carminati). Yet another study pursued a nuanced and multidimensional social network analysis for conceptualizing, operationalizing and measuring trust within participatory partnerships (Gilfoyle, Salsberg, et al.). Alternatively, another study advocates academic partners move beyond measuring trust to demonstrate they are trustworthy (Chinekezi et al.). We believe self-reflection informs the study of an extended community's engagement with diabetes across geographically distant locations (Andersen et al.). We encourage you as readers to determine whether the studies in this Research Topic pursue self-reflection along with other forms of commentary and critique.

Studies within this Research Topic specifically highlight the importance of local context. One research team engaged healthcare workers in Belgium in dialogue about pandemic-related issues to study participant expectations and experiences and how social position, role status and power dynamics influenced that dialogue (Nguyen et al.). A comparative case study of physical activity promotion closely examined co-creation of an intervention through cooperative planning and the subsequent transference and implementation of that intervention into three settings (Popp et al.). Comparisons of local contexts and the application of knowledge are at the center of the Family Listening/Family Circle Program with its focus on family communication and connectedness to culture and language; the study authors recommended community action projects in which participants serve as agents for change by developing community solutions based on indigenous values and practices (Rae et al.). The focus on specific local contexts in these reports may appear to accentuate the contrast between the research goal of developing generalizable knowledge and program evaluation with its focus on outcomes within specific localities. This suggested distinction begins to erode with the emergence of discourse around the diffusion of innovation, knowledge transfer, translation, implementation and dissemination, all of which can be understood as middle range theories.

The immediacy of the study topic reported on may itself demonstrate a self-reflective point of departure as is evident in a qualitative research study focused on ways to reduce social isolation and enhance mental and physical wellbeing before and during the pandemic (Ramji et al.). Reflection on the moment appears within work to create a peer-led intervention to promote COVID testing in a public housing community (Plunk et al.). In another study, community academic partnerships utilized the approach of Paulo Freire to develop a study in which the community members become agents of change through their identification and commitment to work on issues of importance to them (Rae et al.). Similarly, a study pondering challenges involved in identifying domains and competencies to inform an educational program included outcomes involving interpersonal skills and partnership development, requiring introspection by trainees in clinical and translational science (Hallmark et al.).

This Research Topic also includes manuscripts that reflect on how institutional policies, practices, and the infrastructures that have emerged to support research implementation might affect partnership and scientific inquiry. For example, institutional and community critiques and challenges were explored through a summary of an 18-year community-based participatory research (CBPR) partnership in Southeast Minnesota (Wieland et al.). In another example, U.S.-based research institutions were challenged to address the minimal contributions of community voices and perspective within their research policies and practices (Eder). Further, findings from engaging "champion teams" from three very different academic health centers were presented as a way to improve organizational policies and practices to support equity based CBPR/CEnR (Sanchez-Youngman et al.). Another project involved developing a Principles of Trustworthiness toolkit to support how academic medical centers respond to and demonstrate to community partners that they are deserving of the community's trust as they work to advance health and social justice (Chinekezi et al.).

Studies in this Research Topic identify ways that community-engaged research can improve our understanding of individual and community outcomes and our ability to achieve them. In addition to structural barriers to engaging Oregon's Hispanic and Latino community members in cancer early detection research, the authors learned there was a low-level of community awareness of early detection cancer research, uncertainty about the benefits of research participation and few real opportunities for research participation within the community (Currier et al.). In study of a

South African community, authors employed a modified random-route procedure to administer a standardized questionnaire in order to assess the extent to which community members were informed, consulted, involved and empowered to participate in two local public health projects (Mthembu and Chimbari). The authors concluded that while community members were largely educated, involved and informed, the projects lacked development of intrapersonal and personal project components that would better position community members to benefit. A longitudinal cohort study involving Native Hawaiian and Pacific Islanders created opportunities for cultural sharing and education, supporting generational change around diabetes (Mau et al.). Authors considered how deliberative democracy activities could successfully engage citizens of African Ancestry around the pros and cons of targeted screening for breast and ovarian cancer (Guan et al.). The approach resulted in sharing diverse and well-informed views, potentially avoiding misinformation. We also read about the testing of a Native-based nutrition and hypertension action oriented project, created using a participatory process with engaged American Indians and Alaska Natives (Sinclair et al.).

In the spirit of asserting agency and self-reflection within the cultural practices (15) that facilitated the development of this Research Topic, the editorial team identified challenges to the production of knowledge through peer review and publication. We were challenged by the process for identifying peers qualified to review each manuscript, beginning with the effort needed to identify and recruit qualified volunteer reviewers. This challenge may potentially be attributed to institutional expectations about faculty and scholars' responsibilities and priorities. We note with disappointment the withdrawal of a few manuscripts, perhaps due to irreconcilable cultural differences between local beliefs, practices and epistemological perspectives that diverge from a global tradition involving progress, imperialism, specialization and hierarchy. The review process may itself be critiqued as an academically driven process for exercising power over knowledge through the encouragement to correction and conformity with discursive structures that is both a model of and a model for a hegemonic epistemology (16–18). We acknowledge that the absent studies and their stories impeded the inclusion of diverse perspectives on knowledge production and the sharing of stories that diminishes science.

We also acknowledge that no commentaries were submitted that explored traditional measures of academic success such as securing grant funding or publication. These key metrics for community engaged scholarship now more commonly include expectations of joint academic and community member involvement. Common measures of scholarly accomplishment in combination with the scientific understandings of expertise and objectivity seem to be in tension with the goals of changing community-engaged health improvement research practices and policies, particularly with respect to the local dissemination and analysis of findings, to sustaining successful projects and partnerships, and policy development. It appears that current metrics of scholarly accomplishment represent biases that indicate misalignment with community-engaged, community-involved, community-based and participatory research practices. We further suggest that these metrics impede community members' willingness to engage and participate in (clinical) research and ultimately benefit from science (19).

At a fundamental level, all science requires self-reflection. We have considered how community-engaged and participatory research benefits from the deep knowledge, lived experience, and expertise of community members (15). In order for middle range theories to help community-engaged and participatory research teams navigate the theory to practice divide, we must understand both the relative consistency of biophysical interactions and the relative distributions of shared expectations and shared meanings among those involved. As community members increase their involvement in all aspects of the research enterprise and as they focus on addressing and improving community health, additional attention and self-reflection are needed to examine and explore the intersubjectivities encountered by individuals within communities who are both researchers and research participants. For now, the diversity of approaches in this Research Topic offers us an opportunity to celebrate different ways of knowing achieved through community research partnerships.

Author contributions

ME initiated the Research Topic and took the lead in developing this introduction. KD'A, MY, and JO all edited the materials included in this Research Topic. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Exploring the Multidimensionality of Trust in Participatory Health Partnerships - A Network Approach

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Introduction: Previous studies have identified "trust" as a key mechanism to achieve sustainable partnerships in participatory health research, which themselves can represent social networks. A recent review discussed the potential for social network analysis to investigate the development and maintenance of trust and its effects on partnership functioning in participatory health research partnerships. This review also recommended considering a comprehensive, nuanced and multidimensional approach to conceptualizing, operationalizing and measuring trust in research partnerships. Thus, this study aims to explore empirically the conceptualizing, operationalizing and measuring of trust in a multidimensional manner, approaching each trust dimension as an individual trust network, as well as combined as an overall trust network.

Methods: We sampled the whole network, recruiting from a newly established network of 57 individuals that must collaborate to achieve a common goal. These individuals represented academic, service and community organizations of an existing participatory partnership, the *Public and Patient Involvement Ignite Network* in Ireland. Of the 57 individuals invited to take part in the study, 75% ($n = 43$) individuals completed the network survey. A survey about trust was designed based on literature in the area and was administered via Qualtrics. The survey included eight network questions: one on collaboration, and seven on specific dimensions of trust. From this, we constructed a network for each trust dimension. We compared several core network measures of each to identify structural differences between the dimensions of trust. To statistically validate them, we compared them to a random and preferential null model.

Results: All the networks had a high reciprocity but were decentralized. Key differences were identified across trust dimensions, particularly in terms of integrity and shared values, visions and goals. None of the networks compared well to the null models indicating participants did not randomly or preferentially (based on how much trust they receive for a particular trust dimension) trust other partners.

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Discussion/Conclusion: This novel empirical social network analysis of trust in a real-world partnership elucidates the nuances and multidimensional nature of trust. This provides support for expanding this research direction to enhance understanding of and interventions for trust in participatory health research.

Keywords: trust, social network analysis, social networking, participatory health research, public and patient involvement (PPI), patient participation (patient engagement), community participation, community-based participatory research (CBPR)

INTRODUCTION

Participatory health research (PHR) has been gaining recognition on a global scale as an approach that helps to bridge the gap between knowledge and action by promoting culturally appropriate and contextually relevant research findings (1–3). Grounded in principles of social action, justice and emancipatory philosophy, PHR ensures that those who will benefit from the research findings are at the heart of the decisions making (4, 5). PHR serves as an umbrella term encompassing a variety of collaborative research approaches (i.e., community-based participatory research, integrated knowledge translation, public and patient involvement). Although these approaches may differ in origin and heritage, they all strive to bridge this gap between knowledge and practice by promoting inclusivity, while ensuring all partners for whom the research serves to benefit are actively engaged in the research process (2).

With an uptake of PHR, understanding its impact as an approach has been at the forefront for researchers in this space (1, 3, 6). Challenges remain in conceptualizing and thus articulating impact in PHR, in part due to the complex, non-linear and context-specific nature of the approach. A 2012 review by Jagosh et al. (7) highlighted several key benefits of PHR, with an emphasis on partnership synergy as a universal feature of the collaborative process necessary for building and sustaining partnerships that create resilience, sustain health-related goals, and extend program infrastructure while creating new and unexpected ideas and outcomes. Jagosh et al. (8) further explored what supports partnership synergy in successful long-term community-based participatory research partnerships. Building and maintaining *trust* was identified as a key mechanism in this process. However, Jagosh et al. (8) treated trust as a 'black box' concept without unpacking its internal dimensions and processes.

A 2022 review by Gilfoyle et al. (9) sought to address this gap by exploring how trust is conceptualized, operationalised and measured in both PHR and social network literature. Specifically, PHR partnerships can be seen as a *social network,* defined as *connections* (i.e., *edges*) among *people* (i.e., *nodes*), organizations, or other social actors; *social network analysis* is a methodology for describing and measuring these contextual and relational dynamics among and between social actors (10). Authors from this review (9) posited that social network analysis provides tools for investigating the development and maintenance of trust and trustworthiness and their effects on partnership functioning within PHR social networks (11). Social networks have been used to explore trust in education (12), workplaces (13, 14), flood risk management (15) and even health partnerships (16, 17) but trust is not consistently and reliably conceptualized, operationalised and measured, and is often treated in an oversimplified manner. Thus, a comprehensive, nuanced and multidimensional approach to conceptualizing, operationalising and measuring trust in research partnerships is needed. When discussing the multidimensions of trust, we mean that, "the lack of consensus surrounding a definition of trust speaks to its complexity as a concept. Specifically, it is not only a psychological phenomenon but also a social one, and it can vary for each individual, across different social interactions, and across disciplines" (9).

This paper seeks to explore empirically the conceptualizing, operationalising and measuring of trust in a multidimensional manner, looking at each trust dimension as an individual trust network, and combined as an overall trust network. It is important to emphasize that in social network analysis, the networks represent the association of connections *between* individuals/organizations, not the individuals/organizations themselves.

Using an existing participatory research partnership as a case, we explore the following:

1. What are the trust characteristics at baseline of a PHR network?
2. Should trust be looked at multidimensionally?
3. Is there a relationship between the different trust networks explored?
4. Can these different networks of trust be combined to create an overall trust network? And if so, what is the relationship between the combined trust network and individual trust networks?

METHODS

This study was granted ethics approval from the University of Limerick Education and Health Sciences Research Ethics Committee (#2021_03_16_EHS).

Setting

PPI Ignite Network

In 2017, the Irish Health Research Board (HRB) and Irish Research Council (IRC) funded *PPI Ignite Teams* at five universities across Ireland, to build capacity for public and patient involvement (PPI) in health research. In 2021, building on the work from the Ignite Programme, the HRB and IRC funded a *PPI Ignite Network* (2021–2026) at seven universities across Ireland, consolidating and building on the work of PPI Ignite. The PPI Ignite Network "aims to provide a shared voice for PPI across Ireland, aiming to change the research culture, and an important contributor to improving health outcomes for the public" (18).

This Network brings together academic, service and community organizations that must collaborate in an efficient, synergistic and cohesive manner to plan, implement and evaluate the PPI initiatives set out by the network. (For further information on the PPI Ignite Network see: https://ppinetwork.ie/about-us/). The Network is comprised of seven universities, a national office, 10 national-level community partners who contribute to national level governance and activities and 39 local level partners who contribute to governance and activities at one university in the Network. This participatory partnership serves as a case in which to observe the dimensions of trust in action for this study.

Research Advisory Group

The Research Advisory Group for this study is comprised of four research partners representing academic, service, or community organizations in the PPI Ignite Network. All members were involved in the preceding PPI Ignite grant (2017–2020) and thus have a track record of working together. This group provided input and approval for the research objectives for this social network analysis and were similarly involved with the previous scoping review (9). The group was also involved in designing the network survey, specifically by ensuring the applicability and readability of the survey. One Research Advisory Group member has been further involved in the interpretation of the results and authorship of this manuscript (co-author MM).

Sample

Using a sociometric ("whole network") approach, this study aimed to recruit 57 individuals representing academic, service and community organizations acting as co-investigators and collaborating partners in the PPI Ignite Network. Each individual was invited to complete a network survey.

Network Survey

A network survey is a questionnaire used to generate names and connections among individuals in a network (19, 20). The network survey in this study was designed based on the dimensions of trust identified by Gilfoyle et al. (9) and in collaboration with the Research Advisory Group to ensure the appropriateness and readability of survey questions. The survey was administered electronically via Qualtrics software (Qualtrics software, Version May 2021 to August 2021). Survey questions included eight network questions: one question on collaboration from Leppin et al. (21) and seven questions that were found by Gilfoyle et al. (9) to be important dimensions of trust (see **Table 1** below for a description of how each dimension was defined and measured).

Given that the networks represent the association of connections *between* individuals/organizations, not the individuals/organizations themselves, asking these questions mapped eight distinct networks. Although the overall sample consisted of the same participants, each network question mapped a distinct network about a different dimension of trust. We may then compare and contrast networks to explore, for example, if there are differences between trust networks for reliability compared with vulnerability, and so on.

To generate a network, each participant was invited to name up to seven organizations when answering the network survey questions (the same seven organizations for each question). They were asked to consider the *individual person* in the network representing these organizations when responding to the network questions. This was a noteworthy distinction as we were interested in exploring the *partnership* collaboration and trust, not trust for the organization. A list of organizations in the PPI Ignite Network was included as an attachment to the survey for reference, but participants were free to name other organizations not listed.

The first network question was a *name generator* (22), asking participants to list up to seven organizations they have collaborated with on the PPI Ignite Network. We chose this number (7) from "The social brain hypothesis" (23, 24) which estimates five as an average inner layer for core relationships. Empirical work on these layers found that they were right skewed. To account for this, we allowed participants to name up to seven organizations (not all of which have to be used) (25). The network question and scale were informed by the work from Leppin et al. (21) assessing the intensity of collaboration from [lowest level] no interaction at all, networking, cooperation, coordination, coalition, to collaboration [highest level]. Associated definitions were provided for each intensity of collaboration. Following this, participants were asked to answer seven network questions, each tapping into a dimension of trust, for the same individuals generated in the collaboration question. For example, for one dimension of trust, *vulnerability*, participants responded to the following statement: "I would discuss with [name of network member X] how I honestly feel about my work, negative feelings and frustrations." The degree to which they related to the statement was assessed on a 5-point scale, from strongly disagree to strongly agree. The complete survey can be found in **Supplementary Material 1**.

Analysis

Initially we compared the survey responses to each other calculating the correlations between the survey response for each trust item. We then constructed and analyzed the eight social networks of interest (1 re: collaboration and 7 re: trust) to obtain individual and global (or network-level) measures (or properties) described below.

Individual-Level Measures

In-degree: represents how frequently a partner was trusted on a given dimension. In-degree gives the number of edges received by a node, i.e., the number of times a person was nominated by another individual in the network (19). We also obtained the *weighted in-degree*, which represents the sum of the strengths of agreement for each trust question (described further in analysis). As discussed by Valente, 2010 (19), in-degree is one of the most useful measures for researchers as it identified opinion

TABLE 1 | Descriptions of trust dimensions [based on Gilfoyle et al. (9)].

Dimension of trust	Definition	Network question
1 – Vulnerability	Describes the willingness of an actor (trustor) to be vulnerable to the actions of another actor (trustee). The trustor does not have complete control over how the trustee will behave and is thus, uncertain about how the individual will act, which also implies that there is something of importance to be lost, and in turn, risk involved. Therefore, to be vulnerable, there must be an opportunity for risk where the trustor must then decide if they are willing to take the risk of placing trust in the trustee. Furthermore, if there is the possibility of risk, this implies that there will be some level of uncertainty regarding how the trustee will behave. It is noted that if there is trust between partners, there is a lower level of uncertainty between how the trustee will behave. In summary, for this sub-theme we consider uncertainty and risk as necessary aspects of vulnerability.	"I would discuss with [name of network member X] how I honestly feel about my work, negative feelings and frustrations"
2 – Integrity	Concerns the extent to which the trustor thinks that the trustee will act in their best interest and the belief that the trustee will follow a set of principles, deemed acceptable by the trustor, such as they will say what is true.	"[name of network member X] keeps my interest in mind when making decisions"
3 - Reliability	Describes the confidence in and extent to which the trustor believes the trustee's will follow-through on commitments, perform a given task, and/or make decisions about something.	"[name of network member X] is dependable. For example, they stick to their word and makes sure their actions and behaviors are consistent"
4 - Ability	Describes an individual's (trustee) ability to perform a given task or make decisions about something based on their perceived skill set and competence from the perspective of another individual (trustor).	"I am comfortable asking [network member X] to take responsibility for project tasks even when I am not present to oversee what they do"
5 - Shared values, visions and goals	Highlights the need to have shared visions, values and goals in partnerships. Specifically, common goals, missions, and plans can promote trust.	"I feel that [network member X] shares a vision with PPI Ignite Networks vision and goals?"
6 - Power sharing and co-ownership	Sharing power, and fostering co-ownership in partnerships as a dimension of trust.	"I feel that [network member X] is open to discussion* about matters pertaining to the PPI Ignite Network" *Note: When we say open to discussion, we mean that this individual is willing to engage in frank, open and civil discussion (especially when disagreement exists). The person is willing to consider a variety of viewpoints and talk together (rather than at each other) and you are able to communicate with this individual in an open, trusting manner.
7 - Reciprocity	This sub-theme describes the presence of trust based on the notion that they think the trustee also trusts them back. Thus, if a trustor thinks that the trustee also trusts them, trust is thought (by the trustor) to be reciprocated (by the trustee).	"I feel that [network member X] trusts me"

leaders or "popular" individuals in a network as well as being the most robust measure of centrality to missing data. This measure allowed us to identify who are the most trusted individuals for each trust dimension.[1] We also calculated *betweenness centrality* which represents how many times a person lies on the paths between trusted partners, i.e., the frequency a node lies on the shortest path between all other pairs of nodes in the network (26). Betweenness centrality is a useful measure in this study because it identified those who occupy a strategic position in the network, acting as "gatekeepers" to those not currently connected in the network. Removing nodes with high betweenness can lead to the network becoming disconnected, i.e., breaking the structure of the network down into more than one component (27).

Network-Level Measures

Average In-degree: looks at the mean number of received nominations across the network. This helped us identify how high trust is overall in the network. *Clustering coefficient:* measures the degree to which there are dense pockets of interconnectivity in the network (i.e., clumpiness) (19). Thus, a high clustering coefficient means if you trust two people, they are also likely to trust each other. Measuring the clustering coefficient helped us to identify if there were certain trusting groups throughout the network. *Assortativity:* measures the tendency for nodes to connect to nodes that are similar to themselves (28). It is related to the notion of homophily (that nodes link to those similar to themselves). For example, assortativity is positive if people with a high in-degree have a higher tendency to connect to

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[1] We do not present out-degree as each organisation had a limit to how many organisations it could name (i.e., there is a maximum out-degree of 7). Also, not every organisation named was surveyed. Therefore, we only used the out-degree to calculate the reciprocity including in this calculation only individuals that were surveyed.

nodes who also have a high in-degree. Assortativity is negative if those with a high in-degree are more likely to connect with others of a low in-degree. *Reciprocity:* occurs when edges go both ways. For example, if both individuals agreed or strongly disagreed with the same trust dimension, then reciprocity was present. This was important to measure as reciprocity is described as an important mechanism of trust (29, 30). *Freeman Centralization about the In-degree:* measures whether the network is centered around a small group of individuals, i.e., the degree to which the edges of a network focus around an individual or a set of individuals (19). If the network was centralized, it meant that one or a few individuals were in a position of power and control; decentralized would imply the opposite, where the power and control were distributed across many individuals. These measures allowed us to compare the structural properties of trust dimensions.

Pearson Correlations

Before constructing the networks, we calculated Pearson correlations between each pair of survey questions where a correlation of one implied each entity answered the same response value to each question for everyone named. This gives an indication as to how similar the response to the individual trust items may be before taking a more fine-grained network approach.

Individual Trusts Networks

We constructed individual trust networks derived from each of the seven dimensions of trust explored (i.e., seven trust dimension questions) in the survey. This was done by assigning a value from −1 to +1 depending on the selection of strongly disagree to strongly agree (in intervals of 0.5 for the 5-point scale) for each network question. Specifically, when a participant responded 'agree', an edge weight of 0.5 was added, while "strongly agree" added an edge weight of one. An edge was not added if participants responded with "neither agree nor disagree," "disagree," or "strongly disagree" identifying only a presence of, or absence of, a trust edge. This is because, in alignment with the literature, we did not want to infer neutral agreement or disagreement with each statement as an expression of distrust. Specifically, distrust differs conceptually from trust (31) and more specifically stated by Jones (32), "the absence of trust is not to be equated with distrust."

From these seven trust dimensions, we created an 8th trust network we referred to as *combined trust*. For combined trust, we took all the edges from each of the seven trust dimension questions and assigned an average weight. Thus, if a participant strongly agreed with each question on the network survey, they were present in the combined trust network with a weight of one. If, for example, they strongly agreed with one question and disagreed with the rest, they had a weight of 1/7.

Spearman Correlations

On an individual level, we tested whether the nodes with the highest weighted in-degree and betweenness centrality were consistent in each network. We did this by ordering the nodes, from lowest to highest quantities (for weighted in-degree and betweenness centrality scores), and then performing a Spearman correlation on the rank. To maintain an increasing rank, distinct values were required (i.e., we did not include many nodes at degree 0 as they could not be ranked in a meaningful order), so we limited the correlation to the top 20 nodes in each measure. We only reported correlations that were significant below $p < 0.05$.

Finally, to statistically validate these results, we proposed two null hypotheses. The first randomly selected the number of neighbors for each node as well as randomized the value for their survey scores. This random null model would represent the case where participants randomly filled out the survey. From these, we created the networks as described above and compared the results to the random model.

The second simulation generated networks of the same size using the *preferential attachment* model (33). This model is designed to emulate many real-world complex networks where nodes aim to connect to popular nodes (i.e., high incoming connections for that trust dimension). From this, we identified if nodes are preferentially connected to nodes with a high degree. This yielded a complex network with a high clustering coefficient and Freeman centralization allowing us to statistically compare the values from the trust networks and identify whether people are connecting to organizations with high trust preferentially or if some other mechanism is responsible for the structure of the network.

For both models, a simulation ran 1,000 iterations measuring the same network quantities described above. From these simulations, the 2.5 and 97.5 quantiles for each network score were taken. If the value of the data was outside this range, we said the 95% confidence interval is outside the random or preferential model.

RESULTS

Of the 57 individuals invited to take part in the study, 75% ($n = 43$) individuals completed the network survey. This included 100% ($n = 8$) of the site leads and the national office, 80% ($n = 8$) of the national partners, and 69% ($n = 27$) of local partners involved in the study.

As shown in **Table 2**, findings indicated a statistically significant positive correlation across all trust dimensions ($p < 0.001$), but the positive correlations varied in the strength of correlation. For example, responses for trust dimensions 2 (integrity) and 3 (reliability) were the most highly correlated ($r = 0.70$), while trust dimensions 1 (vulnerability) and 6 (power sharing and co-ownership) were the most different ($r = 0.4$) these findings suggested that individuals who deem others to be reliable, often also thought they had integrity. Comparatively, if others agreed or strongly agreed that they would be vulnerable to a named individual, they were *less likely* to respond similarly to power sharing and co-ownership with that same-named other.

These nuances between trust dimensions were further explicated when exploring network measures for each one (i.e., weighted in-degree, number of edges) (shown in **Table 3** below). Like the findings discussed in **Table 2**, we saw the largest contrast between the networks for trust dimension 1 (vulnerability) and trust dimension 5 (shared values, visions and goals) and 6 (power

TABLE 2 | Pearson correlations for trust networks.

Networks (n = 59)	Combined Trust*	Trust network 1[a] (Vulnerability)	Trust network 2[b] (Integrity)	Trust network 3[c] (Reliability)	Trust network 4[d] (Ability)	Trust network 5[e] (Shared values, visions and goals)	Trust network 6[f] (Power sharing and co-ownership)	Trust network 7[g] (Reciprocity)
Combined* trust								
Trust dimension 1[a] (Vulnerability)	0.79							
Trust dimension 2[b] (Integrity)	0.87	0.67						
Trust dimension 3[c] (Reliability)	0.85	0.59	0.7					
Trust dimension 4[d] (Ability)	0.82	0.58	0.69	0.64				
Trust dimension 5[e] (Shared values, visions and goals)	0.73	0.55	0.59	0.57	0.47			
Trust dimension 6[f] (Power sharing and co-ownership)	0.73	0.4	0.56	0.66	0.44	0.66		
Trust dimension 7[g] (Reciprocity)	0.82	0.56	0.64	0.68	0.67	0.53	0.6	

Sum of scores of trust questions divided by the number of trust questions (7) [a]Trust Network 1 question "I would discuss with [name of network member X] how I honestly feel about my work, negative feelings and frustrations," [b]Trust Network 2 question "[name of network member X] keeps my interest in mind when making decisions", [c]Trust Network question: "[name of network member X] is dependable. For example, they stick to their word and makes sure their actions and behaviours are consistent; [d]Trust Network 4 question: "I am comfortable asking [network member X] to take responsibility for project tasks even when I am not present to oversee what they do," [e]Trust Network 5 question: "I feel that [network member X] shares a vision with PPI Ignite Networks vision and goals?", [f]Trust Network 6 question: "I feel that [network member X] is open to discussion about matters pertaining to the PPI Ignite Network," [g]Trust Network 7 question: "I feel that [network member X] trusts me".

sharing and co-ownership), but also trust dimension 2 (integrity) to trust dimension 5 (shared values, visions and goals) and 6 (power sharing and co-ownership). For example, the number of edges for networks mapping trust dimensions 1 (vulnerability) and 2 (integrity) was nearly half that of trust dimensions 5 (shared values, visions and goals) and 6 (power sharing and co-ownership). This implied that people agreed or strongly agreed to statements about shared values, visions and goals as well as power sharing and co-ownership, but were much less likely to agree or strongly agree with statements about vulnerability and integrity. Trust dimensions 1 (vulnerability) and 2 (integrity) also had a lower weighted in-degree and were less likely to have reciprocal edges compared to trust dimensions 5 and 6. We further highlighted some of these findings in **Figures 1A–C** below, where we mapped three networks for trust dimensions 1, 5 and 6. These networks were chosen to visually demonstrate some notable structural differences at both the individual and network levels. At the individual level, node size was proportional to the weighted in-degree. Furthermore, when looking at **Figure 1A**. Network for Trust Dimension 1 – *vulnerability,* a cluster of four nodes appears to be disconnected from the network. This may be because although the study partnerships consist of lead sites that were part of the initial grant (2017–2020), as well as lead sites new to the second grant (2021–2026), all had the opportunity to bring in local partners that may not have existed in the first round. Thus, at the time of this survey, some were new to the network and had not yet had the opportunity to interact with other members of the partnership, although they may have interacted with each other. Therefore, they may appear in network maps (i.e., vulnerability) as isolated clusters.

On across-network *similarities*, we noted that the trust dimension networks were disassortative, indicating that the nodes with high in-degree were less commonly linked to those with high in-degree compared to nodes with a lower in-degree. Therefore, those who received a lot of incoming edges for a particular trust dimension network were not likely to connect to others who received a lot of incoming edges for that same trust dimension network. This contrasts with existing literature, as social networks tend to have positive values of assortativity where people often associate with those similar to themselves (34). Further, we saw that all trust dimension networks were relatively decentralized,

TABLE 3 | Social network analysis across trust networks.

Networks (*N* = 59)	Number of edges	Weighted in-degree mean (std)	Clustering coefficient	Weighted assortativity	Weighted In-degree centralization	Reciprocity
Combined trust	136	3.13 (4.45)	0.25	−0.31	0.32	0.46
Trust dimension 1[a] (Vulnerability)	73	1.70 (2.96)	0.07	−0.16	0.18	0.29
Trust dimension 2[b] (Integrity)	73	1.56 (2.70)	0.07	−0.24	0.19	0.36
Trust dimension 3[c] (Reliability)	118	3.14 (4.35)	0.12	−0.24	0.27	0.38
Trust dimension 4[d] (Ability)	90	2.20 (3.73)	0.04	−0.25	0.21	0.31
Trust dimension 5[e] (Shared values, visions and goals)	145	3.64 (5.60)	0.17	−0.28	0.33	0.48
Trust dimension 6[f] (Power sharing and co-ownership)	142	3.41 (5.01)	0.14	−0.3	0.28	0.45
Trust dimension 7[g] (Reciprocity)	109	2.41 (3.74)	0.11	−0.24	0.23	0.44
Collaboration	137	7.814 (11.173)	0.20	−0.26	0.66	0.45

[a] *Trust Network 1 question "I would discuss with [name of network member X] how I honestly feel about my work, negative feelings and frustrations,"* [b] *Trust Network 2 question "[name of network member X] keeps my interest in mind when making decisions",* [c] *Trust Network question: "[name of network member X] is dependable. For example, they stick to their word and makes sure their actions and behaviours are consistent;"* [d] *Trust Network 4 question: "I am comfortable asking [network member X] to take responsibility for project tasks even when I am not present to oversee what they do,"* [e] *Trust Network 5 question: "I feel that [network member X] shares a vision with PPI Ignite Networks vision and goals?",* [f] *Trust Network 6 question: "I feel that [network member X] is open to discussion* about matters pertaining to the PPI Ignite Network",* [g] *Trust Network 7 question: "I feel that [network member X] trusts me".*

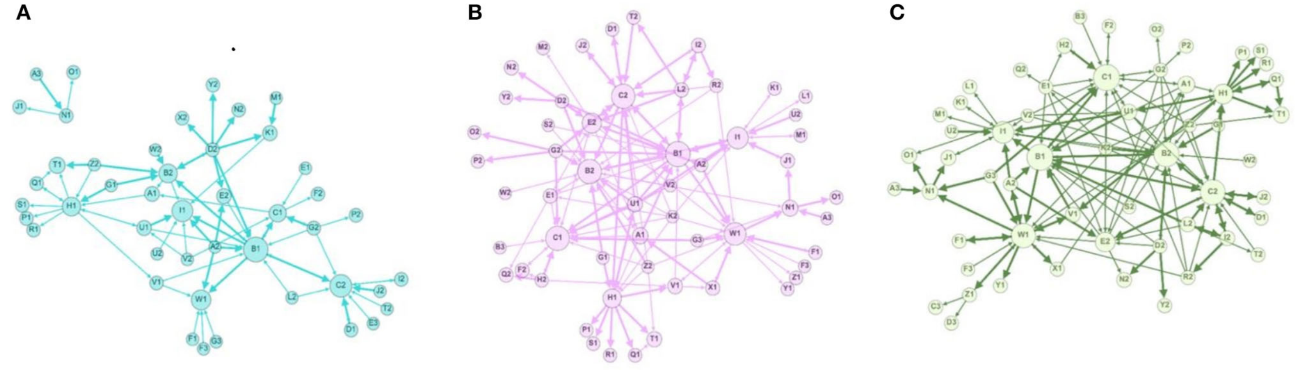

FIGURE 1 | Networks for trust dimensions 1 (vulnerability), 5 (shared values, visions and goals) and 6 (power sharing and co-ownership). **(A)** Network for trust dimension 1-vulnerability. This network was mapped by asking individuals to answer a question pertaining to vulnerability, specifically: "I would discuss with [name of network member X] how I honestly feel about my work, negative feelings and frustrations". **(B)** Network for trust dimension 5-shared values, visions and goals. This network was mapped by asking individuals to answer a question pertaining to shared values, visions and goals, specifically: "I feel that [network member X] shares a vision with PPI ignite networks vision and goals?". **(C)** Network for trust dimension 6-power sharing and co-ownership. This network was mapped by asking individuals to answer a question pertaining to power sharing and co-ownership, specifically: 93I feel that [network member X] is open to discussion* about matters pertaining to the PPI ingnite network".

indicating that edges were generally dispersed across nodes in the network.

To statistically validate the networks quantities in **Table 3**, we compared the results to the two null models described above, random and preferential. **Figures 2–4** show the values of the weighted in-degree, Freeman centralization on the in-degree and the reciprocity for each network as well as the two null models with the 2.5 and 97.5 quantiles around their means from the simulations. Neither model performed well in these measures for each network. The range in assortativity (found in **Supplementary Material 2**) was very large in the null models and all networks fell within the 95% confidence interval. The clustering coefficient (found in **Supplementary Material 2**) for each network was outside the 95% confidence interval for the random model, but within for the preferential model. Comparatively, for the other three measures, the actual values were rarely in the 95% confidence interval for either null model, implying that overall, none of the networks were well described by the null models.

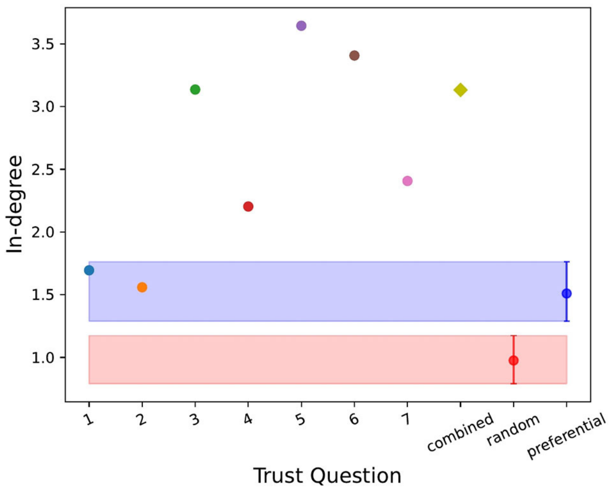

FIGURE 2 | The weighted in-degree for each trust question (i.e., dimension of trust), the combined trust network (yellow diamond) and the random (in red with the mean and 2.5 and 97.5 quantiles around it) and preferential (in blue with the mean and 2.5 and 97.5 quantiles around it) null models. Trust network 1 (vulnerability) and 2 (integrity) showed similar in-degree behavior to the preferential model, however the random model did not perform well as expected.

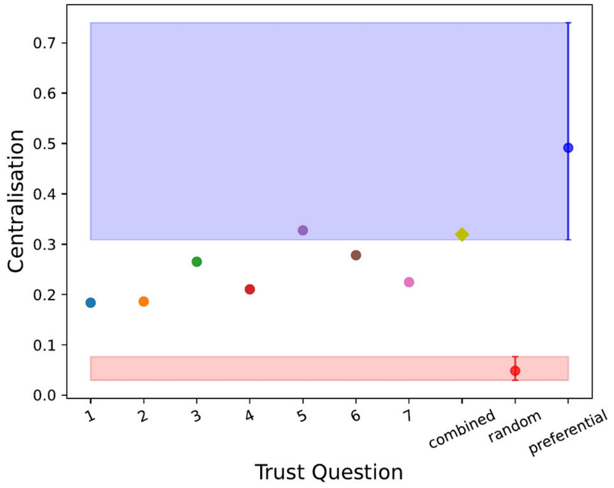

FIGURE 3 | The weighted Freeman centralization about the in-degree for each trust question (i.e., dimension of trust), the combined trust network (yellow diamond) and the random (in red with the mean and 2.5 and 97.5 quantiles around it) and preferential (in blue with the mean and 2.5 and 97.5 quantiles around it) null models. Trust questions 5 and the combined network showed similar behavior to the preferential model, however, the random model yielded low values of centralization.

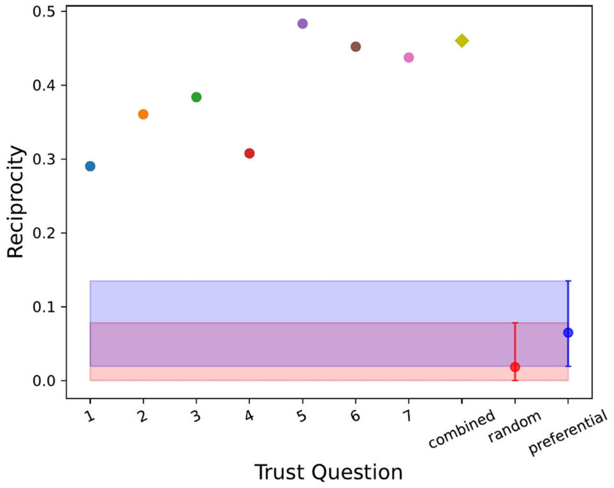

FIGURE 4 | The reciprocity for each trust question (i.e., dimension of trust), the combined trust network (yellow diamond) and the random (in red with the mean and 2.5 and 97.5 quantiles around it) and preferential (in blue with the mean and 2.5 and 97.5 quantiles around it) null models. All the networks were beyond the 95% confidence interval for each null model.

From this, we concluded that for each of the trust networks, neither the random nor preferential model successfully explained the data. Therefore, trust relied on some other mechanism for the formation of these networks. We also observed that the Freeman centralization scores here were low when compared to the preferential model, indicating that these networks were decentralized apart from trust dimension 5 (shared values, visions and goals). Similarly, all of these networks had high reciprocity relative to the two null models and thus reflect specific/authentic characteristics of the PPI Ignite Network under analysis.

Also in **Table 3**, we presented results for the collaboration network. This network utilized a different scale to that of the trust network questions, assessing the level of collaboration. On this scale each response connected the nodes with each increasing value implying further strength of collaboration. Each edge represented a score (i.e., weight) from 1–5 based on survey responses for collaboration [a similar process to the trust network scores described above (see *Individual trusts networks* in Analysis)]. This led to a higher weighted mean in-degree (7.814). Furthermore, the network had different properties compared to the others, such as a higher centralization (0.66).

Spearman Correlations

The following trust questions were found to be correlated by weighted in-degree: combined trust network and trust dimension 1 (i.e., network) (vulnerability) ($r = 0.45$, $p = 0.04$), trust dimensions 2 (integrity) and 3 (reliability) ($r = 0.46$, $p = 0.04$), trust dimensions 5 (shared values, visions and goals) and 7 (reciprocity) ($r = 0.52$, $p = 0.02$), trust dimensions 6 (power sharing and co-ownership) and 7 (reciprocity) ($r =0.56$, $p = 0.01$) and the strongest, trust dimensions 5 (shared values, visions and goals) and 6 (power sharing and co-ownership) ($r = 0.91$, $p < 0.01$).

For betweenness centrality, the following trust questions were found to be statistically significantly correlated ($p < 0.05$): trust dimensions 5 (shared values, visions and goals) and 6 (power sharing and co-ownership) ($r = 0.47$, $p = 0.03$), trust dimensions 4 (ability) and 6 (power sharing and co-ownership) ($r = 0.51$, p

= 0.02), trust dimensions 2 (integrity) and 4 (ability) ($r = 0.55$, $p = 0.01$), trust dimensions 3 (reliability) and 4 (ability) ($r = 0.56$, p=0.01), trust dimensions 3 (reliability) and 6 (power sharing and co-ownership)) ($r = 0.68$, $p < 0.01$). This implied that the highest-ranking individual nodes for each of these networks were very similar to one another.

Summary

In summary, when exploring trust in a multidimensional way using social network analysis, we identified key baseline trust characteristics of the PPI Ignite Network **(RQ#1)** based on 43 completed network surveys. Specifically, we found that the trust networks were relatively decentralized overall, indicating that the trust connections were not, from a network level, focused on a cluster of key individuals. Furthermore, the trust edges had a high degree of reciprocity, indicating that the trust edge often went both ways. As discussed previously, this is important as reciprocity has been discussed as an important mechanism of trust (29, 30). We also found a high mean weighted in-degree across the trust networks. This indicated that the same individuals have the highest number of incoming trust edges across the trust networks. However, the number of incoming trust edges differed depending on the trust network explored. Thus, although the same individuals received the highest number of incoming edges across the different trust networks, the *number* of edges differed. For example, the highest mean weighted in-degree for the integrity (trust dimension 2) was 1.56 trust edges, while for shared values, visions and goals (trust dimension 5), the mean weighted in-degree was 3.64.

This revealed some of the nuances and complexities of trust when looking at trust multidimensionally and from a network perspective **(RQ#2).** From the baseline characteristics explored, we noted some similarities across the different trust dimension networks (i.e., overall centralization), but also important network differences that may not have been revealed if looked at in a unidimensional or binary way (i.e., who do you trust?).

When further exploring the relationship between the different trust dimensions (i.e., networks) **(RQ#3)**, we found that they were positively correlated with each other at a statistically significant level but varied in terms of the strength of correlation i.e., trust dimensions 2 (integrity) and 3 (reliability) [$r = 0.7$] and trust dimensions 5 (shared values, visions and goals) and 6 (power sharing and co-ownership) [$r = 0.66$]. This indicated that certain trust dimensions were more alike than others.

Finally, we found that when exploring trust in combination (i.e., all trust dimension networks combined into one overall trust network compared to individual trust networks) **(RQ#4)** the trust network with the largest network measures (i.e., reciprocity) tended to dominate the network properties of the combined trust network. This suppressed important differences that were found at the individual level. For example, as shown in **Figure 3**, the combined trust network appeared to be centralized compared to the preferential model, while six of the seven individual networks demonstrated decentralization. This indicated that networks with lower values were suppressed by the combined trust network. Thus, like the findings discussed for RQ#2, when we combined trust networks into one overall trust network, important nuances may have been lost.

DISCUSSION

This paper provides empirical support for the findings discussed in the review by Gilfoyle et al. (9). We will explicate this support and how it compares with the wider literature for each research question below.

Research Question 1

The trust networks are *not* dominated by a few central individuals and are relatively dispersed for each of the trust networks. This may be surprising as the PPI Ignite Network was set up with a central administrative structure, mirroring a hub and spokes model, indicating the potential for an inherently centralized structure. However, in the setup of the PPI Ignite Network, resources and decision-making pertaining to goals and objectives were distributed across the Network. In other words, the partnership was set up to be an administratively centralized network, but a power distributed network. This is very similar to, for example, the way universities are set up, with a very hierarchical administrative structure, yet academic resources and decision-making distributed among departments and individual faculty-members. This meant that collaboration and opportunities for trust were dispersed throughout the PPI Ignite Network. Therefore, this analysis provides important empirical evidence about the value of the Network's set up. This contrasts with a *collaboration* network explored in the study by McMullough et al. (16) who found the network ($n = 41$) to be highly centralized. This, however, could be because their survey was administered at a point in time when the network had been collaborating for several years, thus the partnerships could have been well established and strengthened. Similarly, Barnes et al. (35) found both a high degree centralization for both collaborative ties and trust ties in their network of swimming providers (i.e., lessons and/or programs) comprised of 25 individuals representing 25 organizations. However, both studies (16, 35) discussed both benefits and challenges for the network with a high degree centralization. Specifically, in that it helps with efficiency of the network *if* the central individuals are "positive" leaders, but can also create bottlenecks, and reduce the dissemination of information as information must flow through these central individuals before reaching others in the network (16, 35).

Research Question 2

Landmark studies of participatory health research, such as Jagosh et al. (7) identify trust as a critical mechanism underlying partnership function. However, their treatment of trust as a "black box" concept makes it difficult to measure or address, in order to improve partnership outcomes. It is beneficial to conceptualize, operationalise and measure trust multidimensionally to ensure a comprehensive understanding of how trust is operating in a partnership. Specifically, this analysis shows the ways in which certain dimensions of trust, may be more prominent in a network (i.e., shared values, visions and goals), compared to others (i.e., integrity). Thus, the way to strengthen dimensions of trust in a network, such as through structural interventions (i.e., strategic actions that or remove links between nodes) (36), should differ depending on which trust dimension is/is not prominent in a Network. This finding is an especially important contribution to the literature as it is the first study, to our knowledge, exploring empirically the multidimensionality of trust using social network tools, by comprehensively mapping individual trust dimensions. For example, a study by Gursakal et al. (13) investigated general trust pertaining to the entire network by tapping into three trust dimensions (ability, benevolence and integrity), but mapped trust networks more broadly by asking trust in a binary manner: "who do you trust and in which level." Consequently, structural interventions could not be recommended based on different trust dimensions as per the findings we reported here.

Research Question 3

There is a relationship between the trust dimension networks explored, but some are more correlated than others. For instance, power sharing and co-ownership was strongly correlated with shared values, visions and goals and reliability, but only weak to moderately correlated with vulnerability and ability, respectively. Meanwhile, ability and reliability are strongly correlated with each other. Of the studies retained in the scoping review by Gilfoyle et al. (9) that used multiple dimensions - and therefore multiple network questions - to investigate trust, none explored the correlation between these trust dimensions. For instance, Ardoin et al. (12) investigated multiple trust dimensions and network questions pertaining to reciprocity, vulnerability, dependability, and reliability, but do not appear to explore if these dimensions are correlated. It is also unclear if they combined these trust dimensions into an overall trust network or explored trust dimensions as individual trust networks. Similarly, as described above, Gursakal et al. (13) also did not examine if trust dimensions are correlated with each other. Thus, our findings add to the literature by elucidating such correlations.

Research Question 4

Although individual trust dimensions were combined to create an overall trust network, like with RQ#2, important nuances were lost when combined as one overall trust network, compared to when the trust dimensions were looked at individually. For example, when combined, the network might appear to be more centralized overall. Further, as discussed in RQ#2, we would not be able to identify important individual trust dimensions differences (i.e., integrity dimension vs. shared values vision and goals dimension). For instance, Zhou et al. (37) combined responses to three trust dimensions (ability, reliability, and friendship) to create one weighted trust score, limiting the ability to explore specific nuances of these dimensions, such as is one stronger in the network than another? And if so, how does this impact the network? Zhou et al. (37) further highlight the subjectiveness of trust as a concept, and the need to "design more comprehensive ways for quantifying the relationship." Although this is seemingly in reference to other important relationship networks (beyond exploring trust, communication and supervision), it can also be applied to the measurement of trust.

Strengths and Limitations

This study has several noteworthy strengths, addressing current gaps in the trust, social network and participatory health research literature. First, we consistently conceptualized, operationalized and measured trust in a comprehensive way, drawing on the unique experiential expertise of the Research Advisory Board to ensure context appropriateness. This is especially useful, as trust depends on context (38), and involving Research Advisory Board members in the survey development and design who are also involved in the network, helped ensured relevancy and feasibility of the survey, important for our study context. Secondly, this study utilizes an interdisciplinary approach to measuring trust, by incorporating principles and techniques of network science and social science. As discussed by Lewicki and Brinsfield (39), trust is an interest across disciplines, but is often explored within a single discipline. Indeed, convergence across disciplines in how we conceptualize, operationalize and measure trust is important, and as illustrated in this study, can reveal unique insights and solutions often not considered. As highlighted by Lucero et al. (40), "by better understanding trust, we can better understand its process." Furthermore, this study attests to the feasibility of generating and employing a network survey that operationalizes trust in a multidimensional way, which is not overly burdensome on participants. As discussed by Ferrin et al. (41), we also recognize the challenges of exploring trust so comprehensively in a network analysis setting. However, we feel this can be mitigated by seeking stakeholder input and streamlining the process for survey administration. Specifically, involving a Research Advisory Board can then help guide feasible and context-appropriate networks surveys and questions (i.e., limiting the number of names to input for each question), and availing of web mechanics offered in survey software (i.e., auto-population of fields as much as possible based on previous question selection) helps to reduce the information participants need to manually input into the survey.

Study limitations should also be considered. First, our study was cross-sectional. This is limiting as trust is a dynamic construct that is always changing (40, 42) and should be measured over time. We are currently planning for a follow-up study to explore trust at more than one time point. Secondly, from discussions with our Research Advisory Board, we thought it appropriate to measure the strength and quality of a relationship, a dimension of trust revealed by Gilfoyle et al. (9), by assessing the strength and level of collaboration as opposed to asking questions about friendship, which may not be relevant to this type of network. However, as collaboration was asked on a different scale to other trust dimensions, it was difficult to assess its correlation to other trust dimensions. Therefore, we decided to exclude it in the correlation measurements.

Finally, network findings on their own can be limited to the interpretation of the researcher and the network questions posed, underscoring the importance of employing mixed methods when interpreting the network results (i.e., follow-up interviews with certain individuals in the network to verify findings). Although we employed strictly quantitative methods in this study, the consultation with the Research Advisory Board, one of which was involved in the interpretation of the network findings (co-author MMC), provides contextual support for the findings.

Implications for Research and Future Directions

This research provides empirical evidence in support of findings revealed by Gilfoyle et al. (9) and explicates several key considerations for researchers. First, we understand that the relational dimensions of trust are inherently complex, and depending on the context, may not always be relevant or appropriate when creating a network survey. Therefore, we encourage researchers at minimum, to consult with those who hold unique experiential expertise of a network when deciding which trust dimensions are most appropriate for their research context. As trust is seen as a key mechanism in partnership functioning, those interested in understanding how and why partnerships succeed or fail need to carefully match the aspect of partnership function they are examining to the correct trust dimension. This has implications for fully understanding the several conceptual models that have been proposed for participatory research. We also urge researchers to consider an interdisciplinary lens when tackling complex conceptual and operational issues about trust (and other relational constructs), that both fall within and extend beyond their discipline, and to move away from reducing trust to a binary form (present/absent). Finally, it is important to consider trust dimensions as individual networks to ensure a nuanced understanding of trust in a network. This is helpful for identifying and applying appropriate structural interventions to enhance trust in a specific network, and ultimately the likelihood of successful outcomes of the partnership.

We understand trust changes over time, and not exclusively in a linear manner (40) (i.e., lack of trust to trust). Thus, we plan to conduct a follow-up study exploring trust longitudinally and employing a mixed-methods study design, adding to the robustness of these findings. Specifically, we explore if these methodological techniques reveal insights into how trust changes over time in a network/partnership, if this varies depending on length of time in the network/partnership, and if certain combinations of trust dimensions could be grouped together. Finally, although non-systematic consultation was appropriate for our purposes here, future research could investigate more generally if and what dimensions of trust are important for different types of partnerships and collaboration. For example, although the trust dimension for vulnerability had fewer connections than that of power sharing and co-ownership, it may not be as important in certain contexts.

CONCLUSION

In conclusion, this study provides empirical evidence that there is merit in investigating trust both consistently (i.e., measured in line with how it is defined and operationalized) and in a multidimensional manner. As the first study to our knowledge examining trust in this way, we hope this work provides empirical and conceptual clarity for exploring trust in partnerships and encourages future research that will add to these findings.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Limerick Education and Health Sciences Research Ethics Committee (#2021_03_16_EHS). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

MG conceptualized and led the study, drafted, and edited the final manuscript. PMC secured funding, analyzed the data and contributed to the study design, data analysis and interpretation, writing, and editing of the manuscript. JS secured funding, contributed to the study conceptualization, data analysis and interpretation, and contributed to the writing and editing of the final manuscript. AM and MM contributed to study conceptualization, interpretation of results, and reviewed and approved manuscript. All authors have made substantive intellectual contributions to the development of this study.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.925402/full#supplementary-material

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Effective leaders(hip) in community-academic health partnership projects: An inductive, qualitative study

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To deepen our understanding of how project leaders can lead effectively in different community-academic health partnerships (CAHPs), we conducted an inductive, qualitative study through semi-structured interviews ($N = 32$) and analyzed the data with Grounded Theory approaches. By presenting a process model illustrating the cycle of effective leaders(hip) in CAHP projects, we contribute to the literature on CAHP, leadership development, and complexity leadership theory in three ways. Firstly, the model depicts the strategies enabling leaders to navigate typical project challenges and perform leadership tasks effectively. Secondly, we distill four beneficial qualities (i.e., adopting a proactive attitude, having an open and adaptive mindset, relying on peer learning and support, and emphasizing self-growth and reflexivity) which CAHP project leaders require to develop themselves into effective leaders. Thirdly, we illustrate leaders' dynamic developmental logics and processes of effective leadership and their contributions to better project functioning in diverse CAHPs.

KEYWORDS

community-academic health partnership, effective project leadership, Grounded Theory, qualitative research, thematic analysis

Introduction

Nowadays, public health challenges such as drug addiction, obesity and physical inactivity are increasingly addressed through community-academic health partnerships (CAHPs) (1). In a CAHP, academic researchers actively include and recombine diverse community stakeholders' knowledge, resources, and capacities to generate rigorous research and/or targeted health interventions and innovations (2). However, CAHPs addressing such wicked health challenges are often intrinsically complex, networked systems that are resource-intensive to manage (3, 4). Moreover, their successes depend heavily on the dynamic interplay between community and academic partners (5, 6). Growing literature has pointed to the decisive role of effective leadership in orchestrating such complex dynamics (7–9) and steering the partnerships toward successful and sustainable outcomes (4, 10).

Nevertheless, such outcomes are often undermined by numerous challenges that CAHP project leaders constantly need to tackle when bringing diverse stakeholders together for the common purpose of the project (11). These challenges can hinder their ability to perform project leadership tasks effectively (12). For example, beyond the daunting duty of securing project resources and reaching goals (13), they often need to operate in ambiguous leadership roles (14), act in uncertain environments (15) and must manage the unavoidable conflicting interests or demands between the diverse partnership members (8). Nevertheless, only a few concrete field studies have illustrated *how* project leaders address such complex challenges in different CAHP settings (13, 16). As a result, how project leaders pursue effective leadership sustainably in diverse CAHPs remains largely unexplored (5, 15).

This knowledge gap can be attributed to two main reasons. Firstly, most studies have been criticized for reporting only on the effectiveness of specific health interventions and accomplishments whilst neglecting to include details of any struggles, unsuccessful attempts, and useful strategies or processes employed in response to these challenges (13, 17). Secondly, despite the recognized significance of leadership on CAHP effectiveness in the literature, there were considerable variations and ambiguities in how scholars conceptualize "leadership" (18). For example, some studies have considered leadership as individual leaders' traits or characteristics (14); others have examined more distributed forms of leadership, such as collaborative leadership (19), collective leadership (20) and shared leadership (21). The inconsistencies in leadership conceptualization, coupled with the overlooked dynamics and impacts of CAHP project settings on leadership practices, have precluded scholars from drawing answers on how effective leadership and leaders, from decision-making to strategic issues, jointly contribute to effective CAHPs (7).

Hence, to examine how leaders can perform their leadership functions and roles sustainably and effectively in complex CAHP systems (8, 22), a more focused perspective accounting for both effective *leadership* and effective *leaders* is required (23). Additionally, CAHP scholars have called for empirical work to obtain a more nuanced and thorough understanding of the complex inner workings of project implementation (24) and leaders' efforts in handling the dynamics in different CAHPs (11). To this end, a growing body of health care research has proposed to examine the interplay of project leaders' behaviors under varied contextual forces (e.g., actors, challenges, and contexts) through the lens of Complexity Leadership Theory (CLT) (22).

Complexity leadership theorists posit that a triadic model of operational, enabling and entrepreneurial leadership behaviors allows leaders to unite diverse perspectives and create shared values in collaboration (25). This theory further complements extant leadership research by highlighting the critical role of environmental dynamics on leaders' actions (26) and bringing greater attention to the facilitative mechanisms and processes for better learning, innovation, and adaptability in CAHPs (27). However, CLT falls short in three aspects in explaining how CAHP projects can be led effectively. Firstly, although CLT provides a meta-framework for leadership behaviors at the organizational level (25), it remains conceptually abstract and lacks empirical descriptions of the strategies for addressing the specific challenges in diverse interorganizational, networked settings like CAHPs (23, 28). Secondly, the theory has not offered much guidance on becoming a better leader in complex, networked project environments (25). Thirdly, how leadership and leaders evolve and contribute to desirable outcomes in complex systems like CAHPs remains largely unexplored (22).

Independently, both CAHP and CLT scholars have called for qualitative research to offer richer insights into project leaders' notions of effective leadership (20, 29), particularly on strategies and qualities that enhance leaders' readiness and ability to excel in complex, networked systems (30, 31). Thus, to deepen our limited understanding of effective leadership and leading in different CAHP contexts and in an effort to fill some gaps in CLT, we embarked on a study to address the research question:

How do project leaders perform their leadership functions and roles effectively in complex CAHP systems?

We adopt an interpretivist approach to explore project leaders' subjective lived experiences and perceptions of effective CAHP leadership and leading. This study aims to contribute to the burgeoning CAHP and leadership research in three ways. Firstly, by exploring the inner workings of CAHP projects, we aim to unpack CAHP project leaders' practical strategies for navigating the challenges while performing *leadership* tasks effectively in CAHPs and similar complex network settings. Secondly, we aim to advance leadership development by exemplifying the beneficial qualities that project leaders should possess to become effective *leaders* in CAHPs. Thirdly, we aim to extend CLT by depicting the dynamic developmental logics and processes of effective *leadership* and *leaders* in a CAHP project and their contributions to enhanced project functioning.

Materials and methods

Study design

We conducted an inductive, qualitative inquiry with leaders from diverse CAHP projects in Germany to explore their lived experiences in leadership and leading. By conducting semi-structured key informant interviews, we aimed to capture the characteristics of effective leadership and leaders based on their past efforts to address the challenges that arose in their projects. This qualitative method provides a rich and detailed description of the often-neglected inner workings of CAHP project leadership with a focus on differentiating between the characteristics of effective *leaders* and those of effective *leadership*.

Recruitment and sample characteristics

In the absence of a complete, updated list of all German CAHP projects, we were unable to generate a comprehensive sampling frame for random sampling (pp. 298) (32). Therefore, we adopted a heterogeneous purposive sampling strategy (pp. 337) (32) and compiled a sampling frame based on active web searches to identify eligible CAHP projects (e.g., project websites and participatory project networks). The key terms used for searching were: ("patient* *OR* "community*" OR "societ*") AND ("universit*" OR "academic" OR "research*") AND ("alliance*" OR "collaborat* OR "participatory" OR "partners*") AND "health"). As inclusion criteria, eligible CAHP projects were identified based on (1) definition of a community-academic partnership: a collaborative relationship between at least one researcher and at least one community member(s) (i.e., representative or agency) from the field(s) of business, health care organization, policymaking, or civil society (e.g., nongovernmental organizations, churches, charities, schools); and specific health-promotional cause(s) that is/are relevant to the community of interest. To reduce the chances of recall bias, we only considered ongoing or recently completed CAHP projects between 2019 and 2021. Any projects that did not clearly describe their projects' causes, partners involved, or the relationships between community and academic partners were excluded. To ensure a broad range of perspectives, project leaders of eligible CAHP projects were selected regardless of their gender, experiences in CAHP project leadership, and backgrounds. Eligible project leaders were invited to participate in an interview *via* email. A reminder email was sent to the nonrespondents 1 week later.

Of the 137 formal CAHP project leaders invited, 32 participated in the study (23%). Thirteen (9.5%) of the invited leaders rejected the invitation due to unavailability (N = 10, 7.3%), retirement (N = 1, 0.7%), or being occupied with pandemic-related work (N = 2, 1.5%). Four contacts were no longer accessible (2.9%), while no replies were received from others after the reminders were sent (N = 88, 64.2%). Meanwhile, twenty-one of the participants were women, and eleven were men. All of them worked on entirely different projects. A detailed overview of each study participant and their CAHP projects is provided in Supplementary material 1. Interviewees were 49 years old on average (29 – 68 years old), with an average of 11 years of experience in CAHP project leadership (SD = 5.66). A majority of them also had a job position affiliated with a research institute or university (62.5%, N = 20), followed by (university) hospitals (12.5%, N = 4), government authorities (9.38%, N = 3), nongovernmental organizations (9.38%, N = 3), business/industries (6.25%, N = 2) and insurance companies (3.13%, N = 1). The thematic focuses of the CAHP projects in which interviewees were involved were diverse, ranging from health treatment/care improvement (N = 12), community health promotion (N = 10), education/training for health professionals (N = 4), patient support (N = 3), disease management (N = 2) to disease prevention (N = 1). The average duration of the projects was 4.5 years (SD = 3.54) (Table 1).

TABLE 1 Participant characteristics (N = 32).

Gender (%)	Women	21 (65.6 %)
	Men	11 (34.3 %)
Age [Mean (Range)]		49 (29-68)
Years of experience in project leadership [Mean (SD)]		11 (5.66)
Project duration in years [Mean (SD)]		4.5 (3.54)
Project leaders' affiliation (%)	Research institute/university	20 (62.50%)
	(University) hospital	4 (12.50%)
	Government authority	3 (9.38%)
	Nongovernmental organization	3 (9.38%)
	Business/Industry	2 (6.25%)
	Insurance company	1 (3.13%)
Education level (%)	Professorship	11 (34.38%)
	Doctorate	11 (34.38%)
	Postgraduate	6 (18.75%)
	Undergraduate	3 (9.38%)
	Diploma	1 (3.13%)
Project theme (%)	Treatment/care improvement	12 (37.50%)
	Community health promotion	10 (31.25%)
	Education and training for health professionals	4 (12.50%)
	Patient support	3 (9.38%)
	Disease management	2 (6.25%)
	Disease prevention	1 (3.13%)
Project funding source (%)	Federal funding	13 (40.63%)
	State/Regional funding	11 (34.38%)
	Insurance company	5 (15.63%)
	Private funding	3 (9.38%)
	European funding	2 (6.25%)
	Membership fee	1 (3.13%)
	Bank	1 (3.13%)

Research instrument

A semi-structured interview protocol was developed and piloted with three project leaders from different CAHPs in Germany, ranging from health care management and health care education to disease prevention. The content of the interview protocol was then revised based on the interviewees' feedback to ensure the appropriateness, clarity, and comprehensibility of the questions (33). The final interview protocol comprised open-ended questions covering five main themes: project structure, leadership and decision-making processes, reflections on any (leadership) challenges, enablers, and performance in the projects. Interviewees were asked to describe the objectives and structure of their current or recently completed CAHP projects (e.g., "Could you please briefly describe the project?"); their previous experiences in leading any CAHP projects (e.g., "Have you also led/managed similar project(s)?"); their project roles and tasks (e.g., "How would you describe your role in the project?"); and the decision-making processes in the projects (e.g., "How are major decisions made in the project?"). Then, they were invited to illustrate if they had faced any significant challenges in leading the projects and to reflect on how they dealt with those challenges (e.g., "Have you faced any major setbacks/challenges in this project? How did you react to them?"). We also asked interviewees to note any enablers, strategies, or tactics that helped them address those challenges and evaluate their current projects' overall performance (e.g., "What have you found to be important in helping you (or your team members) cope with the challenges?") (Supplementary material 2).

We implemented semi-structured interviews since they were deemed appropriate for deeper probing into participants' perception of effective leadership and leading practices and facilitating the identification and constant comparison of themes (34). All interviews were conducted digitally ($N = 27$) or *via* phone ($N = 5$) between March 2020 and April 2021, following the safety regulations during the COVID-19 pandemic. Interviews were conducted in German or English, audio-recorded and transcribed verbatim by native speakers. German transcripts were then translated into English by fluent bilinguals. The interviews lasted between 30 and 60 min, yielding 382 single-spaced pages for data analysis.

The study was approved by the Ethics Committee of the University and complied with the General Data Protection Regulation. We obtained verbal and written consent from all interviewees before the interviews and reassured them that their participation was voluntary, strictly confidential, and anonymous. Considering the interviews were conducted digitally or *via* phone and that the accuracy of transcripts could potentially be affected by any background noises or technical issues, all transcripts were sent back to interviewees for corrections or additional comments. Transcripts were anonymized to conceal participants' identities and personal information after receiving interviewees' potential corrections or comments.

Data collection and analysis

We followed (34, 35) suggestions and analyzed the data in parallel with the data collection process. After each of the three interview rounds (March–April 2020; October–November 2020; and March–April 2021), we performed preliminary analyses to obtain initial insights and identify knowledge gaps. The interview protocol was then revised as the research progressed to identify the themes concerning our research questions (35). We then collected and analyzed the data iteratively until we reached theoretical saturation, when no new insights emerged from adding further study participants (36).

Using Corbin and Strauss' Grounded Theory approaches (34) and Gioia et al. inductive coding process (35), two bilingual coders analyzed the transcripts and performed the initial inductive coding process separately. Here, open codes adhering to the terms and expressions used by interviewees were generated (34). During the process, the coders also performed memo writing, in which notes and observations were written, sorted, and resorted to offer a firm base for theoretical development (34). Findings were then constantly compared, discussed, and refined between the coders until a consensus on data interpretation was reached (35). Subsequently, the coders discussed any themes or insights derived from the data and performed axial coding, a process in which relationships among open codes (i.e., first-order concepts) were identified to form sub-categories (i.e., second-order themes) after constantly testing the linkages proposed against the data collected (34, 35). This process gave rise to the theory-centric, second-order themes, which enabled us to explore the relationships among the first-order concepts and eventually to cluster the themes into three aggregated dimensions relevant to our research questions (35). The analysis was carried out using the MAXQDA 2020 software. We recursively referred to the collected data, emerging insights, and extant literature to establish linkages between the identified themes. We then synthesized the findings and constructed a process model depicting the cycle of effective CAHP leaders(hip) (Figure 1).

Results

While our primary focus was to answer how project leaders could perform their leadership functions and roles effectively in complex CAHP systems, we present the leadership challenges faced by project leaders as part of our findings to provide a better contextual reference for elucidating the complex realities of leading CAHPs. Accordingly, three overarching themes emerged: (a) leadership

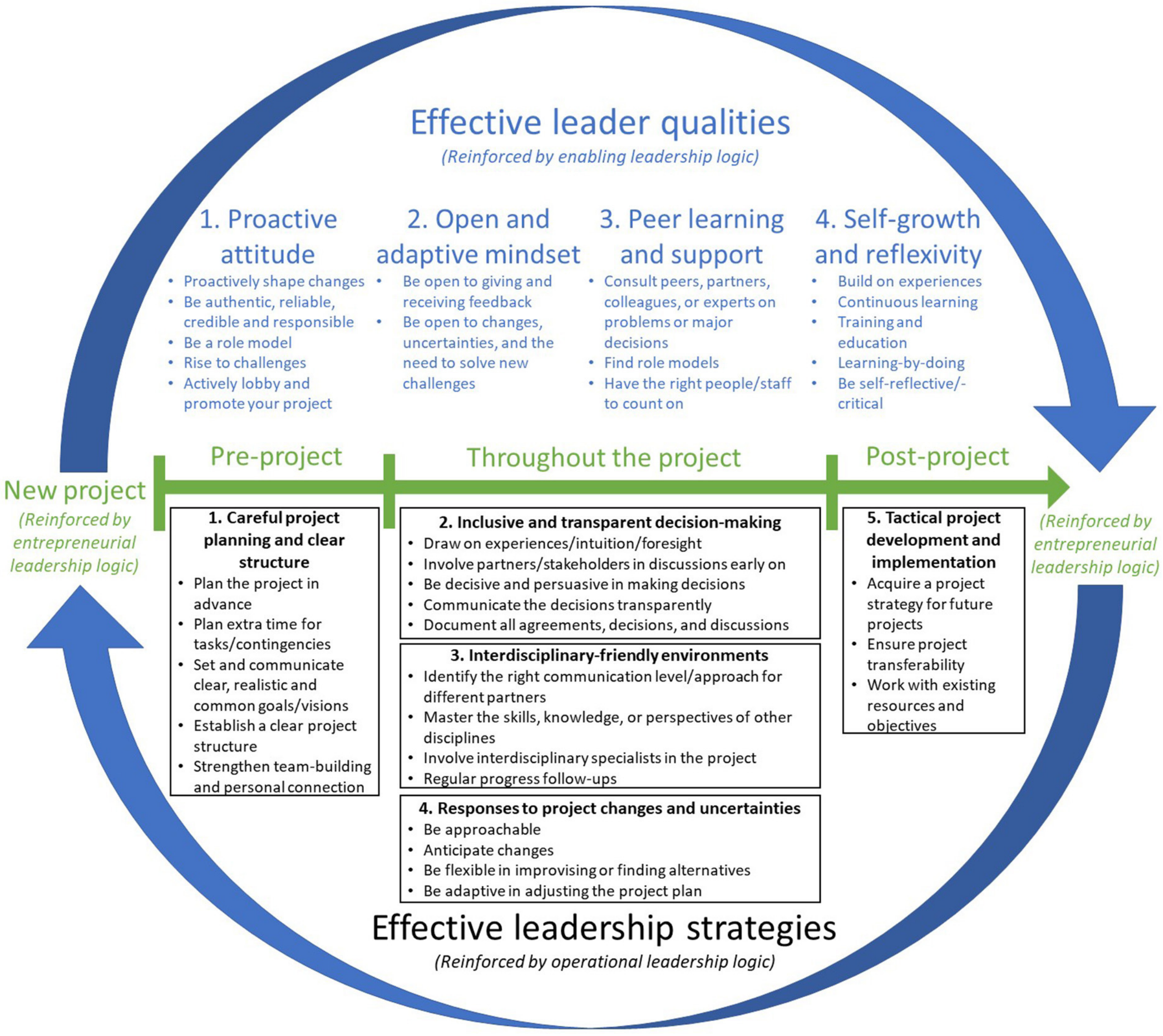

FIGURE 1
Effective CAHP project leaders(hip) cycle.

challenges faced by CAHP project leaders; (b) effective leadership strategies for dealing with those challenges; and (c) effective leader qualities. The data structures for all themes are shown in Supplementary material 3. Illustrative quotes are presented with pseudonyms to protect interviewees' identities, along with their age and years of experience in CAHP project leadership (Y.o.E). Additional responses coded to each theme are summarized in Supplementary material 4.

Leadership challenges faced by CAHP project leaders

Five second-order themes emerged concerning the leadership challenges interviewees encountered while leading their CAHP projects: project planning and management, the balance of participatory decision-making, project interdisciplinarity, project changes and uncertainties, and lacking project impacts and sustainability.

Challenge 1: Project planning and management

In CAHP projects, planning adequate time and resources for project task execution was a common challenge for relatively inexperienced CAHP project leaders (<5 years of experience). For example, one of the interviewees underlined that sometimes they happened to be under-resourced due to unforeseen expenses on some project tasks: *"In some cases, we applied for too little [funding]. For example, in a training course, we did not consider some of the interviews still have to be translated, that we somehow need funds for translators." (Jasmine, Age 35, 2 Y.o.E)*

In the same vein, many interviewees mentioned the complexity of defining and clarifying project management roles and responsibilities in a highly decentralized project setting. For instance, they must first take the time to understand the specific structural conditions and differences among the partner members and their institutions to define their roles and responsibilities in the projects:

> *"At the beginning, it took a lot of discussion for all of us to realize that there is external project management, which is my responsibility; and internal project management, which partners lead a bit like the scouts from different institutions - as they cannot always turn to their original institution when there are things to be clarified for the project. It's like a separate institution where you work together without having the same employer." (Sophie, Age 54, 9 Y.o.E)*

Sometimes, they also had to be familiar with new requirements or structures and help partners understand and deal with them. For example, a respondent noted it was challenging for him to get familiar with legal topics and to manage the finance:

> *"The most difficult thing for me was…to implement the project and to draft it in a way that it would be legally sustainable…I have no idea about the law…" (Moses, Age 56, 2 Y.o.E)*

Accordingly, they often had to tailor their leadership approaches due to the different requirements, organizational structures, project team compositions and working styles of partners and their organizations in each project. One of the participants noted: *"For every project, everything you lead is different. And you'll have to get to know the people that are working on it and in it." (Janet, Age 31, 3 Y.o.E).*

Due to the uniqueness of each project setting, leaders must devote extra time to discuss with the project partners, understand how specific structural and environmental dynamics may impact their project planning and implementation and explore the most effective ways of leading.

Challenge 2: The balance of participatory decision-making

Several interviewees mentioned that their projects adopted a high degree of participatory or shared decision-making processes, where decisions were mostly or always made by consensus among project partners. For example, a respondent mentioned: *"So, there is no hierarchy in the sense that someone has the authority to give orders, but everything* ***only*** *[emphasised] works by consensus." (Moses, Age 56, 2 Y.o.E)*

However, a few interviewees also struggled to determine the *"right mixture of participation and leadership" (Iris, Age 35, 2 Y.o.E)* in their projects and to channel the information to suit partners' desired level of engagement. For instance, a project leader explained that although decisions about project content were always made collectively, she recognized that it is sometimes impractical to adopt a fully participatory or shared leadership style in a large-scale project with remote partners, since the communication process could become time-consuming and strenuous, eventually leading to partner disengagement:

> *"At the beginning, I really asked a lot of questions in the round and tried to decide together, which was very difficult with the number of consortium partners and also the distance... This unfortunately made you realize that certain things simply had to be decided by yourself… you can't give all decisions to everyone because it doesn't lead to consensus. Now many people no longer participate in the decisions. There is no feedback." (Claire, Age 40, 6 Y.o.E)*

It is clear that many project leaders struggled to find the balance between participatory and unilateral decision-making, as they had to adapt quickly to partners' feedback, determine when to make decisions collectively, and adjust their leadership strategy when necessary to keep the project moving.

Challenge 3: Project interdisciplinarity

Despite years of experience leading CAHP projects, harmonizing the diverse perspectives and satisfying the varied needs and interests among partners remained challenging for some project leaders due to the interdisciplinarity in their projects. One of them highlighted:

> *"So, I think that is a challenge… especially when it comes to public health in this project, then you are suddenly in a broad field where quite a lot of perspectives come together: the medical perspectives, the psychological, sociological, and communicative perspectives…and I also find it not quite easy to orient oneself there." (Barry, Age 64, 9 Y.o.E)*

Ensuring effective interdisciplinary communication was also a tremendous hurdle for a few interviewees. According to one of them, for instance, interdisciplinary scientists often "*cannot get into the heads of the others*" *(Bonnie, Age 35, 2 Y.o.E).* Communication became more complicated while leading in the absence of hierarchy, for which leaders must be open to opinions from all sides. Meanwhile, they must also exert their influence on project members to attain the intended goals: *"I don't have any disciplinary responsibility above anyone. This means that I cannot claim a managerial position... I must try to exert influence on other project members, for example, to be able to achieve the goals." (Ron, Age 26, 2 Y.o.E)*

As a result, project leaders had to orient themselves to accommodate partners' diverse perspectives and deal with issues concerning interdisciplinary and interorganizational communication.

Challenge 4: Project changes and uncertainties

Since many project activities were affected by external influences such as the COVID-19 pandemic, some project leaders reported facing a high degree of uncertainty in their projects. One of them underlined:

> *"There was a great deal of uncertainty about how things would continue as a team here... about what to do now... We have, of course, adjusted some of the goals, maybe even reduced them... because the expectation was that we would catch up after the lockdown. But it is not that easy." (Lily, Age 34, 2 Y.o.E)*

Sometimes due to uncontrollable external influences (e.g., change in political will), project leaders were forced to adjust their project direction or even discard the projects. A respondent noted:

> *"If there are external influences, where you conclude that the vision has to be changed, or maybe it has to be discarded, or the project ends for this; that is, of course, a manslaughter. Nothing can be done about that... you have to look for alternatives or go in a completely different direction and redefine it completely." (Elaine, 42, 4 Y.o.E).*

Hence, the need to promptly react to the external changes and uncertainties to adjust or cut back on project goals, as well as to change plans while in progress, could lead to worries and stress about achieving the intended project goals on time.

Challenge 5: Lacking project impacts and sustainability

Some project leaders commented on the lack of impact and sustainability in their projects due to uncontrollable external influences, such as limited funding or project duration and regulation changes, forcing them to seek new projects. For example, an interviewee expressed: *"I would say that the project needs to grow more. And the problem is that it will only be there for four years and then it is gone. There's no continuity." (Carla, Age 49, 5 Y.o.E)*

It could also be demanding for projects that address controversial or unfamiliar topics to the public to gain enough societal support or acceptance to sustain themselves: *"The biggest challenge is to convince the funds because people don't understand what [the project topic] is." (Anna, 53, 12 Y.o.E)*

Consequently, ensuring projects' acceptance, societal impacts, and sustainable outcomes could be challenging for some project leaders. Indeed, a lack of these elements could trigger additional difficulties in project execution (e.g., financial challenges) and threaten partnership sustainability.

Effective leadership strategies

Five second-order themes were identified regarding the effective strategies adopted or suggested by interviewees to deal with the aforementioned challenges. They included: careful project planning and clear project structure; inclusive and transparent decision-making; creating interdisciplinary-friendly environments; responses to project changes and uncertainties; and tactical project development and implementation. These strategies are presented chronologically according to participants' suggested time of relevance in a project cycle (Figure 1).

Strategy 1: Careful project planning and clear structure (pre-project)

In response to the challenges of having inadequate time and resources for project task execution, a few interviewees with prior experiences in similar projects highlighted the significance of careful project planning and better preparation *in advance* (i.e., as early as the project application stage), such as planning a buffer for time-consuming project tasks. For example, an interviewee mentioned: *"I know how often such an analysis goes wrong, and I can build that into the project planning. That works." (Helen, Age 50, 10 Y.o.E)*

Apart from formulating and discussing the shared vision with partner members continuously, some interviewees also found it critical to establish a clear project structure *at the start* *of the project*. A predefined project structure can play a strategic role in facilitating the decision-making process and settling the differences, such as varied ways of working: *"You really get a structure in place and come to a decision, with all the differences that you might have in the team." (Elaine, Age 42, 4 Y.o.E)*

Yet, establishing a clear project structure requires a thorough consideration of the organizational and structural differences of partners and their organizations, as well as communicating the structure to all relevant stakeholders. For example, a respondent mentioned that he had to understand the differences in partnering organizations' funding logics and clarify internally (within the leader's organization) and externally (to their partnering organizations) how the new funding structure worked:

> *"… we had to clarify internally, but it also had to be clarified with [the partnering institutes]… This was also an unfamiliar approach for them because other funding logics simply work differently than health insurance funding, both in science and in sports." (Moses, 56, 2 Y.o.E)*

Meanwhile, early team-building measures were vital for enabling diverse partner members to get to know each other better on a personal level even before the project started officially. Although such activities can be highly time-consuming and costly, interviewees found them helpful in reconciling partner members' perspectives and working styles, which later improved their project involvement:

> *"That was quite a lot of effort, time-consuming for all people. But what I found interesting was that everybody was involved... you get to know each other… I found it very helpful at the time because it loosened up the atmosphere a bit… you got to know people beyond their professional competence." (Bonnie, Age 35, 2 Y.o.E)*

Therefore, many project leaders saw the need to invest time and effort in planning, establishing clear project structures, formulating goals with partners and engaging in team-building activities *as early as possible*. These activities could help partner members align their interests and resources, establish better personal relationships, and lead to smoother project functioning later on.

Strategy 2: Inclusive and transparent decision-making (throughout the project)

While interviewees often relied on their foresight, intuition, or feelings to determine when to engage partners in major decisions or how to communicate with them; they also recognized the need to be decisive in making decisions to ensure project progress, especially for larger projects that involve multiple partners:

> *"When you have so many partners, you naturally want to make decisions together… however, it is still important for a project manager to be able to make decisions… If it comes to the fact that there are problems… you have to hit the table and decide." (Elaine, Age 42, 4 Y.o.E)*

A project leader also highlighted that it was critical to establish a framework and safe space for community partners to enable a highly inclusive decision-making process: *"You have to be very close [to the community partners] and provide a framework so that a "safe space" is created. They [The community partners] bring a lot of resources with them, but we [leadership team] have to set the framework." (Iris, Age 35, 2 Y.o.E)*

Although not all decisions were jointly made, interviewees underscored the necessity to involve partners in discussions early on and ensure a transparent decision-making process *during the project*. This could be achieved by ensuring proper documentation (e.g., minutes or summary reports), which ensures the transparency of all decisions and agreements. One of the participants noted: *"After each meeting, everyone has a different understanding of what was discussed, to put it exaggeratedly. And such minutes help us immensely to make progress and agree on the next steps based on the joint minutes." (Marie, Age 36, 2 Y.o.E)*

Similarly, keeping a daily project diary throughout the project helped a project leader stay aligned with prior decisions and directions, which was a key determinant for project quality and success: *"We keep a project diary in every project, where we write something down every day… That is a crucial success factor. By the way, it's also a quality factor. Otherwise, you do something else after half a year." (Walter, Age 56, 6 Y.o.E)*

Accordingly, proper documentation is vital to keep the decision-making process inclusive and transparent. It also helps project partners to build on prior agreements and decisions and clear up any misunderstandings, thus accelerating the project's progress and promoting its quality and success.

Strategy 3: Interdisciplinary-friendly environments (throughout the project)

A few project leaders underscored the necessity of ensuring an interdisciplinary-friendly environment for partners *throughout the project*. For instance, they would master the skills, knowledge, or perspectives from other disciplines; and foster networking and lateral thinking skills, which, according to one of them, is the ability to *"link things that are not really connected"*: *"Everyone has different aspects, even from their training, which they bring to the team. And this networking and lateral thinking result in teamwork." (Elaine, Age 42, 4 Y.o.E)*

Other interviewees proposed strategies to ensure clear and comprehensible communication for interdisciplinary partners, such as by creating a glossary to clarify any technical terms in each meeting or by involving interdisciplinary specialists to establish an effective communication structure *from the start of the project*:

> *"Right at the beginning... we decided that we would get support and hired two people from a university who know about interdisciplinary work. They have always come to our meetings and listened, for example, how do we communicate? How is that received by everyone?... which worked quite well." (Bonnie, Age 35, 2 Y.o.E)*

Moreover, leaders who led team members in the absence of disciplinary hierarchy often could not direct or decide partners' pace of work in a networked project. A useful strategy was to ask for project updates regularly, to detect any challenges, and to persuade partners to make progress *during project implementation*. Cultivating a strong personal connection between partners also assisted them in overcoming communication problems and promoted effective collaboration. One of the interviewees underlined: *"At the beginning... there have been some misunderstandings and communication problems. But in the end, I think we have come to terms with each other and got to know each other so well that it went pretty well." (Max, Age 68, 14 Y.o.E)*

Creating a friendly project environment on both personal and professional levels was crucial to overcome differences across disciplines and facilitate effective ongoing communication.

Strategy 4: Responses to project changes and uncertainties (throughout the project)

To handle unexpected project changes that arise during the project implementation, a few interviewees highlighted the importance of being approachable for questions, discussions, and prompt clarification: *"I am approachable - always, at all times in the project." (Nelson, 46, 14 Y.o.E)*

Meanwhile, project leaders' experience significantly influenced their adaptability, resilience, and patience in responding to dynamic project environments. For example, more experienced project leaders explained that they acquired the capability of anticipating changes over time, thus were more comfortable in improvising or finding detours upon changing project situations:

> *"Experience also does something to you, that you simply know there is nothing that runs smoothly and everyone who has ever done a project knows that no project is ever implemented the way it was created. Something always happens (laugh). Yes, and in this respect, you need a bit of flexibility and at the same time... you always have to know: 'where are we going?'" (Annie, Age 45, 5 Y.o.E)*

Thus, being available for others, anticipating changes and remaining flexible *throughout the project* were essential for effectively adapting to unforeseen project circumstances.

Strategy 5: Tactical project development and implementation (post-project)

In response to the challenges of lacking project impact and sustainability, a few respondents noted the necessity to consider and explore any opportunities to continue their endeavor *at the end of the projects*. Apart from applying for follow-up funding, one way to ensure project impact and sustainability was to develop a strategic research agenda to retain staff and conduct more projects in the same area:

> *"You have to acquire a strategy… That means: how do you promote this [research topic] over the years? And they have to converge thematically…so that (a) I can handle it with my team of people and (b) they stay with me so that I can pursue my research line?" (Walter, Age 56, 6 Y.o.E)*

Sometimes, that also implies ensuring the project's strategic orientation fit the different interests of relevant parties. For example, a respondent noted:

> *"In terms of content, for me it is a matter of ensuring that the strategic orientation of this project.... This means that I have to keep my entire health reporting [of the city] in mind… but I also have to keep an eye on the strategic orientation of urban renewal. There are overlaps, but they also have their own interests in this." (Moses, Age 56, 2 Y.o.E)*

Alternatively, one could transfer the project idea to other contexts or work pragmatically with existing resources and capacities to ensure project quality and impacts:

> *"We always work within a framework and with the resources available to us, so as not to overburden anyone or anything; because that always leads to measures being implemented inadequately or unsatisfactorily. That's why I think, and here I believe in a more sustainable sense, that I look at 'what's there' and try to implement the project objectives." (Jasmine, Age 35, 2 Y.o.E)*

Hence, strategically planning for the research agenda and transferring project results based on existing resources and outcomes contributed to maintaining a project's impact and sustainability beyond the project cycle.

Effective leader qualities

Together with effective strategies, we also identified four qualities that leaders should possess to effectively lead in CAHP projects. They included adopting a proactive attitude, having an open and adaptive mindset, relying on peer learning and support, and emphasizing self-growth and reflexivity.

Quality 1: Proactive attitude

Whilst many CAHP project leaders explained that they have a coordinating or enabling role in the projects, a few interviewees emphasized the significance of being proactive in asking for new information to understand the project content or to shape changes to make progress in their projects: *"You have to be flexible, trust yourself; but at the same time, be active... you have to be willing to shape changes." (Olivia, Age 29, 3 Y.o.E)*

Sometimes, it also implies that they must set an example to motivate partner members to engage in the project or to rise to any challenges proactively: *"I have to be a role model. I have to do more, know more and always want to… I have to rise to the challenges… If I'd rather not put so much effort into it, then it won't work." (Walter, Age 56, 6 Y.o.E)*

Project leaders can also actively involve policymakers or the press to promote their projects' vision, visibility, and acceptance. For example, an interviewee working on a highly controversial health topic has noted the significance of lobbying and media work on his project: *"We were called names there. We had a television crew every week… We were in every major national newspaper… Public opinion was absolutely on our side… So, we work intensively with the media." (Walter, Age 56, 6 Y.o.E).* Over the years, the project has become one of the successful model projects that convinced former opponents to cooperate and drove several legal changes at the federal level.

Therefore, besides enhancing project-level engagement, leaders' proactivity in advocating for their projects could also radiate to a societal level. This could lead to more significant project impacts and external support from the project environment or society.

Quality 2: Open and adaptive mindset

Despite many project leaders mentioning the need for project planning in advance, each project can be highly different and susceptible to uncertainties. Therefore, it is vital for project leaders to adopt an open and adaptive mindset, to keep an ear open for feedback and criticism and to adjust their leadership styles constantly:

> *"We don't get much feedback from colleagues at my level now...you don't really get much feedback as a leader… However, if they don't react to me, I have no idea how to put it… And vice versa, giving feedback [to others]. Even if it's critical [feedback], stand by it. Otherwise, we won't get anywhere together." (Walter, Age 56, 6 Y.o.E)*

More experienced project leaders also learned to improvise and accept that some things cannot be controlled directly. Instead, they had to be constantly prepared for new challenges and be able to identify and take alternative paths to achieve the same goal when contingencies occurred. One of the participants pointed out:

> *"You certainly have a rough goal and a direction in mind, but you have to be prepared to deviate from the seemingly emerging path under certain circumstances and to take a better path instead, and I think it is important to try to maintain this openness and also to communicate it." (Barry, Age 64, 9 Y.o.E)*

Thus, an open and adaptive mindset allowed leaders to redirect their measures to meet their project goals readily.

Quality 3: Peer learning and support

When making major decisions on complicated issues beyond their scope of expertise, many project leaders would actively discuss or seek advice and support from peers, including their network/partner members, colleagues, experts, or superiors from their organizations: *"Most things are not decided alone but always, at least with my closer team or with the methodological director of the project, who works in [city name] at the university. I discuss this with him." (Claire, Age 40, 6 Y.o.E)*

Alternatively, when there is an absence of role models to refer to in an innovative project, project leaders note that a good way to cope is by reaching out to external experts to learn from their experiences. For instance, one respondent mentioned:

> *"Unfortunately, we did not have so many role models. That means that next time I would perhaps try to network more, also outside the [affiliated organization]… I would probably get help directly from others, perhaps other funds or projects, and simply conduct an interview (laughs) and ask: 'What have your learnings been? And what can you recommend to me?'" (Marie, Age 36, 2 Y.o.E)*

Meanwhile, other interviewees expressed the benefits of having supportive staff or complementary colleagues in assisting project implementation: *"But realistically, I think the key is to have the right people to support you. So, I'm in the fascinating and* *amazing position that I have great people whom I can count on." (Natalie, Age 45, 10 Y.o.E).*

Therefore, peer exchanges and support enabled project leaders to identify ways to deal with complex, challenging, or critical situations and implement their projects more effectively.

Quality 4: Self-growth and reflexivity

Several project leaders reflected on the importance of self-growth and reflexivity in leadership practices. These enabled them to perform more effectively in (future) CAHP projects, such as building on previous leadership experiences and being prepared to learn new things constantly:

> *"When you are that old, you can build on your experience, and you are constantly learning. And I think that was an important asset for me... The best example to prove that you can do it is that you have done it before, successfully. And I think that's how it works in many areas in life and also here in this particular field of science." (Barry, Age 64, 9 Y.o.E)*

That learning process includes taking part in management training or learning-by-doing. In addition, understanding one's leadership styles, strengths, and weaknesses remains critical for improving the ability to lead CAHP projects effectively. Such reflexivity in leadership practices and self-criticism helped project leaders think about their self-image, reflect on their role models, and summarize their learnings. For instance, a respondent noted:

> *"Being able to look back, why is it now? Is that so now? I believe that this is a crucial variable: the ability to reflect... I have to reflect on it, and I have to restructure everything somehow. This ability to reflect and then open up; instead of standing still and burying our heads in the sand, look at it and deal with it openly." (Nelson, Age 46, 14 Y.o.E)*

Hence, the conscious, continuous cycles of self-reflection helped leaders restructure their leading experience and improve their ability to lead more effectively.

Based on the above findings, we constructed a process model summarizing how effective CAHP project leadership and leading can be achieved (see, Figure 1).

Discussion

Although prior CAHP and CLT research has highlighted the influential role of effective project leadership in driving successful partnership outcomes (27, 37), *how* this is achieved in different CAHP settings remains under-defined and under-researched (15, 18). Therefore, through an interpretivist approach, this study purposively approached project leaders of various CAHPs in Germany to explore their perspectives on effective leadership and leading in their unique project settings.

Our findings reveal several insights into the meaning of effective *leadership* and effective *leaders* and suggest the dynamic strategies, qualities, logics, and processes needed to enhance effective CAHP project execution by juxtaposing CLT's operational, enabling, and entrepreneurial leadership logics (Figure 1).

Effective leadership strategies in CAHP projects

Our findings suggest that project leaders may face similar leadership challenges within a CAHP project cycle. Despite the differences in project team composition, project size, and thematic foci, these challenges (i.e., project planning and management, the balance of participatory decision-making, project interdisciplinarity, project changes and uncertainties, and lacking project impacts and sustainability) are known in the CAHP literature (4, 11, 13). Besides corroborating these challenges, our study further highlights the effective strategies that facilitate project leaders in nonhierarchical, complex CAHP settings to perform their *leadership* tasks effectively. Our findings also indicate that these strategies, functioning as dynamic responses to emergent challenges, align with the operational leadership logic of the triadic complexity leadership model (25). For instance, project leaders displayed operational leadership behaviors (i.e., structuring tasks, resources, roles, and responsibilities) while tackling project planning and structural issues. They also actively coordinated with partners and created the inclusive, transparent, and interdisciplinary-friendly environments necessary for participatory decision-making and meaningful collaboration while dealing with decision-making and interdisciplinary communication challenges.

In addition, our findings extend the literature on effective CAHP functioning (10, 29, 38) by unraveling how these strategies promote smooth CAHP project operations by reinforcing facilitating factors of effective collaboration (i.e., project inputs and resources, roles and procedures, communication). Our evidence shows that careful project planning and management can secure adequate inputs and resources for project task implementation. Similarly, participatory decision-making and project efficiency can be reinforced by establishing a clear decision-making structure and delineating partners' roles and responsibilities after understanding partners' unique structural needs. Likewise, effective communication can be strengthened *via* fostering lateral thinking, creating interdisciplinary-friendly environments, or channeling information based on partners' engagement levels.

Effective leader qualities in CAHP projects

Secondly, our study contributes to the theoretical advancements of leadership development in complex adaptive network settings by pointing to a leader's active learning-oriented, individual growth process. Our empirical evidence echoes literature on the enabling leadership logic of CLT (22), suggesting that CAHP project leaders often had an enabling role on top of an operational one. They also found themselves most effective in performing their roles when they actively customized their leadership approaches according to their structural and relational dynamics with project partners, instead of adopting specific leadership "styles". Meanwhile, extant literature generally assumes that a project leader's ability to excel in CAHP projects depends on their professional judgement built upon leadership experiences (2, 39). However, given the heterogeneity, complexity, and uniqueness of each CAHP project (37), project leaders (particularly those lacking such background knowledge and experiences) can only identify the most effective approaches by constantly experimenting and renewing their learnings in a collaboration process (26). Our findings show that four qualities enable CAHP project leaders to lead more effectively, namely: (1) adopting a proactive attitude to move projects forward; (2) having an open and adaptive mindset to embrace learning and leadership improvement opportunities; (3) relying on peer learning and support in addressing leadership challenges; and (4) emphasizing self-growth and reflexivity to improve leadership practices continually. These findings resonate with Bucknall et al.'s (2021) proposition that CAHP project leaders perform better if they remain approachable, are open to conversations and ideas, and are willing to learn and explore new research areas. In line with the proposition of complexity leadership that leaders nowadays must be more flexible, agile, and adaptive in an ever-changing and unpredictable world (25), our findings further elaborate on *how* leaders' deliberate efforts in active learning can help them lead better in complex, ambiguous and heterogeneous CAHP project environments. For example, project leaders' proactive attitudes in shaping changes or rising to challenges help them establish the credibility and legitimacy required to make progress in nonhierarchical, shared power arrangements like CAHPs. As such projects often involve multi-stakeholder effort in innovation and cocreation (31), project leaders' abilities to constantly learn, adapt to new environments and seek support from peers facilitate them to identify innovative approaches for solving community health issues. Thus, our findings indicate that effective project leaders must acquire a growth mindset to strengthen their proactivity, openness, adaptability, resourcefulness, and self-growth in a CAHP project cycle.

The dynamic developmental logics and processes of effective CAHP project leaders(hip)

Thirdly, given that extant CLT literature primarily focuses on complex network interactions instead of positional leaders' contributions (28), our research extends the CLT literature by accounting for the differences between effective *leadership* and effective *leaders* in complex, networked project settings like CAHPs (23). Our research also illustrates the contributions of their developmental logics and processes to enhanced project functioning in a CAHP project cycle. Unlike the linear entrepreneurial-enabling-operational leadership emergence sequence proposed by Uhl-Bien et al. (25), our findings suggest that effective CAHP project leadership emerges from dynamic, fluid changes between the three forms of complexity leadership logics throughout the project cycle. Even though the entrepreneurial leadership logic can be seen as the primary force initiating and driving the cycle, it requires the project process to adapt to the changing or uncertain environments constantly. Hence, only in combination with the other logics can the entrepreneurial process effectively move forward until new opportunities need to be identified for future projects to address the challenge of lacking project continuity and sustainability. Each leadership logic (operational, enabling, and entrepreneurial) thus allows CAHP project leaders to accomplish their versatile leadership tasks concerning project operation, partner relations, and project uncertainty.

Together, CAHP leaders' ability to use the three logics flexibly and in situationally-appropriate ways enhanced the overall project functioning and prevented major subsequent leadership challenges. For instance, adopting an *operational leadership* logic *during project implementation* can help project leaders to create structures, resources, and routines necessary for smooth operation and high project performance and efficiency. Meanwhile, *enabling leadership* logic was crucial for sustaining partner relations and effective leading *throughout the CAHP cycle*. Creating interdisciplinary-friendly environments and fostering relationship-building among partners were essential for establishing trustful personal bonds and resolving subsequent tensions, conflicts, and miscommunication. On the other hand, in the face of persistent project uncertainty (particularly at *pre-and post-project phases*), project leaders may perform their leadership roles more effectively by adopting an *entrepreneurial leadership logic*. This logic allows them to proactively explore and ideate new project opportunities, experiment with novel solutions, or generate paths for sustainable project development. Thus, our findings suggest that project leaders must act under various leadership logics to meet the CAHP's needs for project performance and meaningful knowledge cocreation to develop effective leadership in interorganizational, networked CAHP project settings.

We also found that leaders' identities in CAHP projects could be unstable or evolving, as suggested by Tourish et al. (23). Hence, for CAHP leaders to lead their projects effectively, they should constantly build on the four identified qualities (i.e., being proactive, adaptive, resourceful, and self-growing) *throughout the project cycle* and repeat the same learning cycle in each CAHP project. Reinforcing these qualities would help them develop and evolve into effective leaders over time and strengthen their ability, readiness, and legitimacy to lead as enablers in nonhierarchical and ever-changing CAHP settings. Our proposed process model (Figure 1) provides a unifying theoretical account of the organic task execution and qualities required for CAHP project leaders to achieve high leadership effectiveness. The model highlights the iterative cycle of how project leaders may continuously learn, adapt, evolve, synthesize, and transfer their learnings into their leading process to effectively fulfill their leadership functions and leader roles in new (CAHP) project environments.

Practical implications

Whilst previous studies have investigated effective leadership at a specific project stage (i.e., formation and ending phases) (7, 21), our study captures a full spectrum of empirical insights into effective leading throughout the project cycle by examining CAHP projects in different stages. We also differentiated between effective leadership and effective leaders to synthesize the components of effective leading from diverse CAHP projects, ranging from newly formed to successful follow-up partnerships and those of varied complexity, power dynamics, and sizes. In so doing, our proposed model offers practitioners in CAHP project leadership roles a framework to translate effective leadership into practice. More specifically, the framework provides clear directions on what project leaders can do to prevent and/or navigate the challenges they may face in implementing CAHPs (17).

Another important practical implication from our findings is that although project leaders may address the leadership challenges differently (40), the overarching process through which they can lead effectively can be similar (25). For instance, project leaders can be operational by establishing a clear structure or routine for project practicalities like efficiency and performance. Within the predefined project structure and routine, they may create a flexible and adaptive space or culture to enable innovation and cocreation while embracing the unique tensions, ambiguity, and uncertainty. They may also be entrepreneurial in seeking new ways and plans to adapt to changing environments in a dynamic project process. Thus, the leading process illustrated in our model can offer project leaders a visual synopsis of the fundamental steps to ensure effective CAHP leading.

Moreover, although researchers are often automatically assigned a leadership role to manage CAHP projects (37), our findings indicate that some might not be fully trained or mentally prepared to take up such positions, thus resulting in the risk of indecisiveness and mismanagement due to inexperience. Therefore, our study echoes previous literature (25, 30, 31) by demonstrating the necessity for CAHP project leaders to reinforce their cognitive skills and resilience in handling the project complexity through leadership training. Our evidence also supports (19) that an alternative for project leaders lacking leadership training or support from their affiliated organizations is to leverage their personal (cognitive) resourcefulness. For instance, apart from learning-by-doing the tasks necessary for effective leadership, they may also proactively sustain or boost the project momentum, possess an open, adaptive mindset to handle any project contingencies, and actively seek advice and support from their partnership networks, experts, colleagues, or peers. To become better leaders, project leaders should also develop a growth mindset (30) and be open to new ideas and critical feedback from others.

Our evidence suggests that this cognitive, growth-oriented quality is especially relevant for experienced and high-status project leaders since they may not receive as much feedback on executing their leadership as their inexperienced junior counterparts, thus failing to sense any issues or room for improvement. Therefore, we suggest that CAHP project leaders should regularly engage in open discussions with their peers or partner members in learning communities to share practices and gain critical feedback. Regardless of their experiences and status in the affiliated organizations, they should continuously reflect on their leadership tasks and behavioral qualities in recent practices to improve their leadership effectiveness in complex and constantly evolving CAHP settings. Alternatively, we recommend that experienced CAHP project leaders actively provide and promote leadership training, mentoring, and/or coaching to their successors or peers. This ensures that the extensive practice and hands-on experience, together with the valuable tacit knowledge accumulated over time, are not dissipated and can be passed on as they retire or change positions.

Limitations and future research implications

As with all research, this study is also subjected to limitations. Firstly, readers should remember that our new model discusses how project leaders can perform their leadership functions and roles effectively through different strategies and develop themselves into effective leaders in unique CAHP settings. Hence, the leadership strategies and qualities can be limited to positional leaders' perspectives. We tried to reduce this bias by asking project leaders how major decisions were made in the project instead of their leadership styles, and also by asking them to support the ways of leading they described with concrete behavioral examples. However, from a CLT perspective, leadership is not confined only to positional leaders (25). Effective leadership can also be coconstructed by interacting individuals (27). Indeed, a growing body of literature has highlighted the potential for developing collective and shared leadership capacity (39) and mutual/collaborative learning skills in a partnership (6, 20). Thus, project partners' leadership skills and qualities may also significantly augment effective CAHP project implementation. Whether partner members should possess the same qualities as project leaders and their potential synergetic effect at the project level deserve further research. Future research may explore the applicability of the proposed strategies and qualities to project partners (who are not in formal project leadership positions) or to the collective level. Researchers may also validate the model by conducting an ethnographic or longitudinal observational study on carefully nominated, effective CAHP leaders to examine if the proposed strategies and qualities are reflected.

Secondly, although our research covers a broad perspective of leaders from diverse CAHP projects, our study is based on a heterogeneous purposive sampling (pp. 337) (32) and is limited to projects specific to the German context. Thus, it may have limited generalizability due to its nonprobability sampling and cultural embedding (pp. 296) (32). Therefore, our findings should be interpreted cautiously. Yet, Germany is well known for its capability to organize. Thus, studying and reflecting on German project leaders' experiences may not be so limiting after all. Also, it is worth mentioning that German projects financially supported by the ministries or private nonprofit foundations often strongly align with the German welfare regime (37). Indeed, most CAHP projects reported in this study were third-party funded projects formally led by academic researchers. Therefore, the leadership challenges and strategies reported here might be more specific to academic leaders and are tinged with research-oriented and power imbalance issues (38). Future studies should explore the transferability of our model to other contexts, such as other interdisciplinary projects, or bottom-up, grassroots CAHP projects initiated or led by community stakeholders, where the power dynamics and project structures may differ (16). Thirdly, although the transcripts were sent to interviewees for checking to ensure their accuracy, we did not perform member checking by sharing the completed analysis with interviewees. Our decision was based on Morse's argument (2015), according to which this strategy was not recommended due to its limited value in attaining validity and reliability and the potential negative impact on analysis objectivity (41). However, we followed Morse's suggestion to enhance the credibility of our findings by checking for the presence of any normative behavioral patterns among CAHP project leaders during concurrent data collection and analysis. We did so by referring to other participants' comments during data collection, asking the following question: "Other interviewee(s) mentioned [a specific situation or a response to the same or similar situation]. What was it like in your situation?" (41). Future studies could consider using this approach to further improve credibility of findings.

Conclusion

This study examines the leadership dynamics within the complex realities of CAHPs by underlining the significant yet poorly understood role of project leaders in CAHP project orchestration. Our work links state of the art complexity leadership, wicked problems, and leaders(hip) development processes to illustrate how project leaders in diverse CAHP settings can effectively operate. We differentiated effective leadership from effective leaders and unraveled the strategies, qualities, logics, and processes that support CAHP project leaders to enact leadership and lead more effectively. Extra attention should be dedicated to the selection, development, and monitoring of project leaders' leadership effectiveness and their preparedness in leading CAHPs to ensure fruitful coconstruction between diverse academic and community partners and to fulfill their promise of bringing long-term health benefits to the members of the targeted populations.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author/s.

Ethics statement

The studies involving human participants were reviewed and approved by the BMS Ethics Committee, University of Twente. All participants provided their written informed consent to participate in this study.

Author contributions

CC led the data collection and analysis. Both authors contributed to the writing and revision of the manuscript and approved the final version of the submitted manuscript. Both authors have made a substantial, direct and intellectual contribution to the study conception and design and data interpretation.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.941242/full#supplementary-material

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Co-creating physical activity interventions: Findings from a multiple case study using mixed methods

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Introduction: In health and physical activity promotion, there is growing interest in co-creation approaches that involve researchers and non-academic stakeholders in developing new interventions. Previous research has shown the promising results of cooperative planning as a co-creation approach in building new capacities and implementing physical activity-promoting interventions in nursing care and automotive mechatronics. However, it remains unclear whether (1) cooperative planning for physical activity promotion can be successfully transferred to other settings in the nursing care and automotive mechatronic sectors and (2) what key factors influence its success or failure.

Methods: We conducted a multiple case study in three settings in the nursing care and automotive mechatronics sectors. Following a mixed methods approach, we collected, analyzed, and triangulated data from documents ($n = 17$), questionnaires ($n = 66$), and interviews ($n = 6$). Quantitative data were analyzed descriptively and through using nonparametric analyses of variance; qualitative data were analyzed using qualitative content analysis by extraction.

Results: The transfer of cooperative planning to new settings was realized, though the impact varied by setting. While the interventions were developed and implemented in nursing care settings, interventions were developed but not implemented in the automotive mechatronics setting. In this context, intervention implementation was influenced by 11 key factors: *champion*, *commitment*, *embedment*, *empowerment*, *engagement*, *health-promoting leadership*, *ownership*, *relevance*, *resources*, *responsibility*, and *strategic planning*. Furthermore, the transfer of cooperative planning was influenced by different activity characteristics, namely *elaboration & reconsideration*, *group composition*, *number of meetings*, *participation*, *period*, *prioritization*, and *researchers' input & support*.

Discussion: The present article contributes to a better understanding of a co-creation approach utilized for physical activity promotion and provides new insights into (1) the transferability of cooperative planning and (2) the associated key factors influencing intervention implementation. The success of cooperative planning varied by setting and was influenced by several activity characteristics and key factors, some of which showed complex relationships.

This raises the question of whether some settings might benefit more from a co-creation approach than others. Therefore, future co-creation initiatives should carefully consider the specific characteristics of a setting to select and apply the most appropriate approach.

KEYWORDS

co-production, participation, health promotion, cooperative planning, nursing care, automotive mechatronics, workplace, school

Introduction

Synergizing the scientific world with the real world is considered a key benefit of co-creation (1). Indeed, co-creation approaches, in which researchers collaborate with non-academic stakeholders (i.e., end-users, practitioners, policy-makers) (2), are increasingly used to develop health-promoting interventions tailored to end-users and the given setting. On the one hand, tailoring interventions to end-users can increase their acceptability (3, 4) and effectiveness (5, 6). On the other hand, adapting interventions to the setting facilitates its contextualization by embedding these interventions into established routines and structures, utilizing existing resources, and building new capacities (7–9), in turn increasing the likelihood of sustained implementation (10–13).

In particular, the postulated fit of co-created interventions through the development of solutions that are suited to local circumstances makes this approach an appealing one for population groups that are characterized by specific needs and resources. Employees with higher levels of occupational physical activity (PA) are one such population group because PA is associated with fewer beneficial health effects for this group compared with employees with lower levels of occupational PA (14, 15). Following this, fostering the competencies needed to master physical demands in a healthy manner and adopt a physically active lifestyle might be a good focus of PA promotion for people with physically demanding occupations, rather than focusing solely on increasing PA levels (16).

Against this background, the research project Physical Activity-related Health Competence in Apprenticeship and Vocational Education (PArC-AVE), which was embedded in the research consortium Capital4Health, focused on PA promotion in the automotive mechatronics and nursing care sectors using a co-creation approach called cooperative planning (CP) (17, 18). CP engages non-academic stakeholders, including members of the target population, and researchers in an equal decision-making process to plan, develop, and implement interventions (19). Thus, CP exhibits parallels with other participatory or co-creation approaches (e.g., intervention mapping or community-based participatory research), but offers a unique constellation by combining the four key components of theory and goal orientation, involvement of all relevant stakeholders, knowledge co-production, and the use of progress monitoring and feedback loops (20). In the PArC-AVE project, the primary aim was to develop and implement new interventions to facilitate PA promotion within the given setting while taking the needs and resources of the end-users and setting into account. During the participatory development and implementation of the interventions involving end-users and other relevant actors from research, policy, and practice, the focus was on both the structural level by creating a PA-friendly environment and the individual level by promoting end-users' PA and physical activity-related health competence (PAHCO) (21, 22). Previous research examining CP in nursing care and automotive mechatronics has shown promising results when it comes to building new capacities and (sustainably) implementing PA-promoting interventions (23, 24).

Taking into account the concept of scaling up (25, 26) raises the question of the transferability of such approaches or interventions, i.e., the extent to which their impact could be achieved in another setting (27). More precisely, in our case, it remains unclear whether CP for PA promotion can be successfully transferred to other settings in the nursing care and automotive mechatronic sectors to reach and benefit more employees with physically demanding occupations. Additionally, the question arises as to what factors influence the success or failure of CP as a co-creation approach for PA promotion. The increasing number of studies using CP (28–31) or similar strategies in PA promotion and health promotion (11, 32, 33), along with the critical voices discussing the limitations and challenges of co-creation, such as the resources required or the risk of conflicts because of different interests (34, 35), underscore the need to explore these unanswered questions. Thus, the current study aims to address the following research questions:

1. How (un)successful is the transfer of CP for PA promotion to other settings in the nursing care and automotive mechatronic sectors? (transferability).
2. What key factors influence the success or failure of CP for PA promotion and, in particular, intervention implementation? (key factors).

Methods

Overview

To answer both research questions, we have used a multiple case study design with three different settings in the nursing care and automotive mechatronic sectors, with each representing one case. In each setting, a separate CP process was initiated in 2018 to develop and implement new multi-component interventions, each comprising multiple PA-promoting intervention components. These intervention components were expected to work best when implemented in combination but could also be implemented separately. The intervention implementation was not limited in time but was instead intended for the long term, if possible. The program activities, underlying evaluation theory, and planned methods have already been reported in detail in a study protocol (36). In brief, the evaluation of the transferability of CP and the key factors influencing its success or failure were based on a logic model illustrating the assumed mode of action of CP (see Figure 1). The logic model component *Activities* includes all project meetings and visits in the settings. *Outputs* are the direct products of the CP process, that is, the developed interventions documented in action plans, while *Outcomes* are the subsequent changes at the structural and individual levels. *Contextual factors* are defined as those factors influencing the CP process and its success or failure; these consist of factors that have been predefined based on previous project findings and a literature screening, as well as additional factors that have not yet been identified (36). Following the principles of a pragmatic evaluation (37, 38), we used a mixed methods approach to examine (1) the successful transfer of CP based on the *Activities*, *Outputs*, and *Structural outcomes* and (2) the key factors influencing the success or failure of CP, particularly the intervention implementation based on the *Contextual factors*. By comparing the results of all three settings, similarities and differences could be identified and aggregated to answer both research questions.

Cases and participants

The multiple case study was undertaken in two state vocational education centers for health professions (Setting A: 200 nursing students enrolled in a nursing program, localized in a small city; Setting B: 180 nursing students enrolled in a nursing program, localized in a metropolis), and the assembly department of an automotive manufacturer (Setting C: 12,000 employees in the assembly department, localized in a large city), all located in Germany. The participants included end-users and other stakeholders involved in the CP processes. Table 1 provides more information about the final sample listed by the data sources.

Data collection

Data were collected using quantitative and qualitative methods. To assess the transferability of CP based on planning meetings (*Activities*) and resulting multi-component interventions (*Outputs, Outcomes*), the data from structured minutes (qualitative), action plans (qualitative), questionnaires (quantitative), and interviews (qualitative) were used. Key factors influencing CP, particularly the intervention implementation (*Contextual factors*), were examined based on data from questionnaires (quantitative) and interviews (qualitative). The time points of measurement for all data sources are presented in Figure 2.

Quantitative data

In both questionnaire surveys, we used a maximum variation sampling technique to select the participants (39). To assess organizational readiness for change (40) as a predefined factor influencing CP, all stakeholders who attended the first planning meeting in each setting were invited to complete the Organizational Readiness for Implementing Change (ORIC) questionnaire (41), which had been translated into German [see study protocol (36)] at the beginning of the planning phase in September 2018 and January 2019. The questionnaire consisted of 12 items answered on a 5-point Likert scale (1 = disagree; 5 = agree). In this questionnaire survey, "change" refers to changes at the organizational level targeting PA promotion in the PArC-AVE project.

Furthermore, we utilized setting-specific CP questionnaires to evaluate the organization and realization of planning meetings, implementation status of intervention components, appraisal of the multi-component intervention, and predefined factors influencing CP. The development of these questionnaires is described in the study protocol (36); an overview of all items and subscales can be found in Supplementary material 2. The items were answered on a 5-point Likert scale (1 = disagree; 5 = agree). All stakeholders who attended at least one planning meeting in each setting were invited to complete the CP questionnaire from September to October 2020 in an online format using SoSci Survey ver. 3.2.12 (SoSci Survey GmbH, Munich, Germany).

Qualitative data

To collect detailed information on the planning meetings and number and characteristics of the involved actors, we took structured minutes of all planning meetings from September 2018 to November 2019. At the end of the planning phase, an action plan was created for each setting, documenting the number and description of the multi-component interventions developed (July–November 2019).

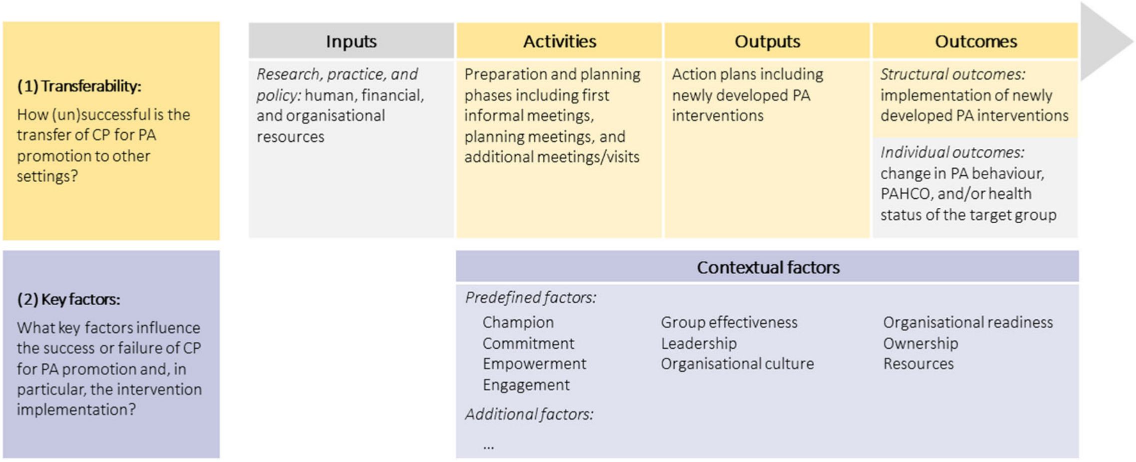


FIGURE 1
Logic model of the PArC-AVE project (including research questions).
CP, cooperative planning; PA, physical activity; PAHCO, physical-activity related health competence.

To identify the key factors influencing CP, particularly intervention implementation, we conducted semistructured interviews from December 2020 to January 2021. We developed setting-specific interview guides by building on data collected via structured minutes, action plans, and questionnaires (see Supplementary material 1). Following a purposeful sampling strategy of information-rich cases (39), we sought key informants with great knowledge about and influence on the PArC-AVE project. Accordingly, we selected two main stakeholders from each setting who were our contact persons and/or were substantially involved in the development and implementation of the interventions for the interviews. In Setting A, one invited stakeholder declined to participate because of a high workload, so another involved stakeholder representing a similar perspective was asked to participate. Two authors (EG and JP) conducted the interviews using the teleconferencing software Zoom Cloud Meetings (Zoom Video Communications, Inc., San Jose, USA). The interviews were audio-recorded and, on average, lasted about an hour (SD = 26.27; range 35.88–103.23 min).

Data analyses

Quantitative data

Following the psychometric assessment studies by Shea et al. (41), we used the revised 10-item version of the ORIC questionnaire and analyzed mean scores of the 10-item total ORIC scale, the 5-item Change Commitment subscale, and the 5-item Change Efficacy subscale. The non-parametric Kruskal-Wallis test and Dunn-Bonferroni *post-hoc* tests were employed to examine differences across the settings. To compare the characteristics of the CP processes between the settings (i.e., planning meetings, implementation status, interventions' appraisal, influence of predefined factors), the CP questionnaire data were analyzed using the non-parametric Kruskal-Wallis test. Additionally, semantic differential charts were used to visualize the organization and realization of planning meetings and the influence of predefined factors across settings. The statistical analyses were performed using IBM SPSS Statistics ver. 26 (IBM, Armonk, USA); Microsoft Excel 2016 (Microsoft Corporation, Redmond, USA) with XLSTAT was used for the descriptive analysis. A significance level of $p < 0.05$ was applied for all analyses.

Qualitative data

The structured minutes and action plans were analyzed regarding the number and characteristics of planning meetings, involved actors, and intervention components using Microsoft Excel 2016 (Microsoft Corporation, Redmond, USA). The interviews were transcribed verbatim. Although analysis of the interview transcripts using qualitative content analysis according to Kuckartz (42) was initially planned in the study protocol (36), we decided to apply the qualitative content analysis procedure according to Gläser and Laudel (43, 44) instead. The main reason for this change was that Gläser and Laudel's content analysis focuses on the reconstruction of causal relationships, that is, between processes and outcomes, which is not supported by the coding procedure according to Kuckartz in this form. According to Gläser and Laudel (43, 44), the analysis starts with a set of theoretically derived categories, which is subsequently used for extracting relevant information from the interview transcripts. In our case, we referred to the logic model and our research questions to deductively define the categories of *activity characteristics influencing the transfer of CP* and *key factors influencing intervention implementation*. Then, two authors (EG and JP)

TABLE 1 Description of the sample split by data sources.

Data source	Research question *(logic model component)*	Description of the sample	
		Number of documents	
Structured minutes (qual)	Transferability *(Activities)*	**Total: *n* = 14** A: *n* = 4 B: *n* = 4 C: *n* = 6	
Action plans (qual)	Transferability *(Outputs)*	**Total: *n* = 3** A: *n* = 1 B: *n* = 1 C: *n* = 1	
		Number of participants (participation rate)	**Participants' characteristics**
ORIC questionnaires (quan)	Key factors *(Contextual factors)*	**Total: *n* = 35** (94.6%) A: *n* = 16 (100%) B: *n* = 10 (83.3%) C: *n* = 9 (100%)	Not applicable *
CP questionnaires (quan)	Transferability and key factors *(Activities, Structural outcomes, Contextual factors)*	**Total: *n* = 31** (54.4%) A: *n* = 8 (42.1%) B: *n* = 14 (77.8%) C: *n* = 9 (45%)	Role: A: 50% practitioners, 0% policy-makers, 50% end-users, 0% other B: 57.1% practitioners, 14.3% policy-makers, 28.6% end-users, 0% other C: 77.8% practitioners, 0% policy-makers, 11.1% end-users, 11.1% other
Interviews (qual)	Transferability and key factors *(Activities, Contextual factors)*	**Total: *n* = 6** A: *n* = 2 B: *n* = 2 C: *n* = 2	Gender; working position: A: 100% female; head of the nursing education program, nursing teacher B: 100% female; head of the nursing school, nursing teacher C: 0% female; occupational physician, assembly department manager

*No information on participants' characteristics due to anonymous data collection.
A = Setting A; B = Setting B; C = Setting C; CP = cooperative planning; ORIC = organizational readiness for implementing change; qual = qualitative methods; quan = quantitative methods.

developed the extraction rules, extracted the information from the text, and generated two extraction tables, one for each category. These tables include all information from the transcripts assigned to the respective categories. More precisely, the information was extracted in the following format: *subject* (one characteristic of the respective category labeled with a keyword), *content* (more detailed description of the subject), *reported cause* (information about a cause of the subject) and/or *reported effect* (information about the effect of the subject), and *source* (link to the relevant text passage in the transcript). These extraction tables were subsequently sorted by setting; the subjects were thematically grouped and summarized where appropriate and subsequently analyzed within and across settings. Microsoft Word 2016 (Microsoft Corporation, Redmond, USA) with MIA software (Ger.: Makrosammlung für qualitative Inhaltsanalyse; Eng.: macro collection for qualitative content analysis) (45) was used for the qualitative data analysis.

Data triangulation

Following the separate analyses, the quantitative and qualitative data were triangulated at the interpretation stage (46, 47) to provide a comprehensive description of transferability and key factors. First, the quantitative and qualitative findings were triangulated separately for each setting by identifying and comparing the main findings. Subsequently, patterns of similarity or difference were examined among the three settings. Two researchers (EG and JP) participated in the triangulation procedure to minimize potential bias in analyzing and interpreting the different findings. For discrepancies between researchers, consensus was reached through discussions.

Results

To present the results split by the research questions, we built on the previously described and assigned logic model

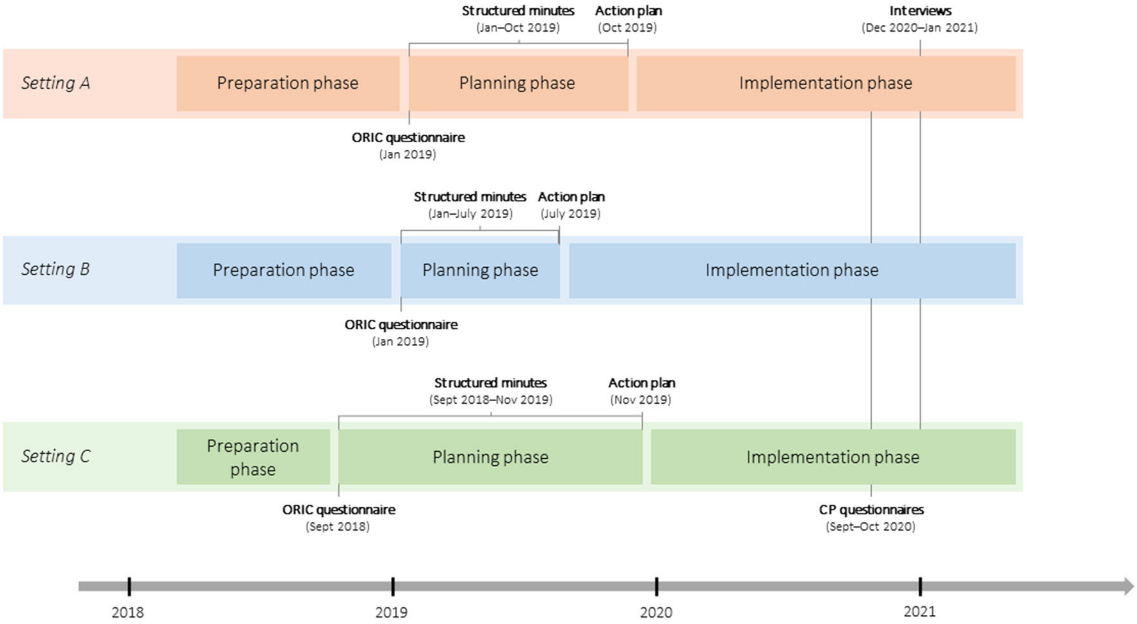


FIGURE 2
Cooperative planning processes and moments of data collections.
CP, cooperative planning; ORIC, organizational readiness for implementing change.

components of *Activities*, *Outputs*, *Structural outcomes*, and *Contextual factors*.

Transferability: Success or failure of the transferred CP processes

Activities

Our analysis of structured minutes revealed differences in the number and time periods of meetings and number of involved actors among the three settings. The number of meetings varied from four in Settings A and B to six in Setting C, with each meeting lasting 3 h. The meetings took place over a period of 10 months in Setting A, 7 months in Setting B, and 14 months in Setting C. The number of involved actors varied between 17 and 19 in Setting A ($M = 17.8$), 7 and 15 in Setting B ($M = 13.0$), and 5 and 13 in Setting C ($M = 10.5$). The involved actors were researchers (Settings A, B, C: professor, research assistants) and non-academic stakeholders such as practitioners (Settings A, B: teachers, head of the nursing education program; Setting C: occupational physicians, occupational health referents, representative of the health insurance company, member of the works council, training center staff, assembly department manager), end-users (Settings A, B: nursing students; Setting C: assembly workers), and policy-makers (Settings A, B: headmasters, head of the nursing school; Setting C: none).

The analysis of the CP questionnaire data on the organization and realization of planning meetings yielded conspicuous findings. Across all settings, we found no significant differences for the items of the subscale *research*, namely, researchers' input, organization, guidance, and goal setting during CP. For example, the researchers' input revealed no significant differences across the settings ($H(2) = 0.56$, $p = 0.755$). However, for the other subscales *stakeholders*, *planning group*, and *benefits* of CP, significant differences between the settings were found for at least one item. For example, in terms of perceived *benefits*, significant differences across settings were identified for the perceived relevance of PA and health ($H(2) = 11.86$, $p = 0.003$), with higher scores for Setting A compared with Setting C. Details of the descriptive analysis and the significant differences for all subscales and across settings are presented in Supplementary material 2.

Qualitative content analysis of the interview data revealed the following seven subjects for the category *activity characteristics influencing the transfer of CP*: *elaboration & reconsideration*, *group composition*, *number of meetings*, *participation*, *period*, *prioritization*, and *researchers' input & support* (for detailed information, see Figure 3). In addition to the identified activity characteristics, we found numerous effects of these. For example, in all three settings, the identified activity characteristic *researchers' input & support* led to a high relevance of the project within the setting. In Settings A and B, the intensive *elaboration & reconsideration* during intervention development, the *participation* of relevant stakeholders (i.e., nursing students and teachers), and the *period* including timing and regularity of meetings had positive effects (e.g., the *elaboration & reconsideration* and *participation* positively influenced the empowerment of stakeholders to contribute to the intervention implementation). However, the absence of relevant stakeholders in the planning group (*group composition*) had negative effects in Settings B and C, such as a missing definition of responsibilities or low engagement of stakeholders to contribute to the intervention implementation. In Setting C, the insufficient *number of meetings* and *prioritization* of collected ideas during one meeting also had a negative effect. For example, prioritizing ideas led to a loss of innovation in interventions, in turn reducing commitment to the project and interventions. All discovered causal relationships between the identified activity characteristics and effects for the three settings are visualized in Figure 3.

Outputs and outcomes

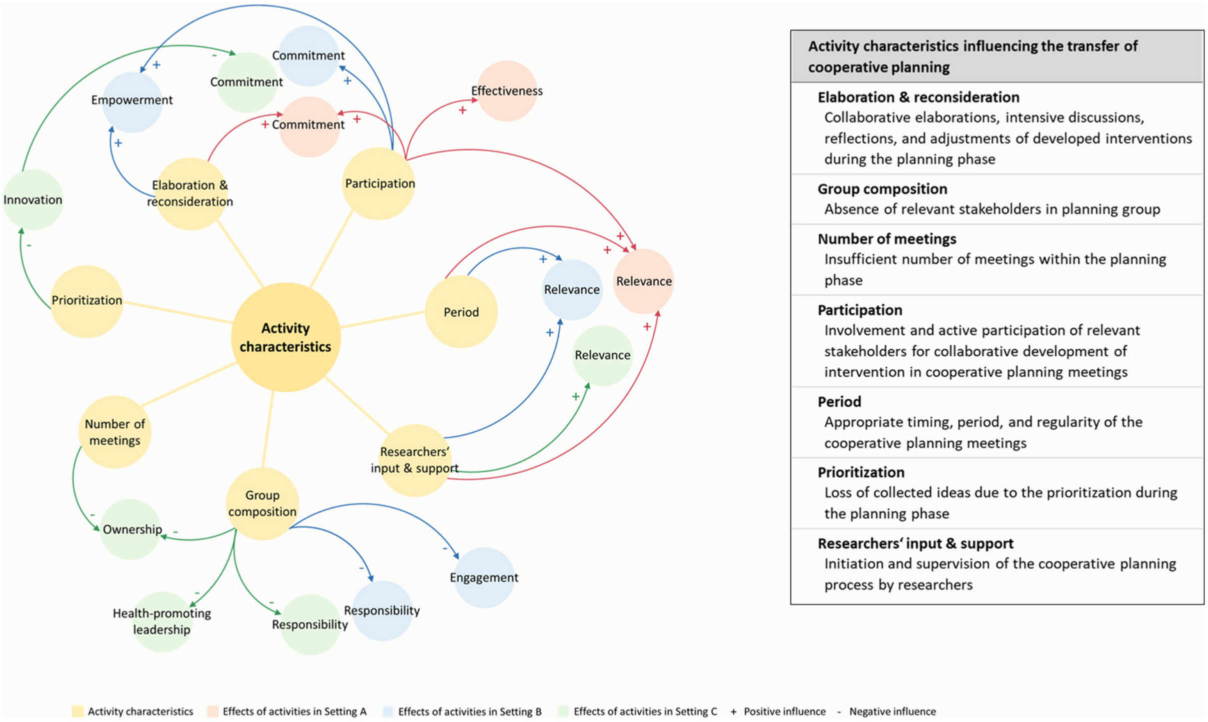
According to the action plans, the planning meetings resulted in one newly developed multi-component intervention per setting, including 12 intervention components in Setting A, 11 in Setting B, and six in Setting C. Examples of the single components are the provision of information (intervention component *information for teachers* in Setting A), competence training (intervention component *training module PAHCO* in Setting C), or PA programs (intervention component *BuG lesson* in Settings A and B). An overview of the interventions, including a description of each intervention component, is provided in Supplementary material 3.

The analysis of the CP questionnaire data on the current implementation status and expected sustainability of the individual intervention components revealed heterogeneous results across the settings (see Supplementary material 3). Notably, only a few of the participants had information on the implementation status and sustainability of the intervention components; in addition, the participants' responses were not always consistent. Thus, the data analysis was based on an agreement rate of at least 66.7% (i.e., more than two thirds of the participants with information gave the same response) to make conclusive statements about the implementation status and expected sustainability. Overall, 33.3% of the intervention components ($n = 4$) were implemented in Setting A and 18.2% ($n = 2$) were implemented in Setting B. In Setting C, 33.3% of the intervention components ($n = 2$) were not perpetuated, and 16.7% ($n = 1$) were not implemented because of COVID-19 restrictions. Sustainable implementation of the intervention was rated as "possible" for 66.7% of the intervention components ($n = 8$) in Setting A, 63.6% ($n = 7$) in Setting B, and 0% ($n = 0$) in Setting C; it was rated as "not possible" for 8.3% of the intervention components ($n = 1$) in Setting A, 0% ($n = 0$) in Setting B, and 66.7% ($n = 4$) in Setting C. For a few intervention components, it was not possible to draw absolute conclusions regarding their implementation status or expected sustainability due to missing information from participants or inconclusive responses (i.e., agreement rate below 66.7%), leaving some percentages. The results of the appraisal of the intervention components regarding the creation of new capabilities, their effectiveness, their fit to the end-users and setting, and their perceived value within the organization can be found in Supplementary material 4.

Key factors: Influence on the success or failures of CP

Contextual factors

Qualitative content analysis of the interview data revealed the following 11 different subjects for the category of *key factors influencing intervention implementation*: *champion*, *commitment*, *embedment*, *empowerment*, *engagement*, *health-promoting leadership*, *ownership*, *relevance*, *resources*, *responsibility*, and *strategic planning* (for more details, see Table 2). Eight of these key factors, that is, *commitment, embedment, engagement, health-promoting leadership, ownership, relevance, resources*, and *strategic planning*, were identified in all settings; the other three key factors were each found in two of the three settings. Whether these key factors had a positive or negative influence on intervention implementation depended on the reported availability or unavailability within the settings. For example, the availability of *commitment, engagement, health-promoting leadership, ownership*, and *strategic planning* in Settings A and B had a beneficial effect on intervention implementation, whereas the unavailability of these key factors hindered the intervention implementation in Setting C. Furthermore, the presence of a *champion* who is devoted to the project and manages it with enthusiasm facilitated intervention implementation in Setting A, whereas the non-presence of this very *champion* had a hindering effect on intervention implementation in Setting C; in Setting B, this key factor was not mentioned. Moreover, some key factors need to be considered in a more differentiated way because they both facilitated and hindered intervention implementation, such as *resources* in Settings A and C. For example, a lack of personal *resources* had a negative influence on intervention implementation, while the provision of financial *resources* had a beneficial effect. Examining the key factors with respect to intervention implementation in the different settings, successful intervention implementation was associated with a higher number of available key factors, with $n = 10$ key factors in Setting A, $n = 9$ in Setting B, and $n = 2$ in Setting C. Conversely, a high number of unavailable key factors were found in Setting C ($n = 9$), resulting in failed intervention implementation.



Activity characteristics influencing the transfer of cooperative planning

Elaboration & reconsideration
Collaborative elaborations, intensive discussions, reflections, and adjustments of developed interventions during the planning phase

Group composition
Absence of relevant stakeholders in planning group

Number of meetings
Insufficient number of meetings within the planning phase

Participation
Involvement and active participation of relevant stakeholders for collaborative development of intervention in cooperative planning meetings

Period
Appropriate timing, period, and regularity of the cooperative planning meetings

Prioritization
Loss of collected ideas due to the prioritization during the planning phase

Researchers' input & support
Initiation and supervision of the cooperative planning process by researchers

FIGURE 3
Activity characteristics influencing the transfer of cooperative planning identified through qualitative content analysis.

During qualitative content analysis, we were able to extract not only the identified key factors, but also their reported effects and/or causes, thus establishing causal relationships. While the reported effects of the key factors were always associated with (un)successful intervention implementation, there were a variety of reported causes affecting the identified key factors. Hence, these causes behind the key factors can be referred to as the preceding factors. In contrast to the key factors, which showed high homogeneity across settings, the preceding factors were highly setting-specific. An example of a reported causal relationship between the preceding factor and key factor was the positive *attitude* toward PA, leading to high levels of *engagement* in Settings A and B, which, in turn, was a key factor facilitating intervention implementation. In Setting C, the lack of a positive *attitude* toward PA led to a low level of *commitment*, which emerged as a key factor that hindered intervention implementation. Furthermore, *COVID-19 pandemic* and *personnel changes* were found to be preceding factors in all three settings. Although these challenges were largely overcome through *strategic planning* in Settings A and B, they resulted in a missing *champion*, low *commitment*, low *engagement*, low *relevance*, lack of *responsibility*, and lack of *strategic planning* in Setting C. In addition to the identified causal relationships between the key factors and preceding factors, causal relationships were also revealed between the key factors themselves. For example, *health-promoting leadership* influenced the provision of *resources* in all three settings; while *health-promoting leadership* facilitated the provision of *resources* in Settings A and B, the provision of *resources* was deficient because of the lack of *health-promoting leadership* in Setting C. A detailed overview of all identified key factors and preceding factors, including their reported causal relationships, is illustrated in Figure 4.

The analysis of the CP questionnaire data on the predefined factors influencing CP yielded some significant differences across settings (see Supplementary material 2), underscoring the differences in the key factors identified in the interviews. For example, significant differences between settings were found for ownership Item 1 ($H(2) = 10.37$, $p = 0.006$) and empowerment Item 2 ($H(2) = 7.08$, $p = 0.029$), both with higher scores for Setting A compared with Setting C, while higher scores for Setting A compared with Setting B were found for engagement Item 2 ($H(2) = 6.30$, $p = 0.043$). As another predefined factor influencing CP, we also found differences in organizational readiness across settings. We observed significantly higher scores in total ORIC ($H(2) = 7.83$, $p = 0.020$) and Change Efficacy ($H(2) = 9.00$, $p = 0.011$) for Setting B compared with Setting C (see Supplementary material 5). No significant differences were found in the Change Commitment scores across all settings ($H(2) = 4.61, p = 0.100$).

TABLE 2 Key factors influencing intervention implementation identified through qualitative content analysis.

Key factors influencing intervention implementation	Setting A	Setting B	Setting C
Champion Champion who is devoted to the project and manages it with enthusiasm	✓	n.m.	x
Commitment High degree of acceptance and advocacy of the project/intervention by stakeholders and end-users	✓	✓ / x	x
Embedment Embedment of the intervention in existing internal processes and structures	✓	✓	✓
Empowerment Development of abilities for autonomous intervention implementation by stakeholders	✓	✓	n.m.
Engagement High degree of engagement and willingness of stakeholders and end-users to contribute to the intervention implementation	✓	✓ / x	x
Health-promoting leadership Leadership support for the intervention implementation	✓	✓	x
Ownership Assumption of ownership of the project/intervention by the organization	✓	✓	x
Relevance High degree of relevance for PA promotion and high standing of the project	✓ / x	x	x
Resources Provision of financial, personnel, spatial-material and/or temporal resources for the intervention implementation	✓ / x	✓	✓ / x
Responsibility Definition and takeover of responsibilities for the intervention implementation	n.m.	✓	x
Strategic planning Execution of organizational and content-related planning of the intervention implementation	✓	✓	x

✓ = available; x = not available; n.m. = not mentioned.

Discussion

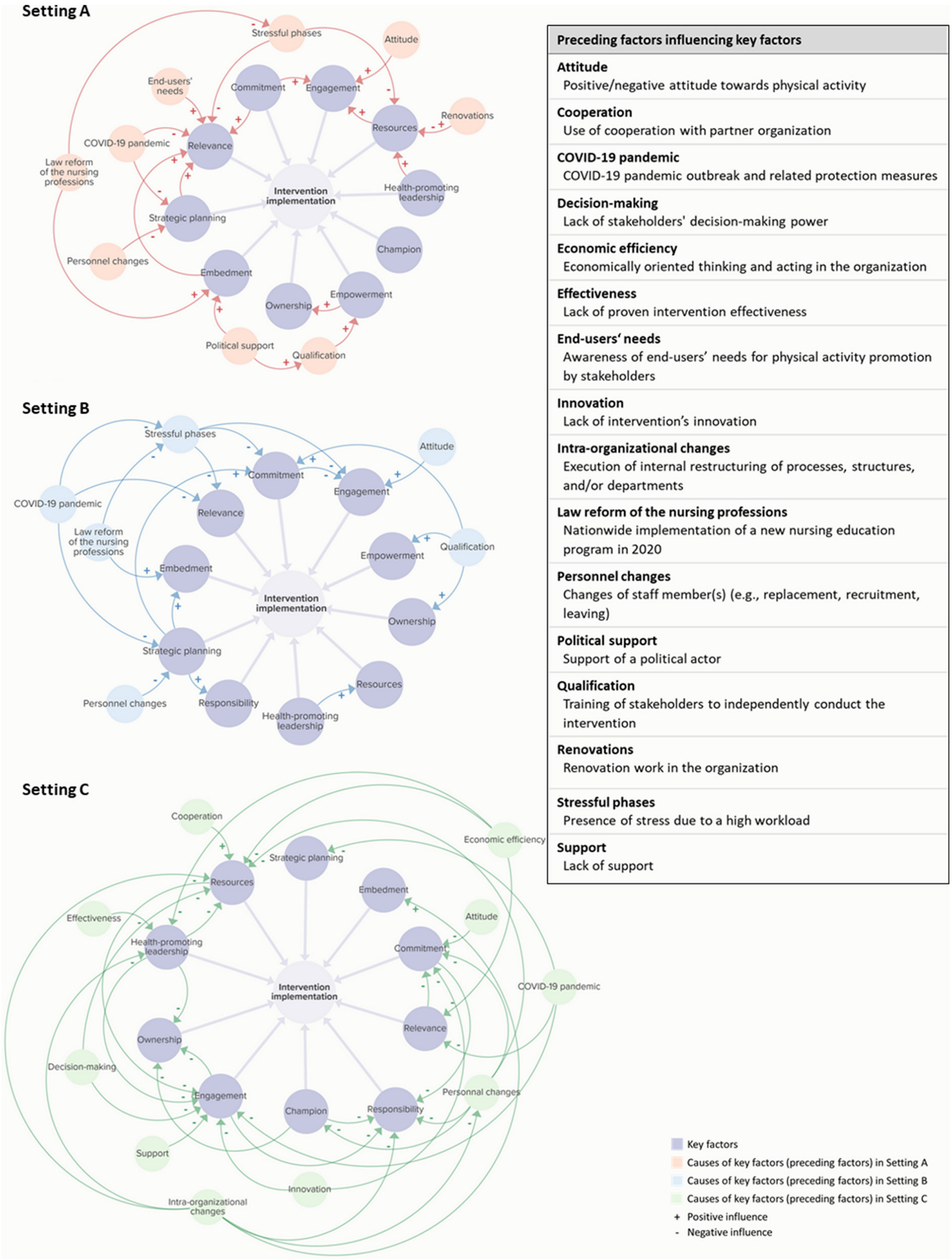
What is the key to successful intervention implementation?

The current study contributes to a better understanding of CP as a co-creation approach for promoting a physically active lifestyle by answering questions about (1) the transferability of CP and (2) the associated key factors influencing its success or failure, particularly intervention implementation. Overall, the transfer of CP to new settings in the nursing care and automotive mechatronic sectors was realized, though the achieved impact varied by setting. Comparing the results of the three settings, CP resulted in the development and implementation of intervention components in Settings A and B, whereas in Setting C, a multi-component intervention was developed but not implemented. In this context, 11 *key factors influencing intervention implementation* were identified: *champion*, *commitment*, *embedment*, *empowerment*, *engagement*, *health-promoting leadership*, *ownership*, *relevance*, *resources*, *responsibility*, and *strategic planning*. The identified key factors are confirmed by the implementation science literature in general (48, 49) and in the specific settings of schools (50, 51) and workplaces (52, 53). Moreover, these key factors show a high overlap with the contextual factors that we have predefined based on previous research (36).

It is striking that the key factors identified were very similar across the three settings, but the different manifestations of these factors seem to determine the implementation or non-implementation of interventions. Thus, the presence of numerous key factors in Settings A and B resulted in the implementation of interventions, whereas the absence of these factors led to the lack of intervention implementation in Setting C. In addition to the key factors, we identified preceding factors that had an impact on these very key factors and, thus, indirectly influenced intervention implementation. These preceding factors were characterized by a high degree of setting specificity. However, some of these factors are consistent with influencing factors reported in the implementation science literature, such as personnel changes, political support, and qualification in the school setting (50, 51) or intraorganizational changes, personnel changes, and support in the workplace setting (52, 53).

The role of co-creation

By triangulating the quantitative and qualitative findings, we were able to uncover the relationships between activity characteristics and key factors. More precisely, some of the



Preceding factors influencing key factors
Attitude Positive/negative attitude towards physical activity
Cooperation Use of cooperation with partner organization
COVID-19 pandemic COVID-19 pandemic outbreak and related protection measures
Decision-making Lack of stakeholders' decision-making power
Economic efficiency Economically oriented thinking and acting in the organization
Effectiveness Lack of proven intervention effectiveness
End-users' needs Awareness of end-users' needs for physical activity promotion by stakeholders
Innovation Lack of intervention's innovation
Intra-organizational changes Execution of internal restructuring of processes, structures, and/or departments
Law reform of the nursing professions Nationwide implementation of a new nursing education program in 2020
Personnel changes Changes of staff member(s) (e.g., replacement, recruitment, leaving)
Political support Support of a political actor
Qualification Training of stakeholders to independently conduct the intervention
Renovations Renovation work in the organization
Stressful phases Presence of stress due to a high workload
Support Lack of support

■	Key factors
■	Causes of key factors (preceding factors) in Setting A
■	Causes of key factors (preceding factors) in Setting B
■	Causes of key factors (preceding factors) in Setting C
+	Positive influence
-	Negative influence

FIGURE 4

Reported causal relationships of key factors and preceding factors influencing intervention implementation identified through qualitative content analysis. The causal loop diagrams were produced using Kumu Inc (retrieved from https://kumu.io/).

identified effects of activity characteristics corresponded to the identified key factors influencing intervention implementation. Thus, these activity characteristics seem to have had an impact on the manifestation of key factors, thereby also influencing intervention implementation.

In Setting A, for instance, all observed activity characteristics resulted in positive effects. For example, the *participation* of relevant stakeholders led to an increased *commitment* to and *relevance* of PA and health. In addition, both *commitment* and *relevance* were identified as key factors contributing to successful intervention implementation. The successful involvement of stakeholders was also supported by the results of the questionnaire survey, which showed high ratings for the subscale *stakeholders* in Setting A. The positive impact of stakeholder participation on commitment and relevance has also been the subject of other research articles (9, 12), indicating that partnerships between researchers and non-academic stakeholders are a promising approach for translating research findings into practice.

In comparison, in Setting B, not only the positive but also the negative effects of activity characteristics were found. For example, the *group composition* resulted in low *engagement* and a missing definition of *responsibilities*. These two effects of the *group composition* were also identified as key factors: *engagement* both facilitated and hindered intervention implementation, while *responsibility* facilitated intervention implementation. What might seem contradictory at first sight is a good example of the complexity of such processes and interactions of activity characteristics, key factors, and outcomes. For example, challenges can arise, while other factors simultaneously contribute to overcoming barriers (54), as the current study has uncovered in Setting B.

In Setting C, on the contrary, the observed activity characteristics mainly had negative effects. In this context, *group composition* appeared to be the most challenging, with negative effects on *health-promoting leadership*, *ownership*, and *responsibility*, all of which were identified as key factors and, thus, contributing to the failure of intervention implementation. The challenges associated with the *group composition* may have been caused by the lack of leadership participation, as well as the great heterogeneity of the involved practitioners (see the results of the structured minutes). More specifically, the lack of leadership participation may have hindered the decision-making process (see the preceding factor *decision making*, showing a lack of stakeholders' decision-making power). This is consistent with the findings from Nguyen et al. (55), emphasizing the importance of including decision- or policy-makers to achieve impact and implement the findings for integrated knowledge translation processes. Moreover, the great heterogeneity among practitioners may have increased the competing interests, which may have complicated the definition and adoption of responsibilities for intervention implementation. This illustrates a dilemma of co-creation because all relevant stakeholders should be involved (2), but at the same time, this increases the risk of conflicts arising from differing interests and perspectives (11, 35, 56).

Notably, the activity characteristic *researchers' input & support* had a positive effect on the relevance of the project in all three settings, underlining the importance of the researchers' role and contribution in the planning phase. This was supported by other studies highlighting the involvement of researchers as a key performance indicator for enhancing CP (19) and recommending that researchers work closely with end-users and other non-academic stakeholders from the outset of a co-creation process to ensure the relevance of findings (57). Overall, the current study highlights the complex and setting-specific interplay between activity characteristics and key factors, as well as the relevance of activity characteristics for the success or failure of the intervention implementation.

Fit of co-creation approaches

The findings suggest that some settings might benefit more from a co-creation approach for PA promotion than others, with more favorable effects in the nursing care setting than in the automotive mechatronics setting. This may question a co-creation approach as a panacea leading to successful intervention implementation. Here, it might be advisable to consider in advance whether or, in particular, how the use of a co-creation approach is appropriate for a particular setting.

A first starting point to determine the fit of a co-creation approach can be the readiness for a change (40), such as PA promotion, in a specific setting. In the present study, we examined organizational readiness as a predefined factor influencing CP, here as operationalized by Shea et al. (41); our results failed to reveal that higher change efficacy and commitment comes with a more successful CP process. A recent review by Miake-Lye et al. (58) has shown that this organizational readiness assessment covers mainly the construct "readiness for implementation" as it is used in the Consolidated Framework for Implementation Research (CFIR; domain "inner setting") (49). Concurrently, other organizational readiness for change assessments [e.g., (59, 60)] cover far more CFIR constructs (e.g., domains "characteristics of individuals," "process") (58). In this context, it may be important to consider more setting-specific information to classify a setting using a readiness scale to predict an organization's ability to conduct a change. However, implementation and especially determinant frameworks include relevant constructs and can be useful for mapping and developing a comprehensive organizational readiness instrument (58, 60, 61). For a more setting-specific application of the organizational readiness concept, the key factors of intervention implementation as identified in our multiple case study might also be useful for a readiness assessment. This readiness judgment should then be followed by a recommendation of strategies to enhance readiness before a co-creation process is conducted, for example, by identifying and preparing a champion [see the typology of readiness development strategies by Vax et al. (62)].

Second, classifying a setting as ready for change may not necessarily mean that this setting is also ready to engage in a co-creation process. Since participation is a core element of co-creation, a setting's readiness for participation, in which stakeholders' participation is considered important and valuable, is crucial for conducting a co-creation process. Vice versa, a setting completely closed to the stakeholders' participation may be unsuitable for a co-creation process (63). Moreover, participating in a co-creation process is not without costs for stakeholders because stakeholders' willingness and opportunities to invest additional resources are major requirements for conducting a co-creation process. Conversely, less emphasis may be placed on using a co-creation process when time or resources are limited (35). To determine a setting's readiness for participation, it might be useful to evaluate this readiness within the scope of an organizational readiness assessment, as done by Robertson et al. (64). This information can then be used to decide whether a co-creation approach seems suitable in a setting, prerequisites first need to be created (e.g., provision of resources), or another approach, such as implementing researcher-developed interventions, would be more appropriate.

Finally, a co-creation approach with the aim of PA promotion should be tailored to the unique needs and opportunities of the setting. This was supported by recent research emphasizing that co-creation is largely context-dependent (32, 57, 65), highlighting the need for localized solutions not only for the development of tailored interventions, but also for the realization of a co-creation process itself to account for the uniqueness of settings. Thus, a setting-specific selection of co-creation steps and principles or potential adaptations may be required to achieve an optimal fit between the chosen co-creation approach and given setting. In this regard, there is a growing body of literature focusing on providing guidance for the design of co-creation processes. For example, principles and strategies for partnerships with researchers and stakeholders (32, 66), or an instrument to help researchers select the appropriate tools to foster the impact of co-creation processes (67) are provided.

Strengths and limitations

The current comprehensive mixed methods evaluation embedded in a multiple case study allowed us to gain new insights into the "black box" transferability and key factors of CP. Given the heterogeneity and flexibility of co-creation processes, this design was found to be appropriate for examining our research questions within and between three settings. In particular, the qualitative content analysis by extraction was a major strength because it enabled us not only to identify important activity characteristics and key factors, but also to determine the causal relationships between them and their reported causes and/or effects. This has given us a deep understanding of the dynamics and complexity of how these factors interact in the respective settings.

However, some limitations must be considered. First, as outlined in the study protocol, the measurement of outcomes at the individual level (i.e., PA behavior, PAHCO, health status) was planned in a pre-post design but finally not possible, as practitioners self-initiated the implementation of intervention components at an early stage (36). Therefore, in examining the transfer of CP, we refer to the logic model components *Activities*, *Outputs* and *Structural outcomes*. Second, the findings of the ORIC questionnaire should be interpreted with caution, as only a small sample size was reached, mainly because only people who participated in the first planning meeting took part in the survey. Third, we had a moderate response rate to the request for participation in the CP questionnaires; thus, not all the perspectives of the stakeholders on the organization and realization of planning meetings, the current implementation status and appraisal of interventions, and predefined factors influencing CP may be represented. However, we aimed to obtain missing information and gain deeper insights into the transferability and key factors of CP in different settings, here by conducting additional interviews and selecting interviewees through a purposeful sampling of information-rich cases. Fourth, the interview guide was pilot tested only within the research team, and the transcripts and findings were not returned to the interviewees for comments and feedback. Fifth, the identified causal relationships only refer to the interviewees' qualitative reports.

Conclusion

The present article contributes to a better understanding of a co-creation approach utilized for PA promotion by providing new insights into (1) the transferability of CP as a co-creation approach and (2) the associated key factors influencing its success or failure, particularly intervention implementation. Specifically, the in-depth mixed methods evaluation in three settings in the nursing care and automotive mechatronic sectors provided relevant findings for future research. As a main result, transferring CP to new settings was achieved, though differences between the three settings were identified and demonstrated. Particularly, the achieved impact of CP varied by setting: while CP resulted in the development and implementation of PA-promoting interventions in nursing care settings, a multi-component intervention was developed but not implemented in the automotive mechatronics setting. In this context, we identified multiple key factors influencing intervention implementation and, thus, the success or failure of CP. These key factors also varied by setting, interacted in a complex way, and were related to co-creation activities. Therefore, future co-creation initiatives should carefully consider the specific characteristics of a setting to determine whether it is truly ready to initiate a change, such as PA promotion, and ready to engage in a co-creation process. Moreover, future research should investigate the complex and dynamic interactions between key factors to generate a theoretical foundation for the implementation and evaluation of such processes.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Ethical Committee of the Friedrich-Alexander-Universität Erlangen-Nürnberg. The patients/participants provided their written informed consent to participate in this study.

Author contributions

JP and EG conducted the qualitative and quantitative data collection, analyzed the qualitative and quantitative data, and drafted the manuscript. JC supported the qualitative and quantitative data collections and analyses. KP and JS acquired funding. KP supervised the work. All authors were involved in designing the study, interpreting data, critically reviewing drafts of the manuscript, and reading and approving the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

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Testing a deliberative democracy method with citizens of African ancestry to weigh pros and cons of targeted screening for hereditary breast and ovarian cancer risk

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Background: Democratic deliberation (DD), a strategy to foster co-learning among researchers and communities, could be applied to gain informed public input on health policies relating to genomic translation.

Purpose: We evaluated the quality of DD for gaining informed community perspectives regarding targeting communities of African Ancestry (AAn) for Hereditary Breast and Ovarian Cancer (HBOC) screening in Georgia.

Methods: We audiotaped a 2.5 day conference conducted via zoom in March 2021 to examine indicators of deliberation quality based on three principles: (1) inclusivity (diverse viewpoints based on participants' demographics, cancer history, and civic engagement), (2) consideration of factual information (balanced and unbiased expert testimonies, participant perceived helpfulness), and (3) deliberation (speaking opportunities, adoption of a societal perspective on the issue, reasoned justification of ideas, and participant satisfaction).

Results: We recruited 24 participants who reflected the diversity of views and life experiences of citizens of AAn living in Georgia. The expert testimony development process we undertook for creating balanced factual information was endorsed by experts' feedback. Deliberation process evaluation showed that while participation varied (average number of statements = 24, range: 3–62), all participants contributed. Participants were able to apply expert information and take a societal perspective to deliberate on the pros and cons of targeting individuals of AAn for HBOC screening in Georgia.

Conclusions: The rigorous process of public engagement using deliberative democracy approach can successfully engage a citizenry with diverse and well-informed views, do so in a relatively short time frame and yield perspectives based on high quality discussion.

KEYWORDS

public engagement, health policy, stakeholder participation, democratic deliberation, hereditary cancer syndromes, minority groups

Introduction

Obtaining public input and involvement in health service planning and delivery, and in setting health policy priorities is both critically needed and difficult to achieve (1). Strategies used to engage public participation span a continuum, ranging from discrete opportunities for engagement (e.g., focus groups, surveys) to serialized involvement requiring extended time commitments (e.g., coalitions, citizen science, or public hearings) (2). Indeed, the latter approaches require sustained interactions with citizens who can thoughtfully advise strategic decision making and the direction of public policy at the local or national level (3).

What public engagement looks like across this continuum differs considerably based on setting. Oftentimes, little attention is given to the appropriateness and standards of the methods used (4). As a result, approaches for public involvement proliferate with little systematic evidence regarding the quality of these approaches. Moreover, strategies to inform priority setting in public health contexts have been focused at the discrete end of the continuum. While discrete approaches benefit from being feasible, low cost, and less time demanding, these approaches arguably do not enable citizen participants to provide well-informed input.

Public engagement has particular importance in the case of complex health topics that involve new or controversial advances, where health priority setting requires balancing multiple tradeoffs. Input from members of the public may be especially helpful, when there is a sizable gap in scientific and public knowledge. Public engagement offers a process of involving target audiences as "co-creators" who can provide citizen perspectives on complex topics such as emerging genomic discoveries and related priorities. In turn, this approach can maximize the likelihood that programs and policies will be relevant, successful, and acceptable (5). Indeed, a recent systematic review examining public involvement in genomics research and translation suggested that sustainable, ongoing deliberative approaches to public participation should receive more attention (6).

Democratic deliberation (DD) is a public engagement strategy that has been used in numerous health contexts internationally (7–9). DD refers to a collective deliberation process that is conducted rationally and fairly among consumers (i.e., those with a stake in the issue at hand) and citizens (i.e., those who have no stake in the issue) (10). Unlike focus groups and other discrete methods, citizens and consumers are provided with focused and neutral factual information about the topic via "expert testimony"; participants' are encouraged to voice differing viewpoints, interests, and experiences; and groups deliberate about tradeoffs they view to be important to come to a consensus opinion that, in theory, would maximize the common good.

Previous literature has found that DD methods provide more authentic public opinions (11). Moreover, DD may be particularly useful when considering policies and programs for marginalized populations (11, 12). Enlisting these groups to generate and thoughtfully consider potential pros and cons of health policies and programs through the lens of personally experienced disparities can be an act of empowerment (12).

DD approaches are appropriate but have yet to be applied for public engagement in considering advances in genomic research and translation. Several national organizations concur that population screening to identify individuals and families at highest risk for inherited cancer syndromes is warranted (13–18). Low-cost genetic risk screening tools, such as family history screening, are available for several inherited cancer syndromes including heredity breast and ovarian cancer (HBOC) (13, 19). Women at increased risk of HBOC can be referred to genetic counseling, and if appropriate, genetic testing to inform lifesaving prevention and treatment options (20). Nonetheless, evidence suggests that early translation efforts to get these cancer genetic services in the hands of underrepresented minority populations are not overcoming existing disparity propensities. This is particularly concerning for women of African Ancestry (AAn) who are more likely to develop and die from aggressive breast cancers than women from other ancestry groups (with the exception of women of Ashkenazi Jewish ancestry) (21, 22). A growing number of studies also show that women of AAn are significantly less likely to seek cancer genetic services than other women even when receiving care in high-resourced specialty clinics (23–27). There have been numerous qualitative and quantitative studies to shed light on logistical and psychosocial barriers to genetic service uptake and research participation among minority populations (28–31). Yet efforts to address these barriers have not shown consistent improvement in uptake of cancer genetic services (30, 31).

Targeting women of AAn for HBOC screening could be controversial as it requires balancing multiple tradeoffs. A number of current realities add complexity to this consideration that warrant community deliberation: (1) deficiencies in family history-based genetic risk screening precision for those of AAn due to their low inclusion in HBOC basic science, treatment, and prevention research (32); (2) high rates of variants of uncertain significance and novel deleterious mutations among those of AAn due to the cascade of low access, provider referral to and uptake of testing (33, 34); (3) poorer understanding and acceptance of negative HBOC screening results (not at increased genetic risk) among those of AAn compared to Whites (35, 36); and (4) historic distrust of health care systems creating heightened privacy concerns related to genetic testing among AAn communities (37). Most research has focused on existing service delivery strategies (e.g., activated providers, telegenetics (27, 38). However, research has yet to enlist communities of AAn to thoughtfully consider whether targeted screening efforts is in

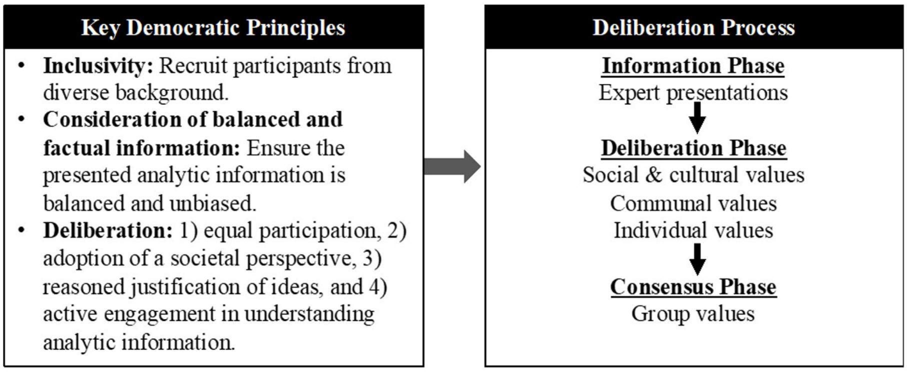

FIGURE 1
Conceptual framework of democratic deliberation design.

the interest of the common good and warranted to redress their poor cancer outcomes.

Because DD requires extensive researcher and community member investment, the feasibility of this method and whether it can achieve thoughtful and useful community input is unclear. To this end, we conducted a DD conference to gain community perspectives on targeting communities of AAn in Georgia for HBOC screening. Informed by previous research (39, 40), we considered three key democratic principles (Figure 1).

Consideration of balanced and factual information

DD requires that participants have basic and unbiased understanding of the issues and tradeoffs to enable active discussion of the questions being deliberated. The requirement is that factual information be presented as free as possible from distortions or attempts at persuasion.

Inclusivity

The deliberation group should reflect on the diversity of citizen and consumer views and life experiences (in this case citizens of AAn living in Southwest Georgia). Deliberation cannot be fully democratic if some parts of society are marginalized or excluded.

Deliberation

Critical to optimal DD processes is that citizens discuss and weigh differing, and often competing, social values to reach consensus as a group (41). Members must have equal opportunity to take part in the discussion and deliberate, which involves listening and reflecting on others' perspectives before reaching conclusions. Members are encouraged to adopt a societal perspective on the issue in question, where the deliberation focuses on what is best for society, rather than on what is best for individual participants. In addition, the group reflects on what they hear and provides their rationale when offering comments.

For this manuscript, we aimed to describe: (1) a systematic process to create expert testimony materials that are informative, balanced and unbiased, (2) a multi-step process to recruit an inclusive group of participants who could reflect diversity of AAn in Southwest Georgia for a multi-day DD conference, and (3) a high-quality deliberation process characterized by participants having equal opportunity to contribute, active engagement in understanding presented information, adopting a societal perspective, and using reasoned justification to support their opinions.

Methods

Expert testimony development process

Participants gained understanding of the different scientific and ethical viewpoints, interests and experiences related to HBOC population screening. Development and formatting of expert testimony was a key design feature for enabling nuanced knowledge and understanding of the topic at hand. Experts in the areas of HBOC, population screening, and bioethics were members of the study team (Drs. McBride, Guan, McCullough and Dickert). These individuals conceptualized a short-list of topics they regarded to be essential for citizens to be able to thoughtfully consider the overarching issue. The testimony scripts and visual presentation were aligned with frameworks of health literacy and co-cultural communication theory (42) to circumvent the limitations imposed by low genomic literacy. Leveraging feedback from a meeting with stakeholders in Southwest Georgia, and in collaboration with our topical expert co-investigators (Drs. Gornick, Guan, McBride, McCullough, Dickert, Woods-Jaeger), we finalized audio-recorded PowerPoint testimony presentations that were 5–10 min long for the five topics relative to specific deliberation questions: *What is HBOC? Why is it important and how to identify people at risk for HBOC? Current HBOC screening program in Georgia, Why screen at the population level? What is ancestry and why African ancestry?* A single narrator was chosen for standardization and to maintain a neutral tone to the information presented. In total, participants viewed seven pre-recorded expert testimonies (two on day 1, three on day 2, and two on day 3).

Population and recruitment

Our target population included citizens of AAn who were living in the surrounds of Albany, Georgia (182 miles South of Atlanta), the location of our community partnering organization Horizons Community Solutions (horizonscommunity.org; previously named Cancer Coalition of South Georgia). The population of Albany is estimated at 77,434; 72% of residents identify as having AAn; the Southwest region has 44.6% residents with AAn. A recent evaluation of HBOC screening in Albany's public health district shows that <3% of women have completed family history-based screening that is provided by the Public Health Clinics in the area (43, 44).

In collaboration with our community partnering organization, working with the community for over 30 years, the study team developed a detailed recruitment rubric (Appendices 1, 2) to track and organize community partner- and participant-level information. We conducted brainstorming sessions to generate the full scope of constituencies of potential residents of the Albany area to ensure that an inclusive participant population was being reached. We organized these indicators of diversity along two domains: viewpoint diversity (e.g., age, gender, faith community involvement, cancer history) and having prior experiences that required consideration of the common good (e.g., civic engagement, community leadership experience, jury duty). Rationale of indicator selection is described in Appendix 2: Definitions/Rationale for Recruitment Rubric.

Based on these discussions, potential participants were required to: self-identify as African American/Black or Bi-racial, indicating African ancestry; and be ages 25 or older when risk-reducing interventions for *BRCA* mutation carriers are typically recommended to begin (45). Additionally, participants were required to speak English as all materials for the conference were created in English. Due to the COVID-19 pandemic, the conference was planned to be virtual requiring that participants have some comfort with the internet.

Recruitment took place in two phases. In the first phase, Horizon Community Solutions' network was leveraged to contact organizations and community-involved individuals to identify partners who might assist in sharing information about the project entitled "The Southwest Georgia Community Council on Hereditary Breast and Ovarian Cancer Citizen Discussion Group." Identified community partners were sent a flier branded with the study name and were encouraged to share the information among their constituents. In the second phase, individuals who were interested in the study followed a link found on the study flier to complete a brief screener to assess basic eligibility criteria and indicators of viewpoint diversity (Appendix 3: Screener 1). Individuals who expressed continued interest in participating were then contacted via telephone by Horizon's staff for further screening on indicators suggestive of ability to consider the common good (Appendix 4: Screener 2).

Invitations to participate in the study were determined based on eligibility criteria and the individual's representing a key constituency identified in the rubric (i.e., viewpoint diversity and ability to consider common good). Participant enrollment was monitored weekly at a minimum to gauge representation of recruited participants and adjust the recruitment strategy as needed. Individuals who were invited and agreed to participate in the study consented via email before the sessions began. To further ensure feasibility of participation, technical assistance for using the online platform was also available for participants.

Deliberation conference procedures

The research team assigned participants to five small groups prior to the discussion sessions, with the goal to have diverse constituencies represented within each small group. A trained facilitator moderated the discussion in each group. Facilitators were recruited from the community and had a background in public health, health education, or qualitative interviewing. Facilitators received a training workbook and 6-h of online deliberation training from a study team investigator (MCG) with expertise in qualitative research and in the conduct of DD sessions. Training materials and procedures were adapted from other published studies using this methodology (46). Facilitators were trained to engage participants with different learning and communication styles and allow the views of less vocal participants to be included (47). In particular, facilitators worked to ensure that everyone in their group understood the deliberation task and had the opportunity to speak and contribute, and that all the perspectives were heard and considered by the group. Facilitators also kept the discussions on topic and ensured each task was completed within the time available. Facilitators were trained to focus on the structure and process of the discussions, rather than content. Facilitators were instructed that they should not express any views on the matters under discussion, nor serve as sources of knowledge.

Participants were assigned to groups so as to balance the number of males and females, age, education-level distributions, and zip code. Participants remained in the same small group throughout all discussion sessions. Upon completion of the

2.5-day conference, participants were compensated with a total incentive of $200. All study activities were approved by Emory University IRB (IRB00114524).

Consistent with prior studies (1), ∼ 1 week prior to the deliberation conference, discussion participants received a workbook by mail that included the meeting agenda, deliberation questions, guidelines for engaging and participating, and slides to be presented in the expert testimonies. The workbook also included activities, space for notes, and reflections that occurred during the deliberation. The deliberation conference included three Zoom sessions: a brief 75-min orientation meeting on Friday, March 12, and two 3.5-h sessions on Saturdays, March 13 and March 20. Deliberation involved viewing seven pre-recorded expert testimonies (two on day 1, three on day 2, and two on day 3) followed by generating and prioritizing pros and cons related to the question with group members. These discussions culminated in participants voting on whether or not they believed (DD Question 1) Georgia should continue its current way of identifying women at risk for HBOC and (DD Question 2) if Georgia should target all individuals of African ancestry in order to identify those at risk for HOBC.

Data collection

Opportunity to consider balanced and factual information

The DD evaluation measures and sources of data are shown in Table 1. Using 10-point rating scales, we also asked DD participants how *helpful* the expert testimonies and interactions with peers and study team members was in their group discussions. Following completion of the DD conference, we convened a group of 14 stakeholders for a 2-h meeting to describe our DD process and hear their viewpoints on pros and cons of targeted screening and share citizen findings. Participants included community partners in Southwest Georgia (DB, JK), policy stakeholders who work across the state of Georgia and are involved in priority setting and decision making for cancer control activities. As part of the meeting, stakeholders viewed the expert testimonies and were asked to provide feedback regarding the perceived impartiality of the expert testimonies.

Inclusivity

Guided by the recruitment rubric, a database was created to record the number of individuals who: completed the initial online screener, were contacted for a second-round telephone interview, were deemed eligible, consented to participate, and attended each day of the conference. Indicators of viewpoint diversity included age, gender, education level, zip code, employment status (including retired), cancer history, faith community membership (Appendix 3: Screener 1). Indicators of ability to consider the common good (e.g., civic engagement, jury service, community leadership experience) were informally assessed during telephone interview (Appendix 4: Screener 2).

TABLE 1 Deliberation evaluation measures and data sources.

Democratic principles	Measures	Data sources
1. Inclusivity	– Age, gender, education, cancer history, employment status, church membership, experiences in voting in elections, serving on community committees	Recruitment screener 1 & 2
2. Opportunity to consider balanced and factual information	– Feedback on expert testimony scripts and videos	Project progress report
	– Perceived helpfulness	Participant post-deliberation survey
3. Deliberation	– Overall satisfaction – Willingness to participate in future deliberations	Participant post-deliberation survey
	– Equal participation – Active engagement to understand analytic information – Adoption societal perspective – Reasoned justification of ideas	Small group deliberation audio recordings

Deliberation

We coded deliberation session transcripts for four indicators of deliberation process quality (48): *speaking opportunities, adoption of a societal perspective on the issue in question, reasoned justification of ideas, and active engagement in understanding presented information*. We assessed *speaking opportunities* quantitatively by counting both the number of statements made by each participant, and the percentage of the statements each participant made in the deliberation (using the total number of statements made by all participants within the same small deliberation group as the denominator). These two measures represent differences in overall levels of participation - some participants provided many short statements, while others provided fewer, longer statements. Appendix 5 shows code definitions and quote examples. *Adoption of a societal perspective* was indicated when participants raised a pro or con based on group-level benefit or harm, or considered the issue from the perspective of cost to a social group. *Reasoned justification of ideas* was indicated when participants explained their viewpoint based on information raised in the expert testimonies, or when their comments indicated they were considering both sides of the issue. *Active engagement in understanding presented information* included statements indicating a participant was seeking to understand the information they had been given, such as confirming their understanding, clarifying a point that was made, checking for accuracy of their interpretation, and showing agreement with peers.

We also collected survey data on Day 2 regarding participants' experience of the process as a complement to the observational data on deliberation process quality. Survey items were adapted from those used previously (48) using 10-point rating scales (1 not at all to 10 very much). Example questions included, "*do you feel that your opinions were respected by your group*," "*do you feel that the process that led to your group's responses was fair*," and "*if given the opportunity, would you participate in a similar deliberation activity again.*"

Data analysis

Quantitative descriptive analyses of survey data were conducted using SAS to characterize the participant's demographics and ratings of their experience with deliberation. Qualitative analyses of deliberation transcripts were conducted using MAXQDA. We adapted a qualitative coding scheme used by others to examine the deliberation process (48, 49), and we developed new codes based on careful reading of the transcripts and study team discussion (Appendix 5). Two study team members (YG and MCG) read through all transcripts and other team members read a subset of the transcripts (CM, JK, DB, SP). All study team members ($n = 8$) coded one small group session to ensure accuracy of coding, as well as to ensure the clarity and completeness of the coding scheme. Coding was then conducted by four team members (KS, GF, MCG, SP). After coding was completed, each transcript was systematically reviewed for the most commonly occurring themes and representative quotes were identified.

Results

Consideration of balanced and factual information

Post deliberation survey responses indicated that participants found the expert testimony videos very useful in their deliberations (M = 9.29, SD = 1.52, range =1–10), and reported it was very helpful to have the opportunity to discuss the issues with other participants (M = 9.43, SD = 1.73, range=1–10). Feedback from community and policy stakeholders supported that the videos presented balanced factual information (e.g., what genetic testing can and cannot tell you) without pushing any agenda or being persuasive.

Feasibility of recruiting an inclusive citizen group

Horizons Community Solutions contacted 149 community partners to facilitate recruitment. The community partners circulated study fliers to their constituents, reaching 23 counties and 20 zip codes in Southwest GA. Across these counties, 78 individuals (59 females, 19 males) completed the online screener and were interested in participating in the online citizen discussion group. Horizon Community Solutions staff then conducted 45 second-round interviews with interested individuals and filled out the recruitment rubric to further assess eligibility criteria; 31 were selected and consented to participate in the citizen discussion group.

Only participants who attended both days of the conference and completed all post-conference surveys are included in the final sample (Table 2). Seven participants (22.5%) were lost to follow-up as 26 individuals attended Day 1 of the conference, and 24 attended Day 2 (one participant did not return, and one participant was asked not to attend Day 2 due to lack of engagement). All participants had Internet access at home. Most participants used email daily ($n = 21$, 87.5%) and video

TABLE 2 Participant characteristics reflecting viewpoints diversity ($N = 24$).

Member characteristics	Total ($N = 24$)
Gender	
Female	19 (79.2%)
Age	
20–29	2 (8.3%)
30–39	2 (8.3%)
40–49	9 (37.5%)
50–59	6 (25%)
60–69	5 (20.8%)
Education	
High school graduate	2 (8.4%)
Some college	5 (20.8%)
College graduate	8 (33.3%)
Trade school	2 (8.3%)
Postgraduate work	7 (29.2%)
Employment status*	
Unemployed/Self-employed	5 (21.7%)
Employed	11 (47.8%)
Retired	7 (30.4%)
Healthcare professional (yes)	
Time living in SWGA	3 (12.5%)
>1 year	1 (4.2%)
1–5 years	2 (8.3%)
More than 5 years	21 (87.5%)
Breast cancer dx (yes)	1 (4.2%)
Primary care in FQHC (yes)	7 (38.9%)
Member of church (yes)	20 (83.3%)

*1 missing response.

conferenced monthly or more frequently ($n = 21$, 87.5%). See Figure 2 for a recruitment flow diagram.

Most participants were long term residents of Southwest Georgia (88%). Participants ranged in age from 27 to 66 (mean 48.7, SD = 11.6). Just over half of the participants (55%) had some college or were a college graduate, 12% had some high school or were a high school graduates and two participants attended trade school. Seven participants were retired at the time of the conference, 12% were unemployed, and 54% were employed including two participants who were self-employed. One third received federally qualified health care (39%). Most had some faith involvement, however, 16% were not members of a church. One participant reported a previous breast cancer diagnosis. In addition, 21% of participants were men ($n = 5$).

Deliberation process quality

Equal participation

We found considerable variation in the level of participation in all five groups. Statement counts for each participant were calculated by tallying each time the individual meaningfully contributed (i.e. exclusion of comments lacking substantive content; for example, passive agreement, comments not related to the discussion) during the deliberation question discussion. The number of statements by participants ranged from a low of 3 to a high of 62 (average = 24). The degree to which individual participants contributed to the discussion varied from 3 to 24% of total statements made during deliberation. Participants were more active and made more statements in Groups 3–5, where facilitators were more involved in actively moderating the discussion, with many checking and paraphrasing statements.

Active engagement in understanding presented information

Review of the transcripts suggested that participants sought to understand the expert testimonies they had been given. For example, participants often re-stated or reflected back information that they had heard from another member to check for accuracy of information, or to confirm a shared understanding of the facts or issues being discussed – e.g., *"I wanted to ask a question, only one percent of those people – was that 'had the BRCA gene?' Is that what it said?" "It's more so asking the question of to what degree of genetic similarity is required to be considered of African ancestry. Because my skin might not reflect that. My recent family history might not reflect that."* These statements illustrate how participants attempted to analyze the information presented to come to a correct understanding.

Another example of clarifying understanding was when participants showed agreement or disagreement with their peers, or referred to statements made by their peers. Overall, agreement with peers occurred more frequently than disagreement. For example, one participant endorsed her group member's views on the cons of genetic screening: *"I agree with what he stated about the insurance companies using that information to either deny insurance or give inflated prices."*

Reasoned justification of ideas

Engaging in quality deliberation is indicated when participants show willingness to explain their own views, rather than just asserting them. For examples, participants often referred to expert testimonies to justify their reasoning for a "pro" or "con" that they were asserting. In all five groups we found that participants recalled and referred to facts from expert testimony presentations in their deliberations. For example, one participant recalled information from an expert testimony about family history screening yielding false negative results as a rationale for an asserted con related to targeting HBOC screening to those of AAn: *"If it's a false negative, you could lose the benefit of treatment early on because you think you're okay. I was saying the uncertainty of the screening results was definitely a top con."* Participants also referred to concepts presented in the expert testimonies to justify their views using terminology related to genetics and inheritance, and the difference between family history and ancestry. For example, *"From the video, it showed to me that the African American descent had more of a possibility of having breast cancer and ovarian cancer than any other ethnicity."*

Participants' ability to consider both sides of an issue by offering a counterpoint to a pro or con was also indicative of reasoned justification. For example, one participant indicated, *"Part of that is going to be a pro. Part of that is going to be a con. The positive part is that now we know they need treatment. The next step will be, 'Now, how do we find that treatment? How do we get them into the treatment? Can they afford it? Is it even available in that community?' All that ripples after that."* This skill was observed infrequently during the deliberation.

Adoption of a societal perspective

Adopting a societal perspective was indicated when participants gave voice to a group perspective that deviated from their own personal interests. For example, a participant raised a pro based on group-level benefit: *"Even in our community, I think that all genders and races can benefit from it because this is a low-income area here that we're living in."*

Participants also demonstrated the ability to consider pros and cons of targeting the screening program among AAn communities from the perspective of economic costs to society. Here a participant considered the pro of targeting communities of AAn: *"Prevention and targeting prevention is less expensive than chemo, radiation, or hospitalization. So, by focusing on prevention, we can help cut down on healthcare costs, which is a plus for everybody across the board."* Another

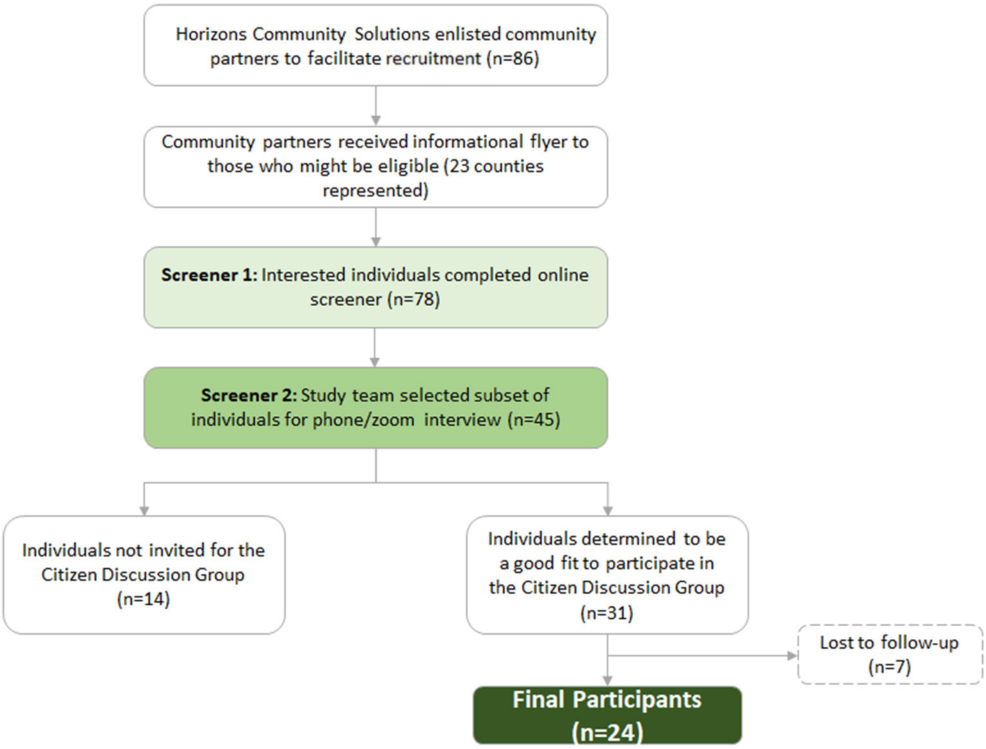

FIGURE 2
Recruitment flow diagram.

participant was concerned about expanding the screening program considering potential insurance discrimination: *"The insurance would come into play at some point where they may want to charge higher premiums for someone who does have that hereditary factor."*

However, we also found several instances of participants offering views indicative of their personal interests or experiences. Here a participant is considering their own race/ethnic makeup as a justification for why they believe everyone should be screened: *"I just found out about a week or so ago I was 20 percent Mawi or something. I don't even know what that is so. We just don't know. So, you might look like you might be a certain race and may not be 100 percent that race. So, I think everybody should be screened."* Another participant reflected on their own experiences: *"This part is kinda tough because I also like the idea of – where I have issue is no consistency. And I have been doing my mammogram. I have masses in my breasts that they've taken out, and some they decided not to take out. But nobody has said to me, "Hey, do you wanna test for any genetic problems?"* However, participants' justifications based on personal interests were relatively less common ($n = 25$) compared to statements reflecting community interests ($n = 134$).

Satisfaction with deliberation process

Participants viewed the community deliberation process to be positive. Participants felt their opinions were respected (M = 8.86, SD = 0.47, range =1–10), they were listened to by the facilitator (M = 8.82, SD = 0.59, range=1–10), the discussion process was fair (M = 8.82, SD = 0.85, range=1–10), and they were willing to abide by the policy decision put forth by the group even if they held a different opinion (M = 8.82, SD = 0.50, range=1–10). Most participants (N =18, 79%) indicated that they would be willing to participate if a conference was held in-person instead of online. When asked if they would participate in a similar conference (i.e., online) on another topic, all but two participants (92%) said they would be willing or very willing.

Discussion

Efforts to foster public engagement in health promotion interventions and policy design have focused largely on the low end of the engagement continuum. For example, focus groups and structured interviews predominate as public engagement strategies. These methods commonly garner participants' personal views, experiences and preferences relating to a health topic drawing from small and self-selected samples (50, 51).

Information processing theories suggest these approaches likely do not motivate participants to do the work of intentional reflection, consider the complexities of new information, or feel culturally empowered to believe that their viewpoints can make a difference (52–55). This may be especially limiting in guiding interventions and policies in complex health contexts that are unfamiliar to target audiences.

Engagement strategies higher on the continuum such as deliberative democracy (56) that require more active and ongoing citizen engagement (e.g., becoming informed about the topic, learning about ethical concepts such as the common good, and repeated peer discussion) are uncommon as they require more effort and resources to accomplish (8). Implementing deliberative democracy and other high-end engagement approaches may be challenging but worth the effort particularly for timely yet novel genomics policy issues if: (1) a diversity of well-informed citizen views can be attained; and (2) the outcomes can be shown to be of higher quality than approaches lower on the engagement continuum (57). Our results suggest that with careful and diligent methodology, a deliberative democracy approach can successfully engage a citizenry with diverse and well-informed views, do so in a relatively short time frame and yield perspectives based on high quality discussion. We based these conclusions on three democratic principles (i.e., inclusivity, opportunity to consider factual information free of distortion, and deliberation).

First, we were able to recruit an inclusive group of citizens of African ancestry. This thoughtful and focused recruitment process enabled citizens often excluded from public health policy decision making to participate in genomic research in accordance with their communities' values and priorities (58). Recruitment efforts were facilitated by strong collaborations with local community organizations and their social networks. Community partners suggested characteristics specific to their area that would indicate viewpoint diversity (e.g., age, gender, faith community involvement, cancer history) and experiences that required consideration of the common good (e.g., civic engagement, community leadership experience, jury duty). We used these indicators to vet our participants through a structured interview process to create viewpoint diversity amongst our participants that, in turn, would encourage a well-rounded discussion centered on the common good.

We structured the expert testimonies, print materials and deliberation sessions to promote understanding of relevant information, skills to use in discussions with peers, and how to build consensus. All participants viewed the same information describing advantages and disadvantages of specifically targeting communities of African ancestry for family history-based screening for HBOC risk. Participants rated the expert testimony content as concise, unbiased and helpful in their deliberation.

Several studies have attempted to establish hierarchies that rank various levels of public involvement in health care decision making in an attempt to measure quality of a deliberation. Arnstein's (59) original work categorizing citizen participation presented an "eight rung ladder," however several more recent studies suggest simpler frameworks. For example, the five degrees of participation: informing, consultation, partnership, delegated power, and citizen control (60). Another framework, specifically developed to guide genomics activities, uses four themes for deliberative reflection: fairness, context, heterogeneity, and recognizing tensions and conflict (61). Congruently, we found that participants' deliberation met these and other previously identified quality frameworks (48, 62, 63). Dissimilarly, the current study focused on aspects of quality specific to public policy such as adoption of a societal perspective or "the common good." This is the idea that what is best for the individual is not always what is best for the larger community. This concept is critical when discussing and setting priorities for public health policy, as it impacts the entire community, not just the individual participating in the peer deliberation.

Our analyses of transcripts suggest that there was active participation in which individuals were heard and respected. While we observed significant variations between participants where some participants spoke more than others, we attribute this to differences in styles with some participants expressing their views more concisely than others. In post-deliberation surveys, participants also strongly endorsed feeling able to participate, respected and heard.

We examined other process evaluation indicators to assess whether the deliberation process succeeded in encouraging citizens considered expert testimonies to justify their input. Indeed, we found that participants justified their viewpoints by referring to information they learned from the expert testimonies, previous knowledge of the subject, and/or showing agreement with comments made by other participants. However, this did not occur consistently suggesting that additional brief training of citizens in how to support their viewpoints in discussions with fellow participants could be helpful.

Consistent with taking the perspective of the common good, citizens gave thoughtful and expansive consideration of the pros and cons of targeting those of African ancestry for accelerated HBOC screening in Southwest Georgia. Our citizen participants generated a more diverse slate of pros and cons than state-level cancer policy stakeholders. As a follow-up to the community deliberation, the study team shared the citizen generated advantages and disadvantages with state cancer policy stakeholders in Georgia. Stakeholders not only supported participants' viewpoints but also complimented how unique and useful citizen perspectives would be for setting related cancer policy priorities in the state.

In conclusion, while a deliberative approach might be considered resource intensive, the community partnerships, recruitment efforts, and facilitator training efforts we employed led to high quality public input. Recruiting for and implementing less intensive approaches such as focus groups can be demanding. An important consideration is whether the quality of the information attained is worth the effort. Yet, few public engagement studies have evaluated the quality of the information yielded by less intensive engagement strategies. Much of the extra effort we expended was in developing the recruitment rubric and preparing the participants to thoughtfully reflect on the issues in family history screening. Recruitment rubrics are often implemented when forming community advisory boards. Indeed, these boards could serve as an ongoing group engaged for deliberation. The unbiased expert testimonies were regarded as critically important for reflective participation in intervention and policy development. Once the testimonies have been developed, however, these materials would only require periodic updating similar to most health education materials. It is noteworthy that we were able to complete all these steps in a 9-month time frame.

Like any study, there are limitations to our process. We relied on self-determination of African ancestry for the current study. We acknowledge that it is currently not possible to determine or differentiate African ancestry from a person who identifies as being African American in the absence of a genetic test. Although we used a multi-step and systematic process for developing expert testimonies, we did not conduct a formal evaluation of how the information was perceived by participants. Further, our process to assess feasibility of the method was conducted in one geographic area and relating to one health context. The process likely would need to be adapted for other community settings and health contexts.

In sum, we conducted a rigorous process of public engagement using deliberative democracy techniques, showed it to be feasible and to yield high quality output. This and other public engagement methods warrant more attention. This can begin by challenging ourselves to operationalize higher intensity strategies to ensure that our interventions and policies align with citizen perspectives. Ultimately, this pursuit has the strongest likelihood for public health benefits.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by Emory University IRB. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

All authors conceptualized and designed the study, prepared the manuscript, analyzed and interpreted data, and critically revised the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.984926/full#supplementary-material

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The public and patient involvement imperative in Ireland: Building on policy drivers

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What can we learn from the history of Public and Patient Involvement (PPI) in healthcare and research across global jurisdictions? Depending on region and context, the terminology and heritage of involvement in research vary. In this paper, we draw on global traditions to explore dominant themes and key considerations and critiques pertaining to PPI in order to inform a PPI culture shift in Ireland. We then describe the heritage of PPI in Ireland and present the case for combining methodological imperatives with policy drivers to support and encourage *meaningful* involvement. Specifically, we propose that PPI can be enriched by the theory and processes of participatory health research (PHR); and that implementation requires concurrent capacity building. We conclude with a call for Irish researchers (authors of this paper included) to consider the conceptual complexities and nuances of a participatory approach to build on the policy imperatives driving PPI and to contribute to the international evidence base and research culture. Specifically, we call for Irish health researchers and funders to consider and reflect on: (1) the rich literature of PHR as a resource for enacting meaningful PPI; (2) the roots and origins of varying participatory health research methods; (3) how community/patient groups can lead health research; and (4) co-learning and partnership synergy to create space for both academic and community expertise; and (5) the importance of using standardized reporting tools.

KEYWORDS

participatory health research, public and patient involvement (PPI), meaningful involvement, policy, co-design, health service research, methodological, community-based participatory research (CBPR)

Introduction

Evidence shows that involving patients and members of the public across crucial stages of research improves both process and outcomes and renders invaluable additional insights which could have otherwise been missed (1–3). The public and patients' contribution to the design, implementation, and evaluation of research leads to increased effectiveness, credibility, and often more cost-efficiency (4). Public and patient involvement (PPI) in health research thus addresses the modern imperative that high-quality research must bring real benefits for patients and other beneficiaries in their daily lives (5). Increasingly, research with PPI is becoming the encouraged norm in many jurisdictions (i.e., USA, UK, Canada, Australia).

Depending on region and context, the terminology and heritage of research involvement varies. A review by Boote et al. (6), exploring public involvement in health research between 1995 and 2009, emphasized that the UK, USA, Canada and Australia had the largest body of published work in this area. Further, a report published by the Australian Health Research Alliance in 2018, identified four leading agencies for promoting involvement, from the UK, USA, Canada and Australia (7). Thus, in this paper we draw on traditions from these countries when exploring dominant terms, traditions, and key considerations/critiques pertaining to collaborative research and practice (described in Additional File 1). As members of the Irish health research community, we are interested in exploring the multiple drivers for PPI and notable regional differences in the heritage of PPI.

In this paper, we critically reflect on the role of policy and argue that policy messaging can be enhanced if it is combined with clear messaging about the methodological gains of PPI. In doing so, we believe this will optimize the conditions for PPI to become the norm in practice. We describe the heritage of PPI in Ireland and present the case for combining methodological imperatives with policy ones to support and encourage the normalization of *meaningful* involvement. Drawing on the work by Cornwall (8, 9), when we say meaningful involvement, we mean that patients and members of the public have both the power and control to be equitably involved (as they see fit) in all levels of decision making and that *via* the participatory process, are facilitated to overcome both social and structural barriers to exercise such power. By normalization we mean that PPI is a routinised way of working that is integrated into stakeholders' daily practice (10).

Drivers for PPI in international settings: An overview

Over the past decade, policy-driven initiatives in the USA and Canada have promoted greater *patient engagement,* currently the predominant term used in North America. The US Patient-Centered Outcomes Research Institute (PCORI), a health research funder formed under the Affordable Care Act (11, 12), has promoted a research culture that links funding to authentic stakeholder engagement, where stakeholders are communities, patients, or public and community organizations (13). As described by Woolf et al. (13), authentic stakeholder engagement is a term used to "characterize the involvement of all relevant stakeholders in all phases of research." Similarly, Canada's Strategy for Patient-Oriented Research (SPOR) (14, 15) is a concerted policy drive to fund research that addresses patient-centered outcomes with the collaboration of patients and other members of the public. SPOR defines collaboration as "working in common cause with partners and key stakeholders on the development and implementation of the Strategy and on achieving its goals" (15). There are notable examples of community/patient drivers such as the need for patient centered outcomes (16, 17) spearheaded by organizations like the USA PCORI, and the right for patients to be involved in their own healthcare decision making (18). There are also new networks of academics and practitioners advocating for PPI capacity building [e.g., the North American Primary Care Research Group (NAPCRG), the International Collaboration for Participatory Health Research (ICPHR), and the Integrated Knowledge Translation Research Network (IKTRN)]. Further, there are examples of policy drivers from governmental departments and agencies including health research funders (19–21).

In Australia, collaborative research is commonly referred to as consumer-led research or consumer and community engagement/involvement (CCE). Examples of CCE as described by the National Health and Medical Research Council (NHMRC), include public consultation, representation on NHMRC committees, community and consumer advisory groups and on peer review panels (22). These examples stem from the NHMRC Act 1992, which depicts the statutory responsibility of the NHMRC "to raise the standard of individual and public health throughout Australia and foster the development of consistent health standards between various states and territories" (22). In line with this statutory responsibility, certain CCE engagement activities are mandated by the state (i.e., procedures and requirements for meeting the 2011 NHMRC standard for clinical practice guidelines) (22). These examples of involvement in health research are complemented by a policy foundation of involvement in health services (23, 24).

Comparatively, in the UK, the genesis of PPI is often framed as a response to "public demands for a greater voice in decisions about their services, and demands from politicians for greater efficiency, quality of services and effectiveness in the use of public funds" (25). The various PPI initiatives often reflected these demands, again as a policy imperative that became mandated by the governing authority at a given time. As Gibson et al. (25) discussed, "PPI is now more than ever embedded as an official ideology in legislation, and apparently official practice at all levels and in every aspect of policy" (25).

Abbreviations: PPI, public and patient involvement; PCORI, patient-centered outcomes research institute; SPOR, strategy for patient-oriented research; CCE, consumer and community engagement; NHMRC, national health and medical research council; HRB, health research board; HRCI, health research charities Ireland; PHR, participatory health research; UL, University of Limerick.

PPI is thus situated as a key element in health and social care research in the UK, receiving strong policy support and active promotion through organizations such as INVOLVE and emphasized by funding bodies such as the National Institute for Health Research (20, 21).

Despite these ever-evolving policy traditions of PPI and the opportunities presented for involvement, there are challenges in these jurisdictions with PPI *in practice*. Sustained involvement is infrequently achieved (4) in part due to superficial, often tokenistic, engagement on the part of researchers. Taken simply as a policy imperative (i.e., do it because we say so), conflicting political values, ideologies and agendas of both researchers and public partners can impact the outcome of any involvement initiative (25). Further, as legislative policy provides guidance on PPI for commissioners of health services, such guidance is described as "open to interpretation" fostering varying approaches to the practice of PPI and, thus, varying outcomes (26). Indeed, it can be challenging to determine the outcomes of PPI when evaluations are based on initiatives that may not have effectively or meaningfully involved patients and the public at all (27). This leads to concerns about how to achieve genuine involvement that is not tokenistic, impacting the improvements in quality and efficiency (25). Specifically, Madden et al. (28), discuss that in this current context "PPI operates as an empty signifier, intermittently populated with whatever policy ideas of citizen engagement are *a la mode*."

Drivers for PPI in Ireland

Notwithstanding notable examples of internationally recognized meaningful PPI in the Irish context [i.e., (29, 30)] and important patient/community driven initiatives [e.g., (31, 32)], PPI is still in its formative days in Ireland as a normalized way of researching. We position the heritage, terminology and considerations for PPI in Ireland in comparison to other countries in Additional File 1. As in other countries, policies in Ireland have been in place for some time about service user involvement in health policy and service development. This includes the Health Service Executive National Strategy for Service User Involvement 2008–2013 (33), as well as Health Research Board (HRB) funding initiatives like the joint funding scheme with the Health Research Charities Ireland (HRCI, formally Medical Research Charities Group) (2006) or the Knowledge Exchange and Dissemination Scheme (2012) (34). However, PPI in health research remains relatively nascent. Arguably, it was not until 2014 that PPI became a *focal* priority explicitly discussed by funders and health researchers in Ireland (29, 30). That year, HRCI held its first ever Irish Health Research Forum to provide "a single Irish voice for research to improve health" with the focal theme of PPI (35). This forum was the first national health research discussion of "PPI as a priority" in Ireland (35). It was also in 2014 that HRB funding applications first included a question on PPI, but not as a mandatory assessment criterion (19). Specifically, most HRB funding calls ask researchers to explain how PPI will be incorporated in all stages of the research cycle, and if not why (36).

In 2016, the HRB Strategy 2016–2020 included its first explicit strategic commitment to "develop and promote PPI within the HRB and in HRB supported projects and programmes" (37). This included a new public review process, creating a panel of public reviewers who have contributed to the scoring of applications within at least seven HRB funding streams since 2018. Importantly, learning from other countries' experiences, both good and bad, the HRB recognized the need to *build capacity* to support PPI prior to mandating it in funding applications. In 2017, the HRB launched the "PPI Ignite Award," a 3-year programme to build capacity and influence institutional research culture within Irish higher education institutions (38). In 2020 this transitioned into the 5-year "PPI Ignite Network," expanding on the progress of the initial programme with more of a national rather than institutional focus (39) (see https://ppinetwork.ie). Moving forward, the HRB strategy 2021–2025 is "committed to ensuring that people remain at the very heart of everything we do" (37). PPI will be mandated by the HRB and will feature in the scoring of grant applications in the coming years. Thus, like other countries, policy drivers have played an important role in Ireland but, unlike other countries, the HRB's *approach has been incremental*, committing space and opportunity for building PPI knowledge and competencies within the health research community.

With regard to capacity building, as suggested by O'Shea et al. (40), Ireland can benefit from other countries' successes in relation to optimal approaches to PPI in health research (18, 41, 42). Ireland does not have to reinvent the wheel, e.g., initiatives like that of INVOLVE (43), have available resources on good practice and approaches to PPI in the UK, including a *Values and Principles Framework* (40). There may, of course, still be a role for national resources where there are gaps (44) or where adaptations are needed for the Irish context (45), but these represent advances or modifications to existing resources and foundations for good practice.

Accompanying these opportunities to learn from the successes of other countries, we must be mindful of challenges that may impede progress, and set us on a path of tokenism, if not fully considered. For instance, we must consider the limitations of approaching PPI *simply* as a policy imperative. If PPI is implemented *only* because it is a policy imperative, and *without capacity building* for it to be implemented meaningfully, it can reinforce existing power asymmetries between the academy and community. If, for example, the decisions about which community members are invited to participate in projects [the legitimate public, see Barnes et al. (46) vs. the usual suspects, see Beresford (47)] and if their role is pre-defined by academics in terms of how they should behave [what is sayable or doable by them in the research meetings, see Renedo and Martin (8, 48)], then the capacity for meaningful contributions is diminished. Further, an emphasis solely on policy mandates can obscure the methodological imperatives for, and benefits of, PPI and the growing evidence base about their positive impact on the generation and use of actionable knowledge from research.

To promote a PPI culture in Ireland, health researchers and funders should consider building on policy imperatives by looking beyond the "because we are told to," message. We have the opportunity to reinforce the ethical and moral obligations for PPI, as well as recognizing the emergent evidence of methodological impact (18, 49, 50). Building on the considerations and critiques discussed above and described in Additional File 1, we suggest a way forward.

The way forward: Participatory health research

As discussed by Gibson et al. (25) it is important to consider the emancipatory perspective and framework for PPI in health and social care to ensure that we are not harnessing a "PPI industry" fueled by imperatives at the system-level (such as government health policies), which can become more focused on efficiency and outputs than the experiences, needs and concerns of the public and patients (25). The moral, ethical, and methodological drivers for community and end-user involvement, discussed by Cargo and Mercer (25, 51), are reflected in the origins and practice of participatory health research (PHR).

PPI can be enriched by the theory and processes of PHR, defined as research undertaken in collaboration with those affected by the issue being studied, for the purposes of taking action or effecting change (52). PHR has a rich tradition of literature, resources and evidence about the rationale for and value of partnerships. Promoting multiple ways of knowing, while highlighting relational and reflective knowledge as well as transformative learning, PHR strives for broad impact (53). There are two historical traditions that describe the origin of PHR: the Northern tradition, striving for societal change through action research (54) and the Southern tradition, striving for social justice and emancipation through self-determination (55). Lewin's action research (the origin of modern implementation models) (54) speaks most directly to the knowledge utilization driver, while Freire's work in critical pedagogy resonates most closely with the drivers of social justice and self-determination (55).

For example, in the USA, for more than four decades, communities have mobilized to broaden the involvement of people and organizations in research to address community-level problems related to health and social issues (56). The recognition and understanding of the impact of the community voice in effectively and efficiently achieving challenging health objectives, led to increased investment in community partnerships and participation initiatives by USA agencies (57–59). As mentioned earlier, in the USA, PCORI has been a major champion of this shift in expectations (11, 12). For instance, PCORI has followed through/developed its policy mandate for patient engagement by promoting a research culture that links funding to the authentic stakeholder engagement characteristic of participatory health research (13).

A growing body of evidence has accumulated recognizing the methodological and impact benefits from PHR's value base. For example, a review by Jagosh et al. (1), discussed PHR's benefits from a methodological perspective, such as generating greater recruitment capacity, as well as impacts, such as stakeholder competency and capacity and sustained partnerships. As described in a position paper by the ICPHR (60), "impact through PHR is embedded in a dialogical process of critical reflection in and on action (60)," through its collaborative and emancipatory roots exploring the needs and issues pertinent to the community. Through reflexive practice, co-learning and action, transformative knowledge is entrenched in the process in doing PHR (60). There are also a variety of tools and techniques in the PHR literature that can be used to support partnerships (i.e., sharing the decision-making, data generation and co-analysis) with diverse stakeholders, for example, participatory learning and action (61, 62). This highlights that it is incumbent on researchers to think critically and creatively about the methods they use to involve stakeholders in research.

There are gaps in knowledge about PHR internationally. For example, Hannigan (63) argues for the need for more direct involvement of partners in quantitative data analysis and statistical modeling. Patients and the public have been described as the missing stakeholder group in the modeling process and the benefits of participatory approaches to modeling are increasingly being recognized (64, 65). Quantitative data are "not just numbers, they are numbers with a context," and a key strength of PHR is better understanding context (51).

While the HRB in Ireland does not expressly employ a PHR framework, it does emphasize some important processes that resonate with its principles (such as involving people early in the research process, or later in dissemination planning). This is similar to Canada's SPOR, which scores grant applications on patient or community involvement at different research stages (14, 15). An example within the Irish context, where aligning with PHR has explicitly shaped PPI in research, is that of the HRB-funded PPI Ignite programme at the University of Limerick. As described earlier, the purpose of the 2017 PPI Ignite Award was to support universities to build capacity for involving patients and members of the public in health research. The University of Limerick (UL) took the decision to approach PPI by drawing on the rich tradition of PHR, adopting its participatory principles and practices with a multi-sector audience. Specifically, *PPI Ignite@UL* (66) has co-developed with health sector, community and patient organizations who directly co-governed the project and partnered in creating and deploying training and development activities. These partners also contributed to evaluating the programme's products and outcomes. For more information on how the PHR approach was important for capacity building see Additional File 2. This work continues to be developed in the PPI Ignite Network (described earlier), alongside additional successful national initiatives such as the PPI Festival (see https://ppinetwork.ie/festival/).

Discussion

Need for more consistent PPI reporting

There has been a significant lack of reporting on involvement within this field, and subsequently a lack of consistency with reporting when it does occur (63, 67–73). Capturing and documenting wider forms of impact remains underrepresented in published accounts of research evidence (60). This is problematic for many reasons, but arguably, at the forefront of this issue is the lack of available, or non-fragmented evidence to assess impact, impeding "our collective understanding of what works, for whom, why, and in what context" (69). As discussed by Staniszewska et al. (69), many of the papers published "provide little information on how members were involved and the results of this involvement." Staley (73), posits that this problem is 2-fold: (1) there is a problem for assessing impact; and (2) there is a lack of structure and guidance on involvement in peer-reviewed journals.

This issue of reporting, however, is not due to the lack of tools, frameworks, guidelines, and critical appraisal checklists available for public and patient involvement in research, as demonstrated in a systematic review by Greenhalgh et al. (71). This review (71) sought to identify, synthesize and critically examine the published frameworks available for use, further identifying if they had been actually used and why. The most recent and arguably most accepted reporting framework is the new "Guidance for Reporting Involvement of Patients and the Public 2" (GRIPP2), which precedes its earlier version GRIPP (69).

However, are researchers using these frameworks? This question is explored in the second objective of the systematic review by Greenhalgh et al. (71). For the reporting guidelines available at the time of the review, the study had not identified any papers describing the use of the framework, beyond those who developed it (69).

Call for Irish health researchers

Issues identified by Staley (73) such as, inefficient, standardized, and inadequate reporting, continue to plague this field. These issues need to be addressed to achieve a better understanding of how certain variables/processes/constructs within the partnership process are impacting health outcomes.

We now call for Irish health researchers (authors included) and funders to consider and reflect on: (1) the rich literature of PHR as a resource for enacting meaningful PPI; (2) the roots and origins of varying participatory health research methods; (3) how community/patient groups can lead health research; and (4) co-learning and partnership synergy to create space for both academic and community expertise; and (5) the importance of using standardized reporting tools. Specifically, Irish researchers could use these lessons to ensure a PPI trajectory that moves away from tokenism and a checklist approach to partnerships by also using moral, ethical, and methodological drivers for PPI in health research. By approaching this incrementally and allowing researchers and their partners to gain comfort and competency in PPI, the HRB is wisely avoiding some of the pitfalls experienced in other jurisdictions. PHR provides theoretical and methodological resources to *enact* key values that support and create meaningful and sustainable partnerships that, in turn, improves the *quality* of PPI with scope for positive outcomes on the *process* and *outcomes* of partnered research.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author/s.

Author contributions

MG conceptualized, wrote the first draft of the paper, and applied edits based on feedback from other listed authors. JS, AM, and AH provided thorough revisions and feedback to all drafts. AM also drafted Additional File 2. VN contributed to background and literature synthesis and writing. ZH helped to conceptualize the paper and provided revisions and feedback of drafts. All authors made substantial contribution to the conception, writing and reviewing of the work, and have approved the submitted version of this work.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.1038409/full#supplementary-material

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Impact of a CBPR-informed physical activity intervention before and during COVID-19 among women from a disadvantaged neighborhood in Sweden

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Background: Public health practitioners have been striving to reduce the social gradient and promote physical activity among citizens living in disadvantaged neighborhoods. The emergence of the COVID-19 pandemic, which has affected these citizens extensively, has posed a significant challenge to efforts to maintain a physically active lifestyle. Thus, the aim of this study was to explore the impact of a CBPR-informed physical activity intervention before and during the COVID-19 pandemic from the perspective of women from a socially disadvantaged neighborhood.

Methods: A total of 34 women participated in a CBPR-informed physical activity intervention previously developed in collaboration with lay health promoters and other citizens from the same neighborhood. Focus group discussions were conducted at four time points, namely, at baseline prior to the intervention, post-intervention, 6 months after the intervention ended, and during the COVID-19 pandemic. The data were analyzed using qualitative content analysis following an inductive approach.

Results: In total, four themes emerged from the discussions: "Wavering between frustration and action," "Shifting from prioritizing family needs to taking control of self," "Between isolation and social support," and "Restricted access to health-related knowledge vs. utilizing internalized knowledge".

Conclusion: The results of this study reveal that building on CBPR-informed health promotion initiatives has the potential to foster individual empowerment and assist during acute situations like the COVID-19 pandemic through mobilizing communities and their resources, which leads to increased community resilience and health. This study is regarded as unique in that it involves evaluation of a CBPR intervention that was initiated ahead of the pandemic and followed even during the pandemic.

KEYWORDS

community-based participatory research, community resilience, pandemic (COVID-19), social support, community empowerment

Introduction

The world has been confronting novel challenges such as the COVID-19 pandemic and an unexpected increase in non-communicable diseases (NCDs) (1). A fair share of the risk of NCDs seems to occur due to poor lifestyle including a decrease in physical activity (PA) and increase in unhealthy dietary practices (2). Despite the vital role PA plays in health promotion and disease prevention, physical inactivity has reached epidemic proportions globally (3). Health equity is relevant for PA since both physical inactivity and sedentary behaviors are influenced by social determinants; specifically, socially disadvantaged neighborhoods have lower access to PA than their counterparts (4). In addition, the COVID-19 pandemic has created a double burden on health, especially among citizens living in disadvantaged neighborhoods, as physical inactivity and mental illness have been exacerbated (3, 5). Previous research suggests that citizens in these neighborhoods require special support that is tailored to their needs to help them deal with the complexities of newly emerging diseases. Such support should also promote integration to society where healthcare providers can better understand and respond to the needs of marginalized citizens (5, 6).

Furthermore, research also shows that inequalities in health cannot merely be explained by differences in the individual characteristics of citizens living in a neighborhood since the social and contextual features of the neighborhood are also identified to play a role (5). Thus, the current situation demands reorientation of traditional public health practices and shifting the goals of health promotion from solely achieving individual lifestyle changes to a more broadened approach that includes addressing the social and environmental factors (7). The Ottawa Charter of Health Promotion suggests that health is created in the context in which individuals thrive and engage in everyday activities (8). Previous research also suggests that the context is not merely a location where an individual exists, rather an environment in which human social interactions are embedded (9). Thus, a sustainable form of health promotion can be achieved by facilitating health at a community level, where communities become empowered to use and shape their environment to solve problems relating to health. Such an approach is also regarded as a dynamic method to address disease prevention by integrating risk factors and improving quality of life (10). Community health promotion aims to address social, cultural, and environmental processes related to health by enhancing community participation and thus empowering communities within a defined geographic area to increase control over their health and life (11). In recent years, several health promotion initiatives have prioritized efforts to increase physical activity at a community level (12, 13). Enhancing community participation in health promotion makes it a collaborative process, creating an ideological shift. Such a research based on a partnership between community members and academicians has now become both essential and ethical (11).

In contrast to the traditional model in which an academic researcher drives all aspects of research on health promotion conducted in a community setting, a translational research approach known as community–academic partnership (CAP) exists. This paradigm integrates science and practice to improve health equity (14–16). Within the umbrella of CAP lies community-based participatory research (CBPR), an approach where citizens from communities take part in the research process with an equal involvement of both academic and community stakeholders throughout the research process starting from conceptualizing a research problem to final dissemination (17). CBPR is inspired by participatory action research (PAR), as coined by a German-American social psychologist Kurt Lewin (18), and also from participatory research science, as conceived by a Brazilian educator Paulo Freire (19).

The goal of this approach is to achieve community empowerment by actively involving community members in the research processes and assuring that the true needs of the community are effectively addressed (20). Empowerment is a central goal in the theory and practice of health promotion, not least in CBPR programs. Empowerment is the process of taking control over one's own situation focusing on multiple aspects including personal, social, economic, and political forces. CBPR is a participatory approach with a long-term commitment to social action, which is based on the liberatory educator Paulo Freire's approach that states that the cyclic process of knowledge transformation through reflection and action promotes critical consciousness and critical thinking, which, in turn, can foster democratic participation, leading to sustainable social transformation (21). According to Freire, critical consciousness means the ability to gain understanding of the key problems in their immediate environment, which facilitates the ability to change through acting on the problems illuminated by the understanding (21). Wallerstein et al. (22) defined CBPR as a collaborative effort by the community together with academic and other stakeholders, who gather and use research and data, built upon community strengths and priorities to adopt multilevel strategies to improve health and promote social equity. In contrast to top-down approaches, where much of the health intervention is predetermined, this approach has been fruitful in co-developing and implementing interventions in partnership with community members. Building trust between community members, academic researchers, and other stakeholders is key to achieve sustainable and equitable partnerships. Trust depends on the function of relationships between the members of the community, academic researchers, and other stakeholders. It is also depends on how community members connected in social networks. In contexts where growing inequalities drive ill health, a CBPR approach is built on trust and equal partnership with the community.

This approach is regarded as a means to broaden the horizons of traditional public health practices with new visions for improving community health and wellbeing (17). Previous research on disease and natural disaster management and health also showed that an approach driven together with the citizens could help mitigate stress, as well as protect the health and wellbeing of communities by promoting resilience and recovery (23, 24). The value of a well-established CBPR partnership between the citizens, stakeholders, and academic researchers, with its potential to strengthen civil society and citizens, particularly during acute situations like the COVID-19 pandemic, has been established in a few studies. These studies have showed that activities involving a CBPR approach strengthened the individual and collective resilience of participants while mitigating the adverse effects of the pandemic. It also seemed to be an appropriate means to enhance emergency preparedness and communicate risk to vulnerable populations (25–27).

Several CBPR physical activity interventions have been developed and evaluated around the world. However, CBPR interventions implemented in urban residential areas are sparse. Some of the existing CBPR interventions targeted specific groups such as elderly (28), cancer patients (29), members of a church congregation (30, 31), or students (32). These interventions were often quantitatively evaluated from the researchers' perspective and seldom explored experiences of participants over time (33).

A few community health promotion programmes conducted in Sweden do exist but are not common (34–36). Northern European states do have a well-established welfare sector, but given that the sector has been gradually shrinking, there is a growing gap between the citizens and government institutions providing services including social services and healthcare. Therefore, there is an urgent need to find new ways to close this gap as, for instance, the Swedish system cannot only rely on civil society to fill this gap. The administration in the Swedish state is decentralized in that the regional healthcare and local municipal authorities have the power to make local decisions and thus have the capacity to reduce social inequalities. Despite that, there are only few fieldworkers left in these organizations due to budget issues. To fill this gap, a community-based collaboration with local partners and NGOs is important. Academics have a prime role in facilitating such initiatives, advocating for disadvantaged communities. Since Sweden does not have strong communities, new models of working together in an equal partnership is essential. By integrating such an approach into the local governance system while also including citizens from the community in the decision-making process, efforts can be sustainable and also can be relied on even during crisis situations such as the pandemic. Such work will also add important knowledge to the international research community on how the CBPR approach can be applied in a welfare state with a relatively large public sector involvement compared with states with a larger private sector involvement such as the United States.

Based on this background, a CBPR approach was applied within a community health promotion programme, Equal Health. This programme was established in a socially disadvantaged neighborhood in southern Sweden in the year 2017 initiated by researchers from Malmö University together with the citizens from the neighborhood and other stakeholders from public, private, and non-profit organization sectors (37). This neighborhood in Malmö city in southern Sweden was among the areas regarded as highly vulnerable by the Swedish National Police Authority owing to issues such as low education levels, unemployment, high rate of criminality, and poor health among the inhabitants (38). Furthermore, the members in the neighborhood also live in social isolation and lack social context where they can interact regularly with others.

This programme was also established in accordance with the recommendation of a city-level initiative Malmö Commission inspired by the WHO report *Closing the Gap* (39). The main aim of the programme was to promote equal health in socially disadvantaged neighborhoods using an approach where both structure and content were defined by the communities living in a disadvantaged neighborhood (37).

The first step in the programme was the trust-building process, where researchers participated in local activities that happened in the neighborhood meeting places. The research team interacted and familiarized themselves with the community, in particular the local women network. Conversation held with communities living in the neighborhood by one of the authors showed that the citizens had mistrust in healthcare and social services and perceived themselves to be stigmatized when in contact with these organizations. Health-related information and support they received were not suitable owing to language and sociocultural barriers. The process of migration and socioeconomic situation led to physical and psychosocial health problems including lack of sleep, pain, stress, and poor physical health. Despite having mounting health needs, the citizens expressed that they did not have access to health-promoting activities, and those available in their near neighborhood were not affordable. This made it evident that these citizens were not adequately represented in the society and that their voices had seldom been heard.

In the second step in the CBPR health promotion programme, the academic researchers together with the fieldworkers from the municipality invited citizens from the neighborhood to the meeting places to participate in a future workshop (40). The future workshop is a method that emerged during the post-war period in Germany where a group of people gather to discuss social problems and develop solutions through collective decision-making. The residents in the neighborhood were sent an open invitation to attend the future workshop through notices posted in public areas and the municipality meeting places, as well as were reached out through different community groups, such as the local women network. The future workshop was conducted in 2016, where the citizens from the neighborhood discussed their needs with the academic researchers, the fieldworkers from the municipality, and collectively identified strategies to promote health. About 150 participants participated in the future workshop. The academic researchers facilitated the workshop together with and an Arabic-speaking interpreter. This local context, with a well-established collaboration between actors and the pre-existing network with the citizens in the neighborhood who frequented the established meeting places, was a basis to mobilize participants and plan for the future workshops. Through the future workshops, five problem areas emerged from the discussions with the citizens: (a) physical inactivity, (b) poor mental health, (c) lack of access to self-care, (d) poor oral health, and (e) lack of health literacy (41). Some of the citizens from the neighborhood also volunteered to become health promoters to help coordinate the activities within the programme. These representatives called lay health promoters (LHPs) were employed within the programme and were responsible for facilitating participant recruitment, language interpretation, and above all were instrumental in building trust between the research team and the citizens (37).

In the third step, the LHPs together with the research team, community members, and other stakeholders from the municipality, social care, primary care, pharmacy, property owners, and NGOs such as Red Cross and Save the Children created a CBPR model inspired by a model earlier developed by Wallerstein et al. (42) for planning collaboration and implementation of health-promoting initiatives focusing on the problem areas described earlier.

CBPR planning resulted in the development of six health-promoting co-creative labs focusing on problem areas raised in the future workshops such as oral health and diet, physical activity, mental health, women's health, social health, and safety in the area. These labs were driven by the citizens themselves and were facilitated by the LHPs. However, the LHPs worked across boundaries with various stakeholders to plan and manage the activities. The LHPs were also supported by a group of actors including the research team, with whom they shared and reflected on their experiences, and together developed strategies to address challenges. The LHPs were educated in CBPR methods and Freire's ideologies and were trained to manage power mechanisms, both at an individual level concerning their role in facilitating the activities and bringing together members of the community, and at the structural level with stakeholders (43). The different steps within the programme are presented in Figure 1.

The stakeholders or partners, LHPs, and community members who participated in CBPR planning met once every second week to plan, monitor, evaluate, and communicate the programme. The group also collectively defined a process for coordinating the activities and also periodically evaluating and developing them further in line with the citizens' needs. Furthermore, they worked around the values of the programme including mutual respect, mutual benefit, reflection, power-sharing, and knowledge mobilization (Figure 2). Mutual trust was considered central to all of these values. All the members had an opportunity to steer the proceedings by taking turns to be the meeting chairman. Dialogues at the meeting were the basis for various decisions. In case of disagreements, a voting process was initiated to ensure democratic action (41, 43). The partners and community members including the LHPs decided in the meetings to evaluate the health promotion programme in relation to the aforementioned values once every 6 months. This also included the evaluation of the activities in the individual co-creative labs.

All the activities within the programme were also followed by a strategical group, which comprised the vice chancellor of the university, director of the regional healthcare, representatives at the strategical levels from all stakeholders within the programme, and LHPs. The strategical group did not influence the proceedings of the programmes. They mobilized the knowledge from the programme and took it forwards to their organizations to work further with sustainable policy changes. Since the LHPs were also part of the strategical group, knowledge was transferred from this group back to the community.

A PA intervention programme, based on the needs and taking into account the varied capabilities of the community members, was established in the co-creative labs. The initial evaluation of the PA intervention in the co-creative lab showed the lack of activities exclusively for women in their near proximity, lack of affordable transportation to avail facilities elsewhere in the city, and lack of places to gather for group activities in their neighborhood (44). Thus, the PA intervention being evaluated in this study was offered cost-free and exclusively for women in the neighborhood. The evaluation of the intervention was an ongoing and iterative process. The physical activity intervention primarily intended to achieve reduced sedentary behavior and increase physical activity in everyday life among women in the neighborhood. In addition, the intervention did not target a particular aspect of health, but rather focused on the holistic view on health from the perspective of the participants. With the emergence of the pandemic, exploration of the experiences of participants before and during COVID-19 was warranted to understand the impact of the CBPR-informed PA intervention. Furthermore, experience from a prior epidemic has shown that when a new disease emerges and an acute situation arises, an already existing environment built on mutual trust can help improve understanding of disease control and suggest change that is reflective and community-sensitive without compromising on individual safety (45).

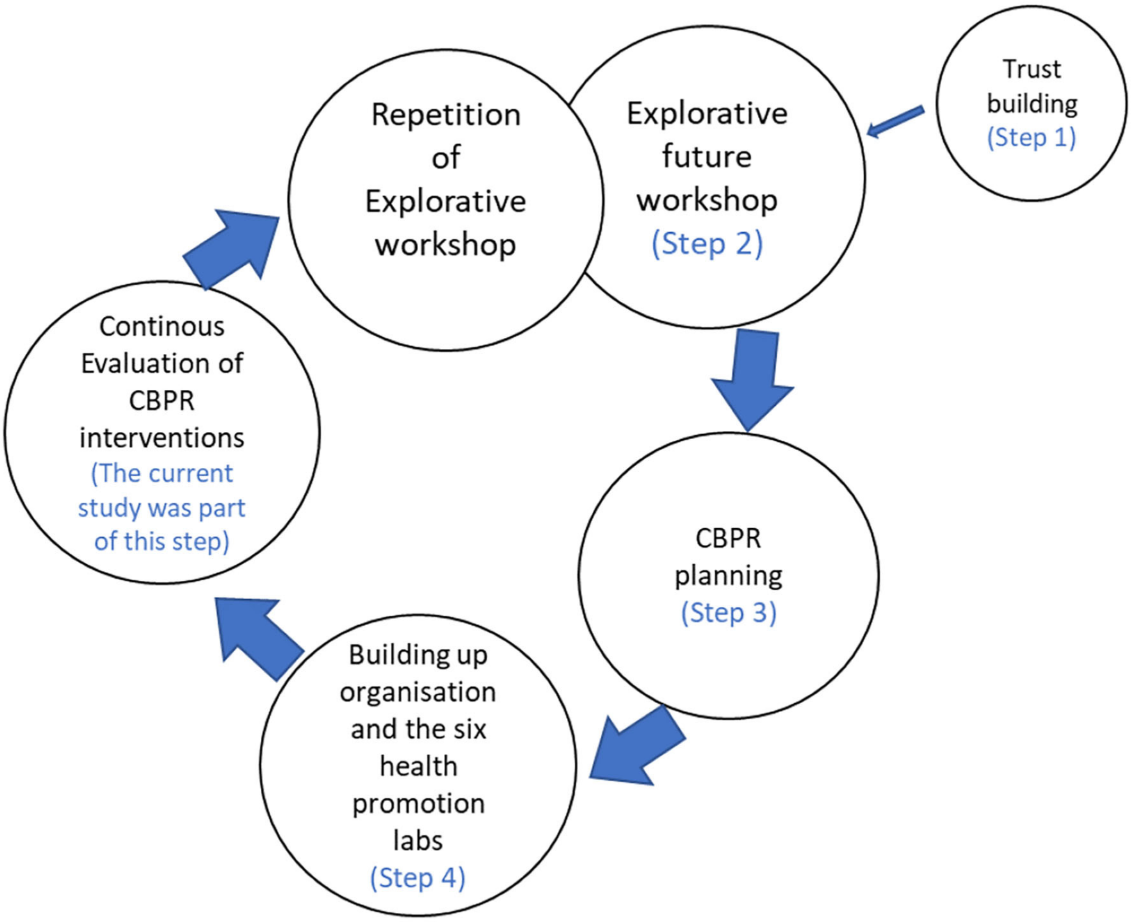

FIGURE 1
Steps within the Equal Health programme.

For nearly two decades, CBPR-based community health promotion has been proven to be an effective intervention approach in reducing inequalities (22, 46–49). Several CBPR physical interventions exist (28, 29, 50), some of which have also been initiated during the pandemic (51, 52). But only few interventions that initiated ahead of the pandemic followed through the pandemic, given that most parts of the world were under lockdown. However, since this study was based in Sweden, where no strict lockdown was imposed, there was an opportunity to evaluate the intervention even during the pandemic, which may give insights into the value-building CBPR work ahead of the emergence of a crisis situation.

> *The aim of this study was to explore the impact of a CBPR-informed physical activity intervention before and during COVID-19 from the perspective of women from a socially disadvantaged neighborhood.*

Methods

The current study reports a qualitative evaluation of a CBPR-informed PA intervention with a COVID-19 pandemic perspective. This was an exploratory study with an interpretative design. The participants were engaged in focus group discussions at four time points, ahead of the intervention (baseline), precisely after the intervention ended (post-intervention), 6 months after the intervention ended (long-term follow-up), and during the COVID-19 pandemic (during pandemic), which was about a year after the long-term follow-up.

Context

The participants were citizens residing in one of the socially disadvantaged neighborhoods located in Malmö, one of the

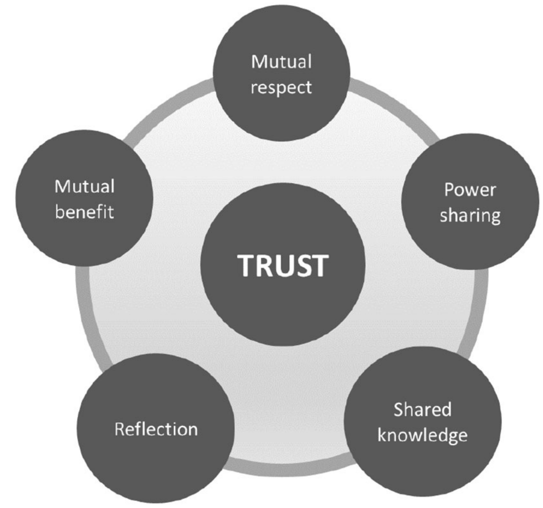

FIGURE 2
Values of the Equal Health programme.

largest cities in southern Sweden (44). Nearly 40% of the population in this neighborhood comprises first- and second-generation migrants who are predominantly from Middle Eastern countries including Iraq and Syria, together with their families from other Arabic-speaking countries, such as Algeria, Egypt, Iran, Lebanon, Palestine, and Sudan (53).

Participants

A total of 34 women aged 23–77 years were invited to participate in this study. All the participants in this study were non-Swedish-speaking migrants of Arabic descent. In this research, three LHPs were involved in contacting the women and facilitating the intervention and the focus groups. Given the results of the feasibility study (44), the intervention was exclusively performed in women as they were often isolated and physically inactive and as they did not have access to health-promoting activities that they could take part in the absence of men. For the focus group discussions held during the pandemic, the health promoters and the research team meticulously followed the recommendations of the Swedish Public Health Agency. The participants were requested to inform the LHPs if they experienced any flu symptoms on the day of the focus group discussion and were offered the possibility to reschedule the session. Of the 34 women in the group, about six of them could not participate in the focus group discussions held during COVID-19.

In this study, the participants were consistently informed *via* the LHPs that this study, which was part of the Equal Health programme, was built on the principles of openness, inclusion, and integrity. The trust-building process started with the strong partnership established between the research team and health promoters. The members of the research team participated in the physical activity intervention and were trained together with the group. Partnership between the participants was built based on trust and transparency. All the participants were informed that the decisions were to be collectively made and that all their thoughts were equally important. There was an ongoing process of reflection, and discussions regarding any conflicts that may emerge during the process were resolved at the end of every meeting. Although the participants were not familiar with other group members in the beginning, they were comfortable sharing their views. This was because they trusted the local health promoters who invited them to participate, who even facilitated the partnership between the members. Despite coming from different countries, the participants still shared the same language, followed similar sociocultural practices, perceived similar problems, and had similar goals, which facilitated and strengthened the group dynamics. This was in line with Etienne Wenger's view that a community of practice, where bringing together individuals sharing a similar concern to interact regularly, empowers the group and facilitates identifying collective solutions. This type of practice enables a collective responsibility where both reflections on their problems and solutions, and the action-taking process happen at the same time. This type of equitable collaboration enables connections that are beyond hierarchies and geographic boundaries (54).

Community-based participatory research-informed intervention

This CBPR-informed PA intervention was developed by citizens from the neighborhood together with LHPs, one of whom was a physical activity enthusiast who was born and raised in the neighborhood. Following the CBPR planning and the establishment of the co-creative labs, 70 community members participated in a new workshop facilitated by the research team, where they together with the LHPs defined their expectations from a physical activity intervention. They also informed about personal, sociocultural, and structural factors that influenced the participation of community members in physical activity programmes. The discussions and reflections were condensed into specific action points. The citizens were particular about that the PA intervention should be tailored to individual capabilities. The citizens wanted the exercises to be related to their everyday activities and did not want it to involve the use of complex equipment that they could not afford. They also wanted to learn the right way to handle training tools and carry their body when performing everyday activities. They also wanted to gain knowledge on healthy diets and healthy mind. The citizens wanted the activities to be free of cost and happen in their near proximity.

A unique physical activity intervention was co-developed by the communities with the aim of building community and diversity together for a fair and equal fitness culture among citizens in the neighborhood based on their own perceived needs. The intervention had four key aspects focusing on natural human movements, nutrition and health, restoration and healing, and reflection session on why physical activity is important and should be available for all without differences. The fitness exercises focused on gradually facilitating a change in the participants' lifestyle, starting from simple body movements, which in due course evolved into more complex exercises customized to individual abilities. The participants in this programme also engaged in reflective dialogues regarding nutrition and the importance of eating fruits and vegetables. The intervention programme involved 10 sessions over a 3-month period, with one training session a week. The programme was coordinated by the LHPs. The programme was not merely a short-term intervention, but it also provided women the skills to become future health ambassadors who could spread the knowledge gained to others in their family and neighborhood.

Based on the results from the feasibility study (44), the intervention was offered two times a week over 3 months, so more participants had the opportunity to participate based on their convenience. In each session, which lasted for about 2 h, 15–20 participants were accommodated. All sessions concluded with a self-reflection. Evaluation of the intervention was an ongoing process where the participants were also actively engaged. The goal of the intervention was to evaluate the experiences of participants focused on broader aspects of health from their own perspective.

Focus group interviews

The current study included data from 16 focus group discussions conducted over four time points. On the first three sessions, namely, baseline, post-intervention, and long-term follow-up, six to eight women per group engaged in focus group discussions. The last focus group discussion during the COVID-19 pandemic happened when recommendations against gathering in public spaces were temporarily lifted in early autumn of 2020. The focus group discussions happened in a large spacious room, where the participants were seated at a distance of 2 meter from each other. All the participants were requested to wash their hands ahead of the session. The participants were informed on all sessions that the discussions would be audiotaped and that the material would be used for research purposes only. Each focus group lasted 1–2 h, and discussions proceeded until no new information was identified. The interviews were primarily held in Swedish, while the health promoters translated back and forth between the participants who mainly spoke Arabic and the research team. The research team included an observer who was the second or third author or another PhD student from the programme (41) together with the first author. During the focus group discussions, the participants discussed between each other and together with the research team.

A CBPR interview guide previously developed by Wallerstein and colleagues (55) was used to initiate the discussion focusing on potential benefits of having participated in the community-based participatory research-informed PA intervention and understand the effect of collaboration with the health promoters and other group members during the activities. The CBPR interview guide focused on the context, group dynamics, equitable partnerships, intervention, and both health-related and structural outcomes of being part of the CBPR process including engaging in the intervention. These were also the domains explored in the focus group interviews. The questions on perceptions related to how their context and surroundings affected the participation in the group intervention and how they perceived the collaboration with the other participants, LHPs, and academic researchers were also asked to understand aspects that may hinder participant development. Further questions also explored the perceived outcomes related to the intervention. Additional questions related to the pandemic were also included in the last focus group discussion: (a) How have your lifestyle changed since the start of COVID-19 in the spring of 2020? (b) How has it been with following the healthy routines that you learned from your participation in health-promoting activities during the pandemic? (c) What kind of information about lifestyle changes related to the COVID-19 pandemic have you received?

Analysis

The audiotaped data from the focus group interviews were transcribed verbatim, and the transcripts were analyzed using the inductive content analysis method guided by the approach of Elo and Kyngäs (56). As a first step, all transcribed interviews were meticulously read to identify text relevant to the aim of the study. Texts that were related to each other in terms of their content and context were grouped together. These interrelated texts known as meaning units were placed in a table for analysis. Later, the different meaning units were condensed into manageable texts. Finally, codes with names as close as possible to the original data were assigned to the condensed meaning units. Codes with similar content were grouped together into sub-themes. The sub-themes and codes were rechecked and compared with each other, as well as the original data. The overall main theme was identified at this stage, which summarized the information from all sub-themes earlier identified. The initial analysis was performed by the first author and the last author of this article and later verified by the second and the third author to increase the credibility of the study (57).

The results from this study were presented to the participants after the analysis was completed. This was carried out in a separate workshop in the presence of all the participants. The different themes were presented to the participants and reconfirmed if the research team had interpreted their thoughts in a meaningful way.

Ethical considerations

The health promoters verbally informed all the participants in Arabic about the purpose of the research study prior to baseline focus group discussions as well as reminded them in the following two sessions. The participants were also assured that participation was voluntary and that they could leave the study at any point in time without any consequences.

The participants were contacted by the LHPs through a video call *via* WhatsApp and informed about the details of the study ahead of the focus group discussions during COVID-19. The participants were assured that all activities were carried out in accordance with guidelines from the Swedish Public Health Agency. The research group also ensured that there were no more than eight participants per group during the focus group interviews. The participants who preferred to avoid social contact due to COVID-19 and not participate in group discussions were offered the opportunity to be interviewed individually or through video conferencing. However, none of the participants desired this alternative.

All the aforementioned information was also provided to the participants in writing together with contact information of the research team both at baseline and when data were collected during COVID-19. The participants were asked to sign an informed consent form at baseline, as well as when they were invited to the focus group discussions during COVID-19. All data collected were anonymized and kept confidential. The data were only accessible to the members of the research team. The Swedish Ethical Review Authority approved this study (DNR 2018-382 and DNR 2020-04063).

Findings

The participants' experiences in the participation in the CBPR-informed PA intervention before and during the pandemic have been described using four sub-themes: "Wavering between frustration and action," "Shifting from only prioritizing family needs to taking control of self," "Between isolation and social support," and "Restricted access to health-related knowledge vs. utilizing internalized knowledge." The themes intend to convey a juxtaposition between the participants' perceptions before and after the intervention, as well as during COVID-19.

The four themes commonly discuss how uncertain feelings experienced by women initially lead to frustration owing to lack of support. These feelings seemed to have resolved through engagement in the intervention, after which they could make more informed choices. However, when distancing led to isolation during the pandemic together with the lack of understanding about the novel COVID-19 infection and the recommendations, they developed conflicting feelings and a state of ambivalence yet again. There was a brief period of hesitance owing to their ambivalent state, following which women eventually identified their inner strengths with the support of the health promoters and other members in their group. This helped them reminisce the knowledge they gained from the intervention. They also gained understanding regarding the roles of the different public actors (whom they did not trust ahead of the intervention) and the recommendations to be followed through the health promoters, which further helped them recover and become resistant toward physical, social, and psychological effects of the pandemic through continuing to maintain their health and being physically active.

Wavering between frustration and action

The theme wavering between frustration and action describes how the women in the group were frustrated and experienced mood swings in general. Their frustration was primarily owing to events from their past in their homelands together with their current life situation where they seldom had time to learn the language, be physically active, and get acquainted with the society. However, after participation in the intervention, they reported that the physical activity seemed to have reduced their frustration. They also started to believe that PA influenced their mental health. During the long-term follow-up, the participants were frustrated only when they did not have the opportunity to be physically active. When the pandemic emerged, the society, in general, was filled with fear and uncertainty, and the women said they were also initially frustrated. The women reported that they later reflected on the past experiences of the effect of physical activity and ensured that they were physically active in the best possible way even when restrictions were in place.

During the baseline focus group discussion, the women explained that they had an inherent tendency to be stressed often. Since they were unemployed and were overburdened by household chores, they mostly stayed at home and had little knowledge on their surroundings. They also perceived a lack of time to develop their local language skills through participating in courses offered in the city center. They experienced mood swings owing to their sedentary lifestyle, lack of social life, and impending thoughts about the conditions in their homeland. Some women also said that they were initially very lonely and sad, and they even refused to participate in the intervention and had to be motivated by the health promoters to take part. After participation in the intervention, they believed that they learnt how to focus on their health and change their lifestyle, rather than being stressed and constantly worried about their wellbeing. The women perceived the participation in the group intervention had helped them recover from their frustration and focus on their health and wellbeing.

> *"Before I easily got annoyed and angry. I was insecure and afraid all the time. Since I started training with the group, I have become calm and happy. I think physical activity has unique effect on our mental health" (Post-intervention, focus group – 2b).*

At the long-term follow-up, the participants mentioned that through participation in the intervention, their body and mind got used to being physically active that if they ever lacked opportunities to being active and were idle, it started to affect their mental health, and so they continued to be physically active even in the absence of group activities.

> *"After participating in the group activity, I have become accustomed to being active and exercising. If I do not do it, I start to feel sad and frustrated" (Long term follow-up, focus group – 3d).*

Women who previously suffered from mental health problems, particularly anxiety, believed that their condition worsened during the pandemic and felt frustrated since they did not receive necessary help to recover. They faced a mix of emotions, including sadness, anger, and helplessness, which led to more frustration since they realized that they were heading to nowhere with their feelings.

> *"I was scared, depressed. I could not do anything. Could not stand it anymore. That is how it was. I feared everything, everything seemed stressful. I got angry for nothing; I could not even go out to get help" (During COVID-19, focus group– 4a).*

The women in the group said that although they were anxious initially when the pandemic emerged, they recovered from fear and sadness through being more physically active. The women reported that the knowledge gained from participation in the intervention had always been with them as an inner resource, and with some motivation from the health promoter, it was activated during the pandemic. They also believed that mental health was related to PA and that poor psychological status led to a decrease in PA, and vice versa.

> *"I have learnt from the group training that if one is sad, they cannot be physically active but if you are not physically active you do not feel happy either it is like a chain reaction. Yes, physical activity helps me to reduce my anxiety" (During COVID-19, focus group – 4c).*

Shifting from only prioritizing family needs to taking control of self

This theme describes how the women perceived that the mounting family duties were the reason for not being able to care for themselves. Even though the women decided to take time to participate in the intervention, they initially felt guilty for missing out on tending to their family during the time they were with the group. However, when the women participated in the intervention in company of others in a similar situation, they received support and helped each other. In addition, through participation, the women also realized that if they did not care for themselves and their own health deteriorated, they may not be able to care for their family. This motivated them further to be physically active. During the pandemic, the women said that they could share their knowledge with their family and help them be physically active. The women began to believe that they were important and that their lives were meaningful following participation in the CBPR intervention.

During the baseline focus group discussion, the women said that as a tradition, they usually perceived their family needs ahead of their own that sometimes they had little time to themselves. After participation in the intervention, the women said that their children observed a positive change in their mothers and were very happy for them.

> *"I have come to understand that healthy women mean healthy family, because we tend to the family, we cook and care for our children." (Post-intervention, focus group – 2d).*

At the long-term follow-up, the women said that the intervention was successful only because it was designed in accordance with their needs. The women said that they were initially hesitant to participate, but they trusted the health promoters as they are more like them than others, given that they are from similar backgrounds and family circumstances and thus had a closer understanding of their individual needs. The women also mentioned that by including them and taking their views seriously, they started to feel that they were important. The women also mentioned that when others realized their importance, they themselves also started to believe that they were important.

> *"It finally felt like our views were heard, that we were important and in fact I started to believe that I am important" (Long term follow-up, focus group – 3a).*

The women in the group said that although initially it was very frightful when the COVID-19 pandemic emerged, they also came to realize that their fear was also affecting their general health in a negative way and that the consequences of it could be more severe than if they contracted the virus. The participants perceived that over time they understood that all that they could do was to be positive and follow the recommendations. They also tried to spread the positivity to their families and friends, which made them feel calm. The women mentioned that they also used the knowledge they gained from participation in the intervention and tried to replicate activities they did earlier such as lifting small weights, where they replaced weights with a bottle of pickled cucumber or a simple ball, and did the same activities they did with the group at home with their families.

> *"I use two cans of pickled cucumber to train. I kept five kilos in one hand and another five kilos in the other and do some movements we learnt in the group. And then, I have a big ball that I also use and then I lie on the floor, and train. I also helped my family to be active" (During COVID-19, focus group – 4d).*

Between isolation and social support

This theme describes how women in the neighborhood were isolated and often lacked motivation to be physically active, but the participation in a group within a social context motivated them to be physically active. Health promoters had an important role in motivating some of the women to participate in the intervention at the beginning. However, following participation, the women themselves began motivating each other to be regular owing to the interaction and bonding established in the group. The women also reported during the long-term follow-up that the support and understanding they received in this group were absent in other similar group training sessions they had tried elsewhere. During the pandemic, the women after, an initial period of isolation and yearning, revived their contacts with their group *via* social media. They particularly trusted only this group and did not part take or trust in other sources on social media.

During the baseline focus group discussion, some of the women said that they decided to participate in the PA intervention to overcome their isolated and lonely lifestyle. They also believed it would give them an opportunity to make new acquaintances and also to do something useful for their body, instead of throwing their time to sitting idly and being depressed. The participants also mentioned that women in the neighborhood often lack motivation and were less informed about the importance of being physically active and therefore lead an idle life and needed someone like the health promoter to motivate them.

> *"I do not have great desire for anything, I live alone and I am very depressed I need someone to push me all the time" (Baseline, focus group – 1c).*

After participation in the intervention, the women believed that doing PA in a group helped them break their isolation, and it also improved their mental health. The women also said that when they felt less motivated on any occasion, the other group members started to message and motivate them on the WhatsApp group created by the health promoters for the group. The women felt meeting regularly made them more comfortable and secured in the group where they could freely share their views and discuss concerns without feeling threatened of their privacy. The women also mentioned that it was not just about being in a group but also the interaction between the group members facilitated by the health promoters. They said that they have participated in other group activities as the sewing circle where there was no interaction at all although they sat in a group.

> *"I have no one in my life and was in a lot of grief, but when I started in the group and met others here, I started to be very happy. It now feels like I have a big family" (Post-intervention, focus group – 2a).*

During the long-term follow-up, the women reported that when it was dark in late autumn and winter, they preferred organized group activities as the climate affected their mental health. They also mentioned that they did not feel motivated to train by themselves in the absence of group activities and it was making them more depressed. Some women also mentioned that despite creating their own groups, they had challenges to find a large enough place and facilitate the activities at stipulated times as health promoters had done. The women also said that they had tried other group training in the neighboring areas, but it was not the same since they did not receive the guidance and help from the coaches in those activities as the health promoters and fellow group members did during the PA intervention.

> *"I have friends who want to train with me but we can not afford to rent a room and do activities, it is difficult to do it at home. It's more fun when we are many, and that is why we need activities that are organized by health promoters" (Long term follow-up, focus group – 3c).*

The women perceived that when the pandemic emerged and the related recommendations were introduced, physical distancing led to social distancing, which contributed to feeling isolated, irrespective of age. The women said they felt captivated, and it also seemed like they were going back to being isolated as in the beginning before they participated in the intervention.

The women also said their mental health became worse because of social distancing, which was perceived as isolation, since initially they did not leave their home or meet anybody. If they later on had not decided to at least go for a walk, they believed that their mental wellbeing would have been seriously deteriorated.

> *"It also got worse and worse since in the beginning I met no one. I've been alone since Corona started. I felt really bad. I felt like I was in prison. I needed to train at home myself. But, I had no desire to train myself. If I had not decided to go for a walk I would have become crazy." (During COVID-19, focus group – 4d).*

The women regarded social media as a means to breaking isolation among community members. The women were aware of the negative effects of being isolated from their earlier experiences and started to use WhatsApp and other social media more frequently during the pandemic as it helped them communicate and stay close to their family and friends from the neighborhood despite the physical distance. The women in the group even shared health tips and COVID-19-related information to each other *via* WhatsApp. Despite access to several WhatsApp groups that provided information on COVID-19, the women said they preferred the group created by the health promoters as it seemed more locally relevant. They also said it felt more comfortable in those groups since they knew other members, and they could freely contribute to the group and learn from each other as they did before.

> *"I do not like social media and stuff like that. But I am in a group together with other women in the area who came with me to the training. We share knowledge with one and other in the group and we compete for being the first to share information, it makes it fun and I think we feel more stronger when we are learning together though we cannot meet in person." (During COVID-19, focus group – 4c).*

Restricted access to health-related knowledge vs. utilizing internalized knowledge

This theme describes women's general sense of mistrust in the healthcare system as it is not culturally and contextually adapted. The women were also apprehensive about the short appointments with the nurses and doctors, thus the lack of opportunity to express their needs. Some experienced language barriers, and even those who could speak the local language were not satisfied with their contact with the healthcare. The women believed that even during the pandemic, they did not receive specific information or knowledge regarding health-related lifestyle. The women through participation in the intervention seemed to have gained much of the support they missed from the healthcare system. They trusted and believed in the health promoters who even explained the recommendations from the public health authorities. During the pandemic, the women although lacked support from the healthcare recalled their internal knowledge previously gained through participation in the intervention. They utilized this internal knowledge to maintain a healthy lifestyle despite staying indoors.

At the baseline discussions, the women in the group believed that there was a need for knowledge regarding how to protect and maintain health among citizens living in the neighborhood. They expressed dissatisfaction with the support they received from the healthcare system since the staff at the primary care and even specialist doctors did not give the necessary time and attention to providing tips to improve health based on their living conditions. They felt language was not a barrier; however, they could not understand how the Swedish healthcare system worked.

> *"It is important for us to know what improves health and also controls blood sugar and hypertension which is a common problem here, nobody has told us things so clearly not even my doctor" (Baseline, focus group – 1a)*

During the baseline focus group discussion, the women said many people who had diabetes, hypertension, and muscle dystrophy were aware that PA had a positive impact on these conditions. They also said the problem was that they were not motivated to be physically active. After participation in the intervention, the women believed that they could change their health behaviors, which they previously could not despite the awareness. They also reported that the nurse at the diabetes healthcare was pleasantly surprised since they suddenly observed changes in blood sugar and blood pressure levels.

> *"I have diabetes and I know its good to train but it was very difficult to change my eating habits and move my body, but now after participating in the activity I have changed everything, and my diabetes nurse is completely surprised as I have much lower blood sugar than before." (Post-intervention, focus group – 2c).*

The women who had visited a medical doctor during the pandemic for control of diabetes or other health ailments perceived that doctors never discussed COVID-19 and its impact on diabetes or high blood pressure. The participants felt that due to social distancing, there was a change in their own lifestyle, regarding which the doctor did not discuss further or give specific recommendations.

> *"We hardly get appointments with the doctor these days for adults they only see children... I go to the doctor once a year for a referral to control my diabetes. They talked about coronavirus but nothing about exercising and eating well during these times." (During COVID-19, focus group – 4b).*

During the pandemic, the women believed that they received health-related information from many sources, but they thought that it was better to know about health and different ways to improve their health from someone in their circle who has a similar background as them and has tried it, and they did not believe in merely following advice from doctors. The women believed that it was better to hold on to one resource for information, although there were many channels of communication. In the group created by the health promoters, the women said that they not only participated in the group activities but also had the opportunity to discuss and understand recommendations from the authorities and their implications.

> *"I am on Whatsapp only in certain groups created by health promoters with other women in the area. Here we have all the activities we used to have before even group training. This is how I also get all-important information that is summarized in a simple language. This way we get to understand what local authorities really recommend." (During COVID-19, focus group – 4d).*

Discussion

The result of the study shows that the women were wavering between being frustrated and gaining relief from the frustration first owing to their own situation and later on because of the pandemic. Therefore, physical activity became a means of recovery from their wavering mental state. Furthermore, the women who initially valued prioritizing family needs over their own health started to take control of their health following participation in the intervention. The women who were initially isolated received support from the group through participation in the intervention and started to feel included. The participants initially complained that they did not receive health-related knowledge from healthcare both before and during the pandemic. However, after participation in the intervention where they could discuss and reflect with other group members, they believed that they gained knowledge, which also became useful, especially during the pandemic. Thus, participation in a CBPR-informed PA intervention helped the women recover from the state of ambivalence. Furthermore, they also became more decisive, making more informed decisions by taking control of their own health and wellbeing while also helping others in their family and community. The social support received from participating in the group with the other women initiated the empowerment processes that led to behavioral change and improved health among the women. Not only did the participants change their lifestyle but also spread their knowledge to their families and friends in the neighborhood, resulting in community capacity. Empowerment was initiated by engaging in reflective dialogues and activities and specifically through the support they received from other participants in the group. Empowerment is a recurrent interpersonal process fostered by setting goals, developing self-efficacy and competence, acquiring knowledge, and taking action to achieve goals (58). The health promoters also linked the group to important institutions in the society such as healthcare and social care, which was in particular highlighted during the pandemic. Given that this is a CBPR programme, there was constant dialogue and reflection within the group, where the need for adapting activities to the pandemic situation emerged. Thus, the health promoters facilitated digital activities bringing together the women and facilitating their recovery through engaging them together in the group. This helped in building community resilience among the participants, which was even transferred to their families.

Above all, the results of this study showed that participating in the CBPR intervention, the women primarily experienced improved mental and social health in addition to positively influencing their physical health. The discussion with the women indicated that the knowledge gained through participating in the group activities together with the support from the health promoters and, most importantly, the empowerment process initiated by CBPR participation seemed to have influenced their mental health.

Improved mental health and sustainability of the CBPR intervention

Lack of physical contact, social isolation, and physical inactivity became an added burden to the existing mental health condition due to traumatic experiences and thoughts of their homelands among the women in this study. The absence of psychosocial support, particularly from the healthcare personnel owing to language and sociocultural barriers, aggravated the situation and made them feel helpless and frustrated. After participation in the intervention, the women realized that being physically active was a means to revival from psychological stress and mental health problems and also made it a routine. Several CBPR intervention studies, especially among Latina, African-American, and Asian- American communities have also shown that in an environment built on trust, participants collectively identify their resources to regain their mental strength and recover from anxiety and mental distress (59–63). Even in the case of this study, the research team was engaged in a prolonged trust-building phase (described as step 1 in the larger program) ahead of establishing a partnership with the communities, which also contributed to a long-standing involvement of the community in this study and in the larger programme.

Furthermore, our results show that after participation in the CBPR intervention, the participants in this study seemed to have experienced poor mental health only when they stopped being physically active. Numerous studies in the past have identified the effect of PA on mental health (64–66). However, in this study, such a relation also led to long-lasting commitment to being physically active since the participants experienced the effect of physical activity on their mental health, which motivated them to continue to be physically active. It can be suggested that the praxis of knowledge and learning from participation in the intervention and sharing experiences with others in the group made this CBPR intervention sustainable. These results were also in line with previous studies assessing CBPR interventions, especially those targeting behavioral change in different populations, where sustainability was related to equitable partnership established between the community members, academicians, and other stakeholders, as well as their collective actions focusing on knowledge transfer and knowledge mobilization (47, 67–69). As suggested by Wallerstein and colleagues (22, 70), the sustainability of the CBPR intervention presented in this study was owing to the fact that the PA intervention was not only built on the needs of the community but also that the citizens were involved in the development of the intervention, including defining the goals for evaluating it. Furthermore, within the larger programme in which the current study was a part, the community members defined their problems and identified themes for promoting health, and only after this phase (described within the larger program as step 2), the other stakeholders were involved together with the citizens in the planning process.

When the pandemic emerged, it had a strong effect on the psychological wellbeing of the participants, especially in the early stages since limited information was available, and the women began feeling unsure and frustrated just as they felt prior to participation. This was also in line with the previous studies (71, 72), where fear, anger, and hopelessness were identified as the most frequent traumatic emotional responses among the general public during the initial outbreak of the COVID-19 while it was still an epidemic and not declared as global pandemic.

Although the World Health Organization had raised the importance of maintaining health and engaging in regular PA during the pandemic, especially to gain relief from the related anxiety and stress (73), the general recommendation against gathering in public places, restrictions in gyms, and training centers together with the fear of even moving out of home have been barriers to PA during the pandemic (3). However, women in this study said that based on the knowledge they gained from participation in the intervention, they realized that the best means to relieve themselves from anxiety and psychological distress caused by the pandemic was by being physically active. Although they could not initially train with their groups as before, many of them started to walk regularly, which helped them alleviate their frustration and decrease their mental stress. This is also in line with the results from a cross-sectional study in Canada, which showed that preserving mental health is a motivating factor for increased PA during the COVID-19 pandemic (74).

Furthermore, the women also reapplied the knowledge they gained from participation in the intervention to be physically active from within their own homes with the limited resources available. They replicated some of the activities they performed together as a group using household tools such as a bottle of pickled cucumber to replace training equipment. They also shared their knowledge with their families and even helped them be physically active based on what they learnt from the intervention, thus strengthening family relationships and spreading a positive spirit to their family and acquaintances at the time of crisis.

Knowledge mobilization during the CBPR interventions

Freirean ideology promotes critical consciousness and critical thinking; in this study, the citizens, when engaged in a reflection, dialogue, and action cycle, were able to link their realities and experiences in the quest of knowledge, which led them to collectively identifying solutions and taking action (75). This is also well-aligned with the results of the current study, especially during the pandemic; the citizens had access to different information from different sources, especially through social media. There was fear of receiving misinformation and thus a lack of trust in the information, particularly when information was from unknown sources. In line with the current study, a recent study has also highlighted the challenges in the use of social media as a communication channel for health-related information during the pandemic as there was an increased possibility of being misinformed (76, 77). However, in this study, the women reportedly trusted only the group created by the health promoter together with other group members with whom they could engage in a collaborative conversation. The discussions within the group together with the health promoters helped the women assess the different kinds of information and collectively assimilate knowledge from trustworthy sources. Studies on community-engaged risk communication also reported similar results including that actively engaging communities has the potential to introduce shared creation and dissemination of health information, while it also increases the possibility to involve in local communities in determining culturally appropriate mitigation policies together with concerned authorities (78, 79). However, the sustainability aspects of these initiatives were unclear since they were not built on previously existing equitable partnerships with the community built on long-standing trust (established in step 1 of the larger program) as in the case of the current study. Furthermore, the women in this study also reported that they trusted the information provided by the health promoters since they adapted and recommunicated the health information from healthcare authorities and other governmental organizations. Previous studies have also shown that lay health promoters are culturally competent in the context and often communicate informally with the community members, thus making them more comfortable (80, 81).

Initiating empowerment during CBPR interventions

In the beginning of this study, prior to participation in the intervention, women explained their social circumstances and culture led them to prioritize their family needs over their own. They lacked time to learn the local language or get accustomed to the context in the host country. Post-colonial theories have raised concepts such as enmeshment and familism when discussing the sociocultural practices, which are common in many Arabic families (82). Arabic women are considered to be deeply bound to their families, and the family played a central role in their life. Women become enmeshed in this situation where they are continuously working to meet family needs that they lose touch with their own needs, goals, desires, and feelings. These theories also suggest that women sense guilt when they choose caring for themselves time to time, assuming that they compromised their families and are frequently lost in the process of identifying a balance (82).

However, through participating in the CBPR intervention, the women identified the strength to rebuild themselves and understood that they needed to take care of themselves so that they could care better for their family, and thus, family became a positive motivation for enabling self-change. The women also explained the feeling of being empowered in that they felt more recognized in the society than they previously did. Previous research has also shown that interventions informed by the CBPR approach has the potential to induce empowerment since the voices of communities which are otherwise not included in traditional research are heard and also recognized (83). Furthermore, the communities take part in the decision-making process, develop critical thinking, gain autonomy over their own life, and thereby the ability to change (84–86). However, in this study, empowerment has been a means to overcome enmeshment without disrupting family dynamics or cultural orientations, but rather affecting them positively, through improving women's health and thereby giving them a better chance to care for their family. The results of this study also draw on Zimmerman's definition of psychological empowerment, which is defined as individuals' perceived control over their lives and is also, in turn, related to their level of participation in community change (87). Several CBPR interventions, especially those among migrant communities, have identified empowerment as one of the key outcomes of participation in the intervention (26, 50, 63, 88). However, what is unique about the current study in contrast to other studies is that the intervention was not part of the pre-determined programme with a well-defined goal; rather, it was co-developed by the citizens of the community.

For some women, participation in the CBPR intervention was an opportunity to being physically active and also making new acquaintances to break their isolation and be included in a social context. Through social support received from fellow group members and the health promoters from their own community, the women in this study became motivated to be physically active. The findings from this study thus highlight the role of participation in the group and the social support received from the community group as a key factor for initiating the empowerment process and thereby behavioral change. The participatory dialogues and reflection within the group helped them move from a confused or ambivalent state to a more stable state, where they could take control of their life to make informed decisions. This is also in line with Freirean ideology regarding empowerment, which suggests that participation in group action and dialogues that aim at community change also enhances participants' control over their own life as well as increases the beliefs regarding their ability to change (89). Prior CBPR studies also showed that facilitating opportunities for communities to influence their development through playing meaningful roles, providing social support, building social networks, and implementing collaborative action can lead to empowerment (90–93).

According to one study among migrant women, empowerment is described as a cyclical, interpersonal process facilitated through dialogue and reflection among a group of individuals with a similar background and interest. For example, the process of empowerment was further explained in the migrant women study as starting with an initial dialogue and reflection, primarily establishing the group goals often aiming for change, further building efficacy and competence through gaining knowledge through discussion and knowledge mobilization, and finally taking action toward reaching the set goals (94). This cycle seems also well-aligned with proceeding of the events in the current study, where the women met in a group with others from the same context facing similar problems and had mutual goals to improve their health and being physically active, they gained knowledge from each other and motivated each other and finally made a change in their lifestyle by becoming physically active with the support of the group. Social support was a motivating factor to be physically active among women in this study since many women could not train by themselves in the absence of group activities during the long-term follow-up.

During the pandemic, the women perceived to be mentally stronger when being connected to the group, despite the distance, since they felt encouraged, motivated, and cheered each other, which helped them live through the acute situation. The women could communicate freely and did not feel threatened about their identity in the group, given the already established relationship with the other group members during the intervention. This strengthened the women and helped them maintain health while also promoting recovery from stress owing to the pandemic and thereby also increased community resilience. These results support the recommendations by the European Union in the OECD report, lifting the need to integrate COVID-19-related prevention work to existing local initiatives based on mutual trust to maximize the reach to communities that are frequently not covered by larger efforts at a population level (7). Prior CBPR studies have also shown that social connectedness may become foundations for recovery from natural and manmade disasters such as wars (26, 95, 96). Furthermore, earlier studies also show the role of social support or social connectedness and its relationship to community health which was facilitated by active community engagement.

The findings of this study were also in line with previous research on disaster management highlighting the role of social capital (social connectedness) in an environment built on trust, where community members bond with each other and further link with societal organizations, resulting in increased community resilience during acute situations (97). This study shows that the CBPR process increased social connectedness and led to individual empowerment, which over time may have led to community empowerment and increased community resilience during an ongoing pandemic such as COVID-19. Community resilience is regarded as the collective ability of a neighborhood to cope with stressors and efficiently return to the rhythms of daily life through a collaborative initiative built on social support following an adverse event such as a natural disaster or pandemic (95, 97).

LHPs act as brokers building community capacity during the CBPR intervention

The local health promoters played a vital role in engaging the women in the PA intervention. In line with the guiding principles of CBPR, such as inclusion, the LHPs initially motivated and brought women together in the community who were otherwise isolated and lacked social contact to participate in the activities. It was also important that the LHPs were part of the community with whom they worked, which can be resonated in relation to the theories of situated learning by Etienne Wenger. According to Wenger, knowledge is situated and embodied in practice, and in this case, it also includes the sociocultural understanding, which results in building inclusive communities (54). The LHPs have also been instrumental in facilitating dialogue with the citizens, with an aim of creating a common understanding of problems in the neighborhood and also relating to the practices specific to the community in question. Having been trained in reflections from the works of Freire (19), and participatory methods, the LHPs individually supported the women who experienced challenges and uncertainties by introducing them to the social context, which helped them recover and identify their own strengths. Furthermore, they worked with the group as a whole to build trust and establish an equitable partnership with the research team and other stakeholders and thereby involving the women in the collective decision-making process. They also facilitated dialogues within the group while acting as bridges between the authorities who have a direct implication on the everyday lives of the community such as the public health authorities, governing bodies, and healthcare staff. All this was possible because of the LHPs' ability to empathize with their fellow community members and also because they followed and adhered to the actions they were promoting. The role of the LHPs as brokers mediating community engagement and facilitating CBPR interventions has also been discussed in previous international studies (98–101); however, they are not as common in the Swedish setting.

One of the COVID-19-related recommendations from the World Health Organization was the need to promote health behavior and PA (102). However, the women in this study said that during their diabetic control visits at the primary care, the healthcare personnel did not discuss the importance of healthy lifestyle or being physically active during the pandemic. Although several studies have highlighted that PA has decreased significantly during the pandemic (3, 103, 104), no study to date has assessed the role of healthcare staff in the context of changed lifestyle during the pandemic. Despite the lack of support from the healthcare system, the health promoters reminded the women about the knowledge they had gained through participation in the intervention. The women believed that a mere text message reminder was sufficient for them to recollect themselves and train from home.

Community engagement through the CBPR intervention

In this study, three key aspects were basis for facilitating community engagement. First, at the start of the larger programme in which this study was a part, future workshops (described as step 2 in the larger program) were conducted ahead of the CBPR planning with other stakeholders (described as step 3 in the larger program). This gave sufficient time for the communities themselves to define the problem and even reach to an open agreement regarding strategies to improve health. Second, the community members were also part of the development of the physical activity intervention and were even actively involved in the planning of the activities together with the lay health promoters. Third, the lay health promoters in this study having a diverse role were involved in the active learning of Freire's participatory method on empowerment, which included support in facilitating the group processes contributed to an increased community engagement.

Implication of the evaluation of the CBPR intervention

Continuous evaluation of the intervention was deemed necessary, given that the context, environmental factors, and even the people are continuously changing. Newer families have been moving into the neighborhood, and more women have expressed their interest in joining the groups, resulting in the need for more training sessions during the week. During the long-term follow-up and ahead of the pandemic, many women expressed challenges to train alone in the absence of the group, particularly in winter when they lacked motivation to go outdoors. Thus, the group activities have been readapted to suit the seasons of the year with more indoor activities during winter and additional walking and trekking activities during summer. Yet another example was the pandemic that necessitated the activities to be moved digitally. Some participants also needed digital support to learn to use applications such as Zoom and WhatsApp.

Limitations

In addition to giving a unique insight on the impact of a CBPR intervention, the current study also takes into account the COVID-19 perspective. The main constraint in this study was that most of the discussions were held in Arabic and were translated to Swedish by the health promoters, and the audio recordings were later transcribed verbatim and again translated back to English for the purpose of analysis and presentation in the article. Such back and forth translation of data could have resulted in translation and interpretation bias, which may affect the trustworthiness of qualitative data. However, the authors of this study have cautiously handled the data. The health promoters who translated Arabic to Swedish were fluent in both the languages. In addition, all the four authors of this study were bilingual in that they could speak both Swedish and English. The analysis was performed after prolonged engagement with the data, which enabled understanding of intricate and implicit reflections of the women's experiences. Furthermore, the analyzed data were presented and discussed with the health promoters and participants to ensure no misunderstanding of the actual views.

Conclusions

A CBPR-informed PA intervention empowered women from a disadvantaged neighborhood to become physically active and remain physically active even during a novel pandemic. Thus, the intervention seemed to have had a positive effect on how women coped with both chronic diseases and newly emerged infectious diseases such as COVID-19. Furthermore, it can be concluded that community-based resources, particularly social support and trust, are critical for promoting wellbeing and resilience among communities living in disadvantaged neighborhoods. Future research must focus on developing community-based initiatives catering to local needs by actively engaging citizens in the research process and thus empowering communities to become resilient in the face of emerging crisis.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

Ethics statement

The initial part of this study was approved by Regional Ethical Committee in Lund (DNR 2018/384) and the focusgroups that happened during the COVID-19 pandemic was approved by the Swedish Ethical Review Authority (DNR 2020-04063). The patients/participants provided their written informed consent to participate in this study.

Author contributions

RR and MR moderated the focus group discussions. AK and EC had the role of observers during the focus group discussions. RR, EC, and MR analyzed the data independently and later discussed it together. AK read the transcripts and reconfirmed the findings. RR wrote the first draft of the manuscript. All authors participated in the design of the study, revised, read, and approved the final version of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Engaging Community Health Centers to understand their perceptions and interest in longitudinal cohort research on diabetes mellitus in Native Hawaiian communities: Initial insights from the Waimānalo community

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Introduction: Despite decades of research on diabetes mellitus (DM) and other health disparities affecting Native Hawaiian and Pacific Islander (NHPI) populations, little is known about the disease mechanisms that underlie these health disparities. Ideally, a longitudinal cohort study is one of the best research design tools to examine underlying mechanisms of disease in health disparity conditions such as DM. The study purpose is to understand the perspectives and insights of people ($n = 29$) living in NHPI communities about conducting longitudinal cohort studies aimed at understanding mechanisms of health disparities in NHPI populations.

Methods: All interviews were audio-recorded, transcribed and de-identified into written transcripts for thematic content analysis.

Results: Four major themes emerged: 1) Diabetes and other **health disparities is a community priority** because these diseases touch nearly everyone; 2) Cohort-type research and its outcomes should extend beyond data collection to include **data sharing using a cultural context approach**; 3) Cohort-type research can **directly benefit everyone, especially youth, through education** on new, locally-derived knowledge; 4) A longterm benefit of cohort-type research should be to support **"generational change" in the community**.

Discussion: In summary, potential "cohort-type research" (a.k.a. longitudinal cohort study designs) was perceived as a worthy endeavor because health disparities, such as DM, affects nearly everyone in

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the community. Cohort-type research is important to NHPI communities as it holds promise for impacting "generational change" on health and wellbeing through the sharing of new community-derived knowledge.

KEYWORDS

community-based participatory research (CBPR), Native Hawaiian, Pacific Islander, cohort study perceptions, qualitative research, diabetes mellitus

Introduction

Type 2 diabetes mellitus (DM) remains a major health disparities problem among Native Hawaiians, Pacific Islander People (NHPI), and racial/ethnic minority populations in the USA (1, 2). To confront the health burden of DM and health disparities in Hawai'i, especially among the NHPI population, several community organizations joined the Ulu Network beginning in 2003 and partnered with academic-based researchers from the Center for Native and Pacific Health Disparities Research (CNPHDR) at the University of Hawai'i at Mānoa, John A. Burns School of Medicine's Department of Native Hawaiian Health to work together with a common goal of reversing health disparities prevalent among the Center's priority populations, including NHPIs.

The Ulu Network is a voluntary coalition of 35+ organizations who have partnered with the CNPHDR to reduce health disparities in ∼70+ locations throughout the State of Hawai'i and Southern California (Figure 1). Extensive collaborations between Ulu Network and the CNPHDR includes: >50 community-directed health education and training workshops, 12+ peer-led health education interventions implemented in the communities they serve. The community-engaged activities included knowledge exchange (e.g., community as part of the scientific team), technical assistance (e.g., data collection, etc.), shared resources (conference sponsorship, program materials, food models, etc.) and actual program funding (i.e., Ulu dissemination awards, etc.). Over the years, these bi-directional, community-led projects have been an overwhelming success to build capacity across the Ulu Network members and the empirically-tested programs have been used by trained community-peers with remarkable fidelity and consistency resulting in positive clinical improvements and successful skill-building of community-based peer-educators (3–7). Today this relationship remains a vibrant, synergistic partnership that has enabled the development of new collaborations both within and external to the CNPHDR, across other academic units at the University of Hawai'i and have also sparked other community-to-community collaborations (5).

Yet, despite the years of successful community engaged research, training and dissemination programs, a number of Ulu Network organizations continued to struggle with the growing burden of DM in their communities, especially with the rising prevalence of obesity and DM in youth (2, 8–10). Indeed, recent national studies showing a decline in DM incidence in the USA highlights the growing gap between most minority populations and whites in the USA. Moreover, multiple studies have shown that DM onset and complications continue to occur at younger ages (10–15 years younger) compared with their white counterparts (11–14). Thus, the health inequity gap continues to widen despite health benefits realized by primarily USA whites.

In September 2016, all 14 Federally Qualified Health Centers (FQHCs) of the Ulu Network were invited to a meeting to specifically discuss the future plans of how best to address diabetes disparities that were occurring in Ulu Network communities. The idea of developing a new longitudinal, observational cohort study of NHPIs with community-led organizations was openly discussed and debated. The overall purpose for creating a new "first of its kind" longitudinal cohort of NHPIs was to enhance our capacity to increase understanding of mechanism of disease, investigate risk exposures and resilience factors in NHPIs prior to onset of DM and associated complications which would, in turn, inform future interventions or programs. Many of the FQHC representatives raised important questions about how such studies were desperately needed and how it would impact their communities and clinics. Some FQHC representatives expressed concern that research studies without direct health programs to benefit communities would be challenging and less favorable. While other FQHC representatives were willing to explore the possibilities of developing a research resource, such as a "prospective, longitudinal observational cohort study," to better understand the underlying cause of common health disparities in their community. All attendees were aware of the tremendous effort it would take to develop, establish and sustain a longitudinal cohort study drawn from NHPI communities and the expenditure of time and funding. After ∼3 months of

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Abbreviations: CNPHDR, Center for Native and Pacific Health Disparities Research; DM, Diabetes mellitus; FQHCs, Federally qualified health centers; NHPI, Native Hawaiian and Pacific Islanders; UH, University of Hawai'i; WHC, Waimānalo Health Center.

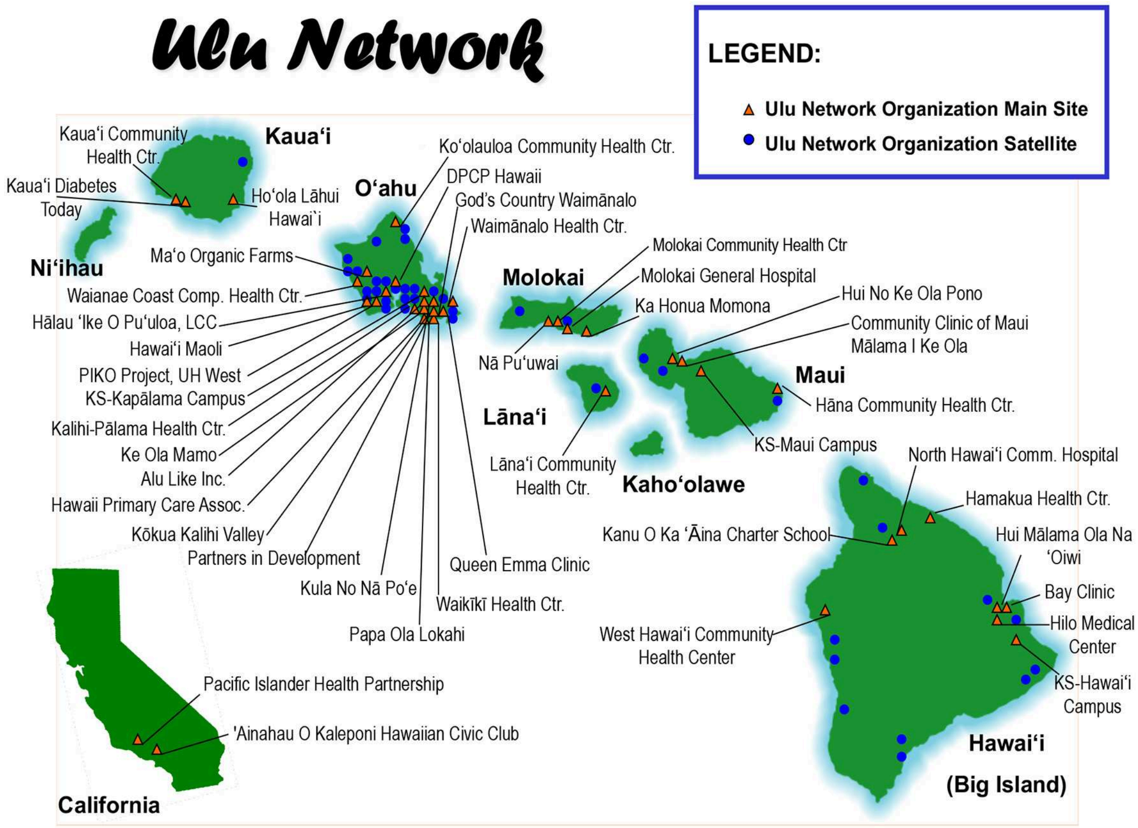

FIGURE 1
Center for Native and Pacific Health Disparities Research's map of the Ulu network community-based organizations in the State of Hawai'i and Southern California.

ongoing dialog and communications with Ulu Network FQHCs, a single FQHC, Waimānalo Health Center (WHC), remained willing and able to take next steps to actually collect data from their community members to gain a deeper understanding of what the Waimānalo community thought about longitudinal "cohort-type" research focused on NHPI health disparities such as DM.

The purpose of this study was to assess the perspectives and recommendations of a single NHPI community served by the WHC, on the potential for conducting longitudinal, observational cohort designed research with NHPI people to address health disparities, such as DM, in their community.

Methods

Study setting

This research study was conducted in the community of Waimānalo, located on the east side of the island of O'ahu, in the State of Hawai'i. This is a close-knit, rural community with stunning natural resources from the mountain (*mauka*) to the ocean (*makai*) that make farming, fishing, canoe paddling and other *'āina* (land)-based activities the foundation of Waimānalo's economy and lifestyle (15, 16). The community of Waimānalo values its connection to the *'āina,* the preservation of agricultural lands, and the perpetuation of Native Hawaiian cultural practices (15).

Waimānalo is a clearly defined geographic community with a population of 6,278 (16). The population demographics reflects a median age of 34.2 years, 15% of individuals are below the poverty level, 3% are unemployed, and 4% are uninsured (16). Thirty percent (30.2%) of the residents in this community are Native Hawaiian and/or Pacific Islander ancestry (16).

This study was co-designed by academic-based researchers (MKM, NKBM, KW) of the CNPHDR and WHC clinical leadership (MFO) and audio recorded and officially transcribed into a redacted written format.

Participants

Purposive sampling was used to recruit participants from the larger Waimānalo community using email, written invitation, or personal contact. Key informants were recruited from attendees at the WHC's established cultural classes and from leadership at Waimānalo community organizations, including the Waimānalo Neighborhood Board and Hawaiian Homestead Association. Focus group participants were recruited from attendees at the WHC's established cultural and diabetes prevention/self-management program classes. Open recruitment from interested community participants who heard about the study, but were not WHC class attendees, were also invited to participate in one of the scheduled focus groups. Key informant interviewees were not eligible for participation in the focus groups and vice a versa. Eligibility criteria included (a) age 18 years or older, (b) resident of the Waimānalo community or a member of a faith-based, health-based, or grassroots community organization located in Waimānalo. Participation in the focus groups and key informant interviews were not limited to only NHPI. Although the intention of the study was to explore the idea of a longitudinal cohort study to address DM in NHPI, the community that the cohort study would be situated in, is comprised of a diverse mix of racial and ethnic groups. Non-NHPI individuals included in the study have deep and longstanding ties to the Waimānalo community through their years of participation in community-based organizations.

Study procedures

Focus group and key informant interviews were conducted by WHC staff and administrative leadership according to protocol using a single prepared moderator's guide (see Supplementary material). All interviews were audio recorded and transcribed. The transcripts were independently coded and then collaboratively reviewed to determine consensus by two academic-based (MKM, NKBM), one "hybrid" academic-community-based (KW) and two community-based members (MFO, CSH) of the research team. Thematic analysis was conducted through a common template in which the reviewing community-based researcher identified key words or phrases related to specific questions asked of participants, then identified the theme related to those responses (17). All participants gave written informed consent prior to any data collection. This study was submitted for IRB approval and deemed exempt by the University of Hawai'i (UH) Committee on Human Subjects.

Moderator guide

The introduction to interview questions included a basic description of the different common types of research study designs (i.e., observational (e.g., non-interventional), clinical trials (e.g., testing an intervention, etc.) with a specific focus on a longitudinal, prospective, observational study design we referred to as "cohort-type" research. We provided brief descriptions in plain-language about how data is generally collected in longitudinal, cohort-type research and what kinds of data are often collected including biospecimens preserved for future analyses. Participants were generally engaged and enthusiastic about the idea of "cohort-type" research and asked questions to the moderator or interviewer to better understand the study process and then proceded with the moderator guide questions. According to protocol, focus groups and informant interviews were initiated using a cultural "talk story" approach to stimulate conversation and to establish a comfortable, "safe" place in which participants could share their opinions and provide feedback without recourse (see Appendix: Description of a "Cohort Study" and Moderator Guide) (18).

Analysis

Written transcript of the audio recorded interviews (focus group and informant) were initially reviewed independently by the research team members and then collated by group discussion, using inductive and deductive approaches to reach group consensus. Initially, all members of the research team reviewed the transcripts to familiarize themselves with the data. During the first round of coding, research team members identified codes that were categorized by the broad themes explored in the interview guide topics: understanding of research designs, culturally-appropriate handling of biospecimens, community engagement, and thoughts surrounding a community/academic partnership. Following the first round of coding, the research team met to discuss, define, and refine themes. A second round of coding identified key words and phrases reflecting the refined themes. We performed synthesized group member-checking to enhance trustworthiness of the data ∼6–9 months following data collection. Participants were invited to share their opinions on the summarized data presented and their reflections are incorporated into the final results.

Results

Of the 29 participants who volunteered for the study six participated as key informant interviewees and 23 participated in five focus groups. Most were women (72%), NHPI (83%) and age >55 years old (59%) (Table 1). Most (83%) of the participants were long time residents of the Waimānalo community (>15 years) with more than half (52%) of the participants had lived in Waimānalo for >30 years. Nearly three-fourths of the participants (71%) lived in multi-generational households and

TABLE 1 Participant characteristics ($N = 29$).

Characteristic	Key informants $n = 6$ (%)	Focus group $n = 23$ (%)	Total $N = 29$ (%)
Age (years)			
25–45	2 (33)	5 (22)	7 (24)
46–55	—	5 (22)	5 (17)
56–70	3 (50)	12 (52)	15 (52)
>70	1 (17)	1 (4)	2 (7)
Gender			
Female	3 (50)	18 (78)	21 (72)
Male	2 (33)	5 (22)	7 (24)
Trans-Female	1 (17)	—	1 (3)
Race (self-reported)[a]			
Native Hawaiian, Pacific Islander	6 (100)	18 (78)	24 (83)
White	—	4 (17)	4 (14)
Asian	—	1 (4)	1 (3)
Marital status[b]			
Married	2 (33)	11 (48)	13 (45)
Not married	4 (67)	12 (52)	16 (55)
Years living in Waimānalo community			
≤15 Yrs	—	5 (22)	5 (17)
16–30 Yrs	2 (33)	7 (30)	9 (31)
31–50 Yrs	4 (67)	4 (17)	8 (28)
More than 50 Yrs	—	7 (30)	7 (24)
Number of generations in household[c]			
One	2 (33)	6 (26)	8 (28)
Two	1 (17)	3 (13)	4 (14)
Three	3 (50)	7 (30)	10 (34)
Four	—	6 (26)	6 (21)

[a] NHPI, Native Hawaiian, Pacific Islander. [b] Not married = single, divorce/separate, widow, etc. [c] Total responses = 28 due to one missing response.

more than half (55%) lived with 3–4 generations residing in the same home. There were a few notable differences between the key informant and focus group participant demographics. All of the key informants were NHPI, one-third (33%) were 25 to 45 years old, and none were extreme-longtime (>50 years) residents of Waimānalo. Whereas, in the focus groups, a substantial percentage (78%) were NHPI, less of the focus group were 25 to 45 years old (22%) and nearly one-third (30%) were extreme-longtime (>50 years) residents of Waimānalo.

Four major themes and nine sub-themes (Table 2) emerged and are summarized as:

(1) **Diabetes health disparities touches the lives of nearly all participants.** *Need to learn more about DM and especially "new" information and "new ways" of improving DM care.*

Participants recognized that diabetes is a "wide spread problem" in their community. Cohort-type research could be a tool to learn more about how to prevent and address diabetes in an impactful way. Nearly all participants shared personal experiences related to living with DM in their own lives, their parents, grandparents, and/or their childrens lives. While participants were eager to know more about DM to affect the next generation, they yearned for "new" information and "new" ways of addressing DM. Educating youth on this new information gathered through this "new" approach to research could be carried out in many places such as schools, churches, or at home.

(2) **Research needs to extend beyond the observational data collection to include cultural activities, values and build upon community resources.** *Research should include data sharing as well as data collection.*

Participants felt that any research in their community needed to go beyond data observations only to include cultural and traditional activities such as storytelling and relationship building opportunities with researchers to educate the community about how and why research is done and to share new findings. Further, opportunities to build upon existing community resources, such as schools, churches, senior housing, neighborhood boards, social clubs, and other healthcare resources, would enhance participation and retention.

TABLE 2 Summary of Waimānalo Community's perspectives on "Cohort-type" Research aimed at Diabetes Health Disparities in Native Hawaiian and Pacific Islander Populations.

Themes / sub-themes	Participant quotes
1. Diabetes health disparities touches the lives of nearly all participants	
Diabetes longstanding impact on multiple generations and race/ethnic groups	[A] cohort study [that] concentrate[s] on diabetes... would be a great benefit...because... it runs pretty deep in not only Pacific Islanders, but Asians and Native Hawaiians... I can speak from personal experience that it exists on my paternal side., so... any research related to this disease and how it could... potentially alter our childrens [risk for diabetes is good]
New and improved diabetes information is needed to be effective	... it would only be effective if the right information was given out.... There needs to be new information, new ways, new awareness
2. Research needs to extend beyond observational data collection to include cultural activities, values and build upon community resources	
Recommendations for data sharing	I would really suggest against just mailing things to people. If there is some kind of interaction between the cohort, that would make it real personal. That would make it more exciting, just engaging relationships
Community approaches to data collection	Food would be a culturally appropriate method of collecting data because it draws them in... If there's an educational aspect or actual hands on something or other. If it's just data collection, sometimes it might be harder to have the participants keep coming
3. Direct benefits of research in the community should include education to families and youth	
Sharing new knowledge with youth	. . . Even in the schools, why not talk to them about... [diabetes], because they experience it through their families. They see family [members] die from it, lose limbs, and they don't understand it. Why can't they teach them that in school?... you need to take care your health, you know this is important
Healthy nutrition resources (access, cooking, etc.) at school translate to home environment	...For the children of Waimanalo, access to food is important, and if the schools can be a breeding ground for [learning about] healthy eating, it potentially could translate at home... Substitute like ʻulu (breadfruit) or kalo (taro) for potato and have those types of cooking demonstrations. Make food more innovative, different approach to see how food is utilized instead of the normal beef stew, is there something we can use instead of beef or make it just all vegetables; instead of using potatoes, you have kalo, . . .
Sharing new knowledge within cultural context	Using "olelo Hawai'i or even just ma ka hana ka "ike (in working, one learns), having that interaction and seeing it happen, just knowing
4. Research should support "generational change" that communities can implement themselves	
Investment in the health of future generations	... it's for the future generations, so really,... you have to think about your kids, think about your grand kids, you know what I mean? Think about the kids in the community because when you talk about kids, that's important. That's like our basis of living, we all work to support our kids I hope that they are able to be changed, have a different type of eating pattern or eating behaviors from previous generations as we have known the different health disparities that we are facing because of whatever foods or even environment that affects us I would like to see the [diabetes] spiral stop. It continues, and I see that it is really difficult to change... Especially in community, because of what's around you. I have tried, I have really tried to change just small little changes, you know, brown rice for white rice at our agency and the pushback is just so amazing
Self-sustaining health that communities can do for themselves	Self-sustainability is important to... health, so learning more about growing [our] own food and [our] own medicine. I know my goal for our community is to become self-sustainable with healthy food and understand more about our herbal medicine which is my goal for my family too

(3) **Direct benefits of research in the community should include education to families and youth.** "*Cohort-type" research should directly benefit the community through sharing of new knowledge with everyone... especially youth.*

Community participants felt that initial and sustained community participation would require efforts to influence behavior changes, keep participants motivated, and provide "direct benefit" to the community. The type of activities needed to meet this expectation might be considered "atypical" for cohort studies in the past and examples included education to families and especially youth through schools, hands-on experiences, and new information that can be applied within the community to improve and prevent DM. Outreach to and collaboration with individuals, community leaders, and key community groups about education were recommended as a means to gain sustained support.

Participants were especially enthusiastic about the possibility of a different kind of cohort-type research that could be more culturally appropriate, based on relationships, and be inclusive of community training and the integration of cultural values and practices. Examples shared included the use of *'Olelo Hawai'i* (Hawaiian language), *mo'olelo* (storytelling) to communicate research findings, and perhaps cooking demonstrations or planting and harvesting of homegrown foods.

(4) **Research should support "generational change" that communities can implement for themselves.** *Support "generational change."*

A cohort-type study should use its research findings and information to support community-led "generational change" that they could implement themselves. The participants wanted to see this future generational change translated into "useable forms of information" to promote healthy eating habits, affordable foods and growing their own food to become self-sustainable to make it affordable for everyone. Participants expressed that breaking-up of old patterns of inter-generational eating that is unhealthful, is critical to self-sustainability and a thriving community.

Discussion

This initial study enabled us to explore the opinions, perspectives and insights of a single NHPI community on the idea of research that, by design, is observational in nature and aimed at understanding disease mechanisms of DM, as identified by the community as an important health disparity. We learned that the community participants understood the scientific importance of a "cohort-type" study and were enthusiastic about conducting this type of research because it offered the possibility of creating new information and approaches for a serious disease in their community. Yet, the "how" of implementing this type of research within NHPI communities, such as theirs, was viewed as equally important to its success as much as the science itself. Much of the subsequent discussion focused on potential recommendations to help create and sustain a potential "cohort-type study" with a focus on their own community. Waimānalo community participants recommended that any new knowledge gained from research to elucidate underlying mechanisms of DM risk and health disparities among NHPIs, be shared first with everyone in the community, especially youth. Information should be conveyed in plain language to educate and remind the community organizations of its vital part in supporting the research results. The need for NHPI-specific data that would improve their risk for reversing current DM trends was noted as a high priority. Concern for sustaining the "cohort-type" study long enough for it to provide new information and possible breakthrough discoveries was an important concern. Recommendations on sustainability from the Waimānalo community included integration of community resources, cultural practices and values in recruitment and retention efforts as key factors for maintaining community participation in the research. This holistic approach of how the community perceived the potential for cohort-type research was also expressed in their hope for the findings of this type of research to benefit future generations of people in their community and to promote positive generational change to reverse health disparities, including DM, in the future. Thus, the emphasis on educating, especially youth, from the community about how best to reverse DM trends by using new information and discoveries produced by cohort-type studies on DM disparities especially in community environments like their own.

In summary, we were encouraged to learn that despite known historical and cultural trauma invoked by research studies performed on NHPI communities in the past, the overriding theme expressed by the participants of this study was refreshingly insightful and encouraging. We learned that longitudinal, "cohort-type research" was viewed as valuable to understanding and gaining new knowledge about DM in NHPIs. What we learned is that the Waimānalo community considered longitudinal cohort research as something valuable enough to provide the research team with recommendations on the process of implementing a cohort study. They proposed a relatively "new" idea about "cohort-type research" studies actually serving a dual purpose. First purpose acknowledged by the NHPI community members would be scientific discovery of a well-designed, longitudinal, prospective cohort study aimed at elucidating underlying mechanisms of DM disparities in NHPIs and other high risk populations. Secondly, that although "cohort-type" studies do not typically provide community outreach and dissemination programs, a potentially "new model" of longitudinal cohort studies designed to serve a dual role of knowledge sharing with the "targeted popuation" as part of the ongoing retention activities. Our study suggests that this type of "knowledge sharing" could take the form of educating youth in schools about DM and how the research being done within the Waimānalo community was contributing to growing "new research" discoveries.

Our results are consistent with prior studies conducted in other understudied, health disparate minority populations for whom participation in longitudinal cohort studies have been challenging and poorly delineated (19, 20). Herring et al. (20) conducted focus groups among Black Seventh-Day Adventist church members and found similar barriers to longitudinal cohort studies including lack of any intervention programs or sharing of study results or information to the community. Our study contributes to the existing literature by confirming similar issues in another understudied, health disparate population (i.e., Native Hawaiians and Pacific Islanders). However, in contrast to prior studies, this project was undertaken within a context of a pre-existing longstanding relationship and with the foresight and intent of understanding the communities' genuine concerns and preferences on observational longitudinal cohort research prior to any grant funding. Indeed, much of the existing literature describes challenges and "lessons learned" after funding has already occurred and when enrollment of minority populations may have fallen short (21, 22). We were intentional in our approach for this study by approaching all 14 Ulu Network CHCs to consider the concept of a longitudinal cohort study prior to any funding as the means for sharing of information and building trustworthy relationships. While this study did not explore the reasons for why the other CHCs declined participation, we expect to share our initial findings to the other CHCs to determine their perceptions about longitudinal cohort research. Thus, our study is a first step and a demonstration of how the context of longstanding trustful relationships are the foundation to community engaged research that seeks inclusion of health disparate, understudied populations such as NH and PI and other marginalized populations in the USA.

Of note, we also recognize limitations of our study, including that our results are from a single NHPI community and thus may not be generalizable to other communities at similar risk. We also acknowledge the limited participation of males ($n = 7$, 24% of total) and individuals between 25 and 45 years of age (24% of total) which suggests caution in generalizing our results across genders and younger (<45 years old) age subgroups. However, we are encouraged by the initial results from the WHC community which is largely NHPI and rural and often mistrustful of research in general. In this study, the participants were diverse and remarkably open to the potential for new types of research studies in their community. In fact, at the end of the formative study, the academic-based researchers were invited back to the WHC and attended two community gatherings to share the results, prior to, manuscript submission (i.e., member checking). The academic-based researchers remain committed to continuing the open discussion about how communities can support research and community-engaged scientists to uncover new discoveries, i.e., underlying mechanisms of DM, a common, persistent and in some cases devasting disease in this and other high risk communities. Our team as a whole felt reasurred that at least for this community, education to youth was a key output of the research and we anticipate engaging other Ulu Network members to learn about their perspectives on the value and suggestions for establishing and sustaining a non-interventional, longitudinal cohort study aimed at health inequities, such as DM, in NHPI communities.

As we move forward with this effort, we intend to build upon our longstanding relationship with Ulu Network members and to specifically invite health care providers such as the FQHCs as they serve as a safety net for any participants who may need medical services for conditions uncovered during the course of research. Inclusion of other indigenous scientists with expertise in genomics, epigenomics and observational epidemiology areas of science may also provide additional insight on "native-driven" models of prospective longitudinal study design. In the end, we anticipate that it will be our longstanding relationship with our NHPI communities (i.e., Ulu Network) which have been built on longstanding trust as the foundation to create a new paradigm for the potential of the first, longitudinal, prospective study on DM risk and health disparities in NHPI communities to be co-led by community and academic leaders as equal stakeholders.

Author's note

The content is solely the responsibility of the authors and does not represent the views of the National Institutes of Health.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, upon request and approval.

Ethics statement

The studies involving human participants were reviewed and approved by the University of Hawai'i Committee on Human Subjects. The patients/participants provided their written informed consent to participate in this study.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.1035600/full#supplementary-material

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Rochester Healthy Community Partnership: Then and now

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Community-engaged research partnerships promote health equity through incorporation of regional contexts to inform partnership dynamics that shape research and interventions that reflect community voice and priorities. Long-term partnerships build trusted relationships and promote capacity building among community and academic partners, but there are many structural barriers to sustaining long-term partnerships. Here we describe lessons learned from sustaining Rochester Healthy Community Partnership (RHCP), an 18-year community-based participatory research (CBPR) partnership in Southeast Minnesota. RHCP collaborates with immigrant and refugee populations to co-create interventions that promote health equity for community health priorities. Challenges to sustainability include a tension between project-based funding and the needs of long-term community-based research infrastructure. These challenges can be met with a focus on shared CBPR principles, operating norms, partnership dynamics, and governance. RHCP began in 2004 through identification of a community health priority, defining the community, and establishment of CBPR principles. It grew through identification of broader community health priorities, capacity building for community and academic partners, and integration of diverse learners. We describe the capacity for RHCP to respond to new societal contexts, the importance of partnership dynamics as a barometer for partnership health, and lessons learned about sustainability of the CBPR partnership.

KEYWORDS

community-based participatory research, sustainability, immigrant health, health equity, health promotion

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Introduction

In 2004, a community-academic partnership developed between Mayo Clinic and an adult education center that serves new immigrants and refugees. Rochester Healthy Community Partnership (RHCP) matured by formalizing operating norms, adopting community based participatory research (CBPR) principles, and adding partners from multiple sectors. RHCP has developed an effective community-based research infrastructure that has facilitated extensive research training for community partners. RHCP community and academic partners have co-created several initiatives that addressed community priorities and contexts (Table 1). RHCP has adapted an empirically derived CBPR conceptual model through in-depth evaluation. Community and academic partners jointly conduct every phase of research including disseminating results, implementing sustainability plans, and co-authoring scientific products.

In this manuscript, we describe the mechanics of starting and sustaining a longitudinal CBPR partnership as experienced by RHCP community and academic partners over the last 18 years. We describe the tension between the biomedical emphasis of funders and the social structure of participatory work and implications for partnership infrastructure. We describe lessons learned about partnership dynamics in the course of conducting specific RHCP projects and responding to specific societal and regional contexts.

RHCP then: Lessons learned from starting a CBPR partnership

Identification of a community health priority and definition of community

Rochester Healthy Community Partnership (RHCP) started in 2004 as a partnership between clinician-researchers at Mayo Clinic in Rochester, an academic medical center in Minnesota, and Hawthorne Education Center (HEC), an adult education center within Rochester Public Schools serving diverse immigrant and refugee communities in Rochester, Minnesota. The impetus for the partnership arose from HEC's concern for tuberculosis (TB) among its learners and in an effort to understand why an established TB prevention and control program was ineffective among its learners. Several cases of active TB had been diagnosed among learners, prompting an environment of fear and TB-related stigma. Previous attempts at voluntary TB screening had very low participation. HEC staff (JAN) approached Mayo Clinic with this concern through a volunteer (JAW), who connected with a TB physician specialist (IGS). Additional HEC and Mayo Clinic staff were engaged, and it became clear that another top-down approach was unlikely to be successful. The team collaboratively explored targeted TB evaluation and developed innovative ways of effective communication of health information, while at the same time, building community trust and capacity to participate in the research process. The team recognized that this approach aligned with CBPR principles (14). Community and academic partners took CBPR coursework together, and this process planted the seed for what would later become RHCP.

Utilizing a CBPR approach, this community-academic team discovered several factors related to knowledge and perceptions of TB, which contributed to avoidance of discussing TB, and unwillingness to participate in screening (15). This led the team to design a community-led TB education and screening program which was implemented at HEC. The program was successful in terms of educating learners and staff and improving screening and treatment rates (1). The program was subsequently incorporated into ongoing HEC processes and has been sustained for several years (2).

Adoption of CBPR principles and operating norms

The HEC-Mayo Clinic partnership established connections with the larger community, engaging additional community and academic partners. Partners discussed an ongoing research partnership to address priority health issues of local immigrant and refugee communities. Thus, RHCP was formed. The mission of RHCP is to promote health and wellbeing among the Rochester population through CBPR, education and civic engagement (www.rochesterhealthy.org). In 2007, through a series of meetings and discussions, the partnership matured by formalizing operating norms, adapting CBPR principles (Figure 1), adding dedicated partners from multiple sectors, conducting community health assessments, and discussing potential CBPR projects. Project-specific work group meetings of community and academic partners occur every week and full partnership meetings occur bi-monthly. Community and academic partners conduct every phase of research and programming together and disseminate research results jointly at community forums and academic meetings.

Challenges of CBPR partnership initiation

RHCP began in response to a specific community concern and without funding. The lack of funding had benefits and drawbacks. The benefits were that community partners were able to drive the agenda to fully align with health priorities, and the process of partnering without money selected for community and academic partners who were fully dedicated to health equity and authentic community engaged research. The challenges of starting the partnership without funding included a relatively slow pace of work that depended on significant volunteer time and a way of working that may unintentionally exclude community partners with socioeconomic constraints to volunteerism as well as junior faculty members who are under pressure to generate grants and publications at a rapid rate. These challenges were overcome through work with a relatively

TABLE 1 Examples of RHCP initiatives.

Title	Description	Funding	Outcomes
Let's talk about TB	**Background:** High incidence of tuberculosis (TB) in Olmsted County, disproportionately affecting refugees **Approach:** Opened a community-wide dialogue around the issue; Described perceptions of TB and its prevention among recent immigrants and refugees	National Institute of Allergy and Infectious Diseases (R03), 2008–2011	Defined prevalence of TB and established an effective community-owned process for screening at an adult education center (1). Sustainably changed TB screening policy for at-risk populations (2).
Healthy immigrant families	**Background:** There is a steep accumulation of cardiovascular risk after immigration **Approach:** Community-derived family-focused culturally-appropriate intervention to improve dietary quality and physical activity among immigrant and refugee families (randomized trial)	National Heart, Lung, and Blood Institute (R01), 2011–2018	Improved dietary quality but not physical activity at 12 months (sustained at 24 months) (3, 4).
Healthy immigrant community	**Background:** There is a steep accumulation of cardiovascular risk after immigration **Approach:** Assess the efficacy of a social network-informed CBPR-derived health promotion intervention on measures of cardiovascular risk in two immigrant communities through this process: Social network analysis → intervention development → pilot test intervention → cluster randomized trial	National Institute on Minority Health and Health Disparities (P50, embedded R01-level project), 2021–2026	Social network analysis with Somali and Latinx communities completed (5, 6). Pilot of the intervention showed reduction of cardiovascular risk (7). Cluster randomized trial is underway.
Club fit	**Background:** Higher rates of overweight among children from low-income households **Approach:** Multi-component healthy eating and activity intervention (policy and practice) at a Boys & Girls Club	Mayo Clinic, 2014–2016	Improved motivation and confidence for healthful behaviors among at-risk youth (8).
Stories for change: diabetes	**Background:** Diabetes has been a RHCP community concern for many years and disparities are significant among Somali and Latinx groups **Approach:** Co-creation of a digital storytelling intervention for diabetes self-management	National Institute of Diabetes and Digestive and Kidney Diseases (R01), 2018–2023	Improved glycemic control among participants who viewed the digital storytelling intervention (9, 10). Randomized trial of efficacy is near completion.
Closing the gap: reduction of cancer prevention disparities	**Background:** People with limited English proficiency (LEP) receive fewer recommended preventive cancer screenings than English-speaking patients, leading to detection of disease at later stages and higher disease-related death than patients who speak English well **Approach:** RHCP-clinic collaboration to open community dialogue; develop and test clinic and community-based interventions	Mayo Clinic, 2018–2023	Pilot test of clinic-based intervention underway (11). Digital storytelling intervention developed with Latinx participants for colorectal, breast, and cervical cancer screening.
COVID-19 community-engaged crisis and emergency risk communication	**Background:** Data emerged around COVID-19 health disparities in early 2020. Credible COVID-19 messages were not reaching immigrant communities with limited English proficiency **Approach:** RHCP developed a community-engaged bidirectional risk communication framework to disseminate COVID-19 information and inform policy makers	Mayo Clinic, 2020–2022	Pilot and implementation studies have demonstrated feasibility, acceptability, reach, 18-month sustainability, scalability and perceived effectiveness of a bidirectional COVID-19 CERC intervention across multiple groups disproportionately affected by the pandemic (12, 13).

small coalition initially that focused on building partnership principles and operating norms. This foundation paved the way for a more sustainable partnership once initial funding was secured.

RHCP then: Moving from project to partnership

Identification of broader community health priorities

RHCP has developed an effective community-based and community-led research infrastructure that facilitates extensive research training for partners and deploys data-driven programming among immigrant populations. RHCP first obtained extramural funding from the National Institutes of Health in 2008 for Let's talk about TB to strengthen the CBPR partnership through developing a culturally sensitive health literacy infrastructure for immigrant populations. In 2011, RHCP received funding for Healthy Immigrant Families to test a family-based intervention to preserve dietary quality and physical activity after immigration. This was followed in 2018 with funding for Stories for Change—Diabetes, a digital storytelling intervention to improve diabetes self-management and outcomes among immigrant populations. In 2021, RHCP was awarded funding for Healthy Immigrant Community to

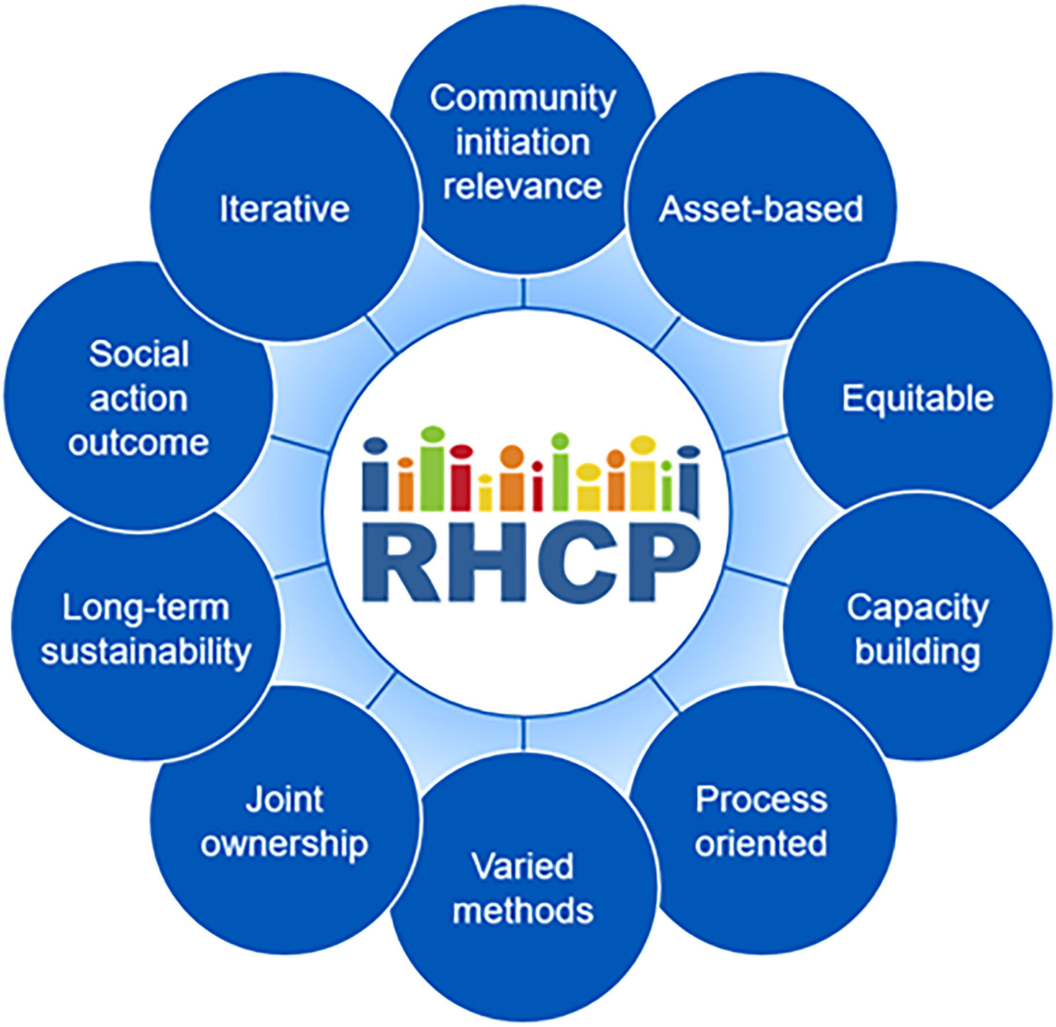

FIGURE 1
RHCP CBPR principles.

foster sustainable health promotion for Southeast Minnesota immigrant communities (Table 1).

Co-learning: Community and academic capacity building

Community and academic partners jointly conduct every phase of the research and disseminate research results together at community forums and academic meetings as well as co-authorship on scientific publications and presentations. For community members to fully participate as equal partners and share power over the research process, Mayo Clinic provides training in the protection of research participants, and opportunities for community research capacity building (16). This includes sessions or classes in CBPR, research design, evaluation, and survey implementation. Mayo Clinic sponsors and facilitates formal workshops attended by both community and academic partners in an environment of co-learning. These workshops have included training in CBPR, focus group interviewing and analysis, and digital storytelling (17). Additionally, during the formative stage of the partnership, RHCP organized symposia (2007, 2008) and workshop (2010) attended by both local and national experts in community engagement and community engaged research, bringing communities and researchers together to promote CBPR.

Challenges of building a longitudinal CBPR partnership

RHCP's move from a project-focused initiative to a community-wide CBPR coalition met with several challenges.

First, new community and academic partners who reached out to RHCP required training on CBPR, basics of study design, ethical conduct of research, etc. Without an infrastructure to support this work, these activities required significant discretionary effort on the part of partners. After learning about the CBPR approach, many potential community partners chose not to participate or disengaged with the work. The primary driver of disengagement early on centered on the tension between research and service. Many community partners and community-based organizations are socialized to partner for the exchange of social services to promote community health, rather than for research. It was imperative for RHCP to be clear that, while social services were often tied into co-creation of interventions, service delivery was not the primary strength or niche of the partnership. It was also important to emphasize that CBPR is not the best approach for all social or health problems. Instead, the focus of RHCP is to rigorously employ research methods through a CBPR approach to impact social change for health equity. This clarity resulted in a smaller coalition of partners than may have been achieved through a broader mission, but it allowed RHCP to thrive through focused action among aligned partners with clear expectations.

Second, the growth of RHCP from project to partnership occurred during a gap in funding that once again challenged the resultant volunteerism of community and academic partners. But, the foundation laid and early partnership successes paved the way for more diverse intramural and then extramural funding opportunities.

Finally, the range of community priorities as identified by the broader RHCP coalition required content expertise beyond the range of the founding academic partners. To meet these needs, RHCP academic partners have systematically engaged content experts from Mayo Clinic and outside academic institutions to fill these gaps. This requires careful onboarding of content experts who are often not used to working in community engaged contexts.

RHCP now: Lessons learned from sustaining a CBPR partnership

Biomedical by name and social by structure

There is an inherent tension that exists between structures of funding and structures of CBPR partnerships. Federal agencies that fund late translational research have become increasingly accepting of participatory approaches to shape intervention development, implementation, and dissemination. Indeed, it is an expectation that investigators describe engagement strategies for community-based and health systems research. However, funding largely remains project-focused rather than partnership-focused. This results in community and academic budgets that target project milestones at the expense of increasing partnership infrastructure needs. Project-specific tasks reflect the biomedical imperative of the intervention (glycemic control, body mass index, etc.,). This model works well for partnerships that are organized around a single study or project. But, for partnerships with multiple concomitant projects, the compounded funding has the potential to strain the partnership's CBPR infrastructure, which is inherently social by structure. Partnership (not project) meetings, community engagement activities, orientation of new community partners and volunteers, CBPR and research trainings, partnership evaluation, and communications (website, social media, etc.,) are examples of longitudinal partnership activities that are vital for partnership health but cannot be funded from protocol-driven budgets. This tension suggests an opportunity for funders and institutions to support the infrastructure to build and sustain partnerships in addition to programmatic support.

Integration of diverse learners

While there is growing appreciation for the importance of CBPR and community engagement more broadly, the pathway for training is not self-evident for students and trainees at universities and academic health centers. Learners in public health and healthcare require training to effectively partner with communities to develop and implement strategies that advance health equity and lift up community priorities (19). Best practices for pedagogy around community engagement includes four phases: preparation, action, reflection, and evaluation. These experiences require strong community partners as co-facilitators, a longitudinal trusting relationship between community and academic partners, and careful moderation of reflection/evaluation that centers community context (20). These on-the-ground experiences can be informed or supplemented by existing CBPR curricula (21).

Longitudinal CBPR partnerships like RHCP are uniquely poised to meet these learning needs. RHCP has provided opportunities for more than 500 diverse learners from various disciplines in medicine, nursing, public health, and psychology. For academic partners, these learning opportunities have taken the form of semester-long externships as part of an undergraduate program, month-long research electives for medical students, residents, and fellows, post-doctoral fellowships, and embedded junior faculty experiences. RHCP has also partnered with Winona State University (WSU) for the past 15 years, where undergraduate and graduate nursing students volunteer for RHCP projects under the supervision of WSU faculty who lead reflection and evaluation exercises with their learners. RHCP leaders also ensure that community partners are able to effectively leverage their CBPR experiences to advance their educational pursuits. As an example, four RHCP community partners have gone on to complete medical school and residency training, lending a community-centered lens to their current practice as physicians.

Partnership responses to societal contexts

Longitudinal CBPR partnerships are uniquely poised to respond to unexpected shifts in regional and societal contexts that impact health through trusting collaboration between community and academic partners as well as community capacity for evaluation and data collection. The COVID-19 pandemic laid bare societal factors, rooted in structural racism, that resulted in stark racial/ethnic and socioeconomic disparities in outcomes (22, 23). In March 2020, RHCP community partners recognized that reputable COVID-19 information and resources were not reaching immigrant communities with limited English proficiency. RHCP adopted a crisis and emergency risk communication framework to address COVID-19 prevention, testing, and socioeconomic impacts with immigrant and refugee populations in Southern Minnesota. Partners used bidirectional communication between RHCP Communication Leaders and their social networks to refine messages, leverage resources, and advise policy makers. Pilot and implementation studies have demonstrated feasibility, acceptability, reach, 24-month sustainability, scalability and perceived effectiveness of the intervention across multiple groups disproportionately affected by the pandemic (12, 13). The framework was also adapted by longitudinal partnerships in Minnesota, Florida, and Mississippi (24). This model of leveraging longitudinal CBPR partnerships for their trusting relationships with traditionally marginalized communities in a research and evaluation context is a promising approach for centering community voice in response to health crises.

Partnership evaluation as a tool for engagement and strategy

Since its inception, RHCP has become a well-established, experienced and productive research partnership, and has included multiple academic and community partners. Over this period of 18 years, RHCP has undertaken a wide-range of health-related projects addressing community-identified health priorities, including those focused on infectious diseases, physical activity and nutrition, diabetes management, and pediatric and adult obesity. During this time, the complexity, breadth and scope of projects also increased, which necessitate increased time and investment from all partners to coordinate and implement projects. Thus, a decade after its inception, RHCP members felt the imperative to revisit the partnership's mission and values and conducted a comprehensive evaluation to determine the overall "health" of the partnership, identify factors that contribute to partnership outcomes, and explore options for sustainability. In 2016, RHCP collaborated with the University of New Mexico Center for Participatory Research for technical assistance, guided by their evaluation tools and empirically-derived CBPR conceptual model (25). The four evaluation steps included: Creation of a partnership timeline; Adaptation of the CBPR conceptual model; Mixed method data collection; and, Participatory data analysis (18). The evaluation showed a high level of trust, a community-driven agenda throughout the research process, and partnership processes that were credited with beneficial RHCP outcomes at the individual, program, community, and policy levels (26). The participatory evaluation analysis enabled partners to explore RHCP's history and contexts, to identify factors that contribute to outcomes, and to plan strategically for the future (26) (Figure 2).

Partnership dynamics as barometer and north star

Because CBPR partnerships include long-term, complex relationships between people from different backgrounds, communities, and cultures, trust is an essential ingredient in developing operational guidelines, selecting goals, and conducting research (27). Past research has shown that trust can be facilitated by multi-directional communication and shared decision-making between community partners and academics (28). Trust can be nurtured through the dialogue and reflection essential in a CBPR approach (29). Yet, trust also runs the risk of being fractured by neglecting partnership dynamics (27). Since its inception, RHCP has strategically worked to foster and maintain trusting relationships and used partnership dynamics as a barometer of success. We build trust by opening space for all voices to be heard at meetings, holding group reflections after each event, resolving disputes as they arise, and celebrating our success by sharing meals together. As a result, together we benefit from effective research processes that are culturally appropriate and responsive to the assets and needs of the community.

Beyond relational dynamics, structural dynamics have shaped the long-term progress of RHCP activities, including shared assets and resources as well as long-term commitments from partners. Recent studies have underscored the compounding importance of structural governance and collective empowerment (30, 31). RHCP addresses structural governance through adherence to shared CBPR principles, operating norms, and its CBPR conceptual model in order to ensure that community priorities guide the research agenda, which is evident by the wide range of research topics undertaken by the partnership. RHCP partners have explored the possibility of becoming a legal entity [e.g., 501(c) (3) organization], but have decided against this structure due to the additional infrastructure burdens it would impose. However, this decision results in a potential missed opportunity for more formal governance structures to codify its values and ways of working, which have been important mechanisms of effective structural governance in other contexts (32).

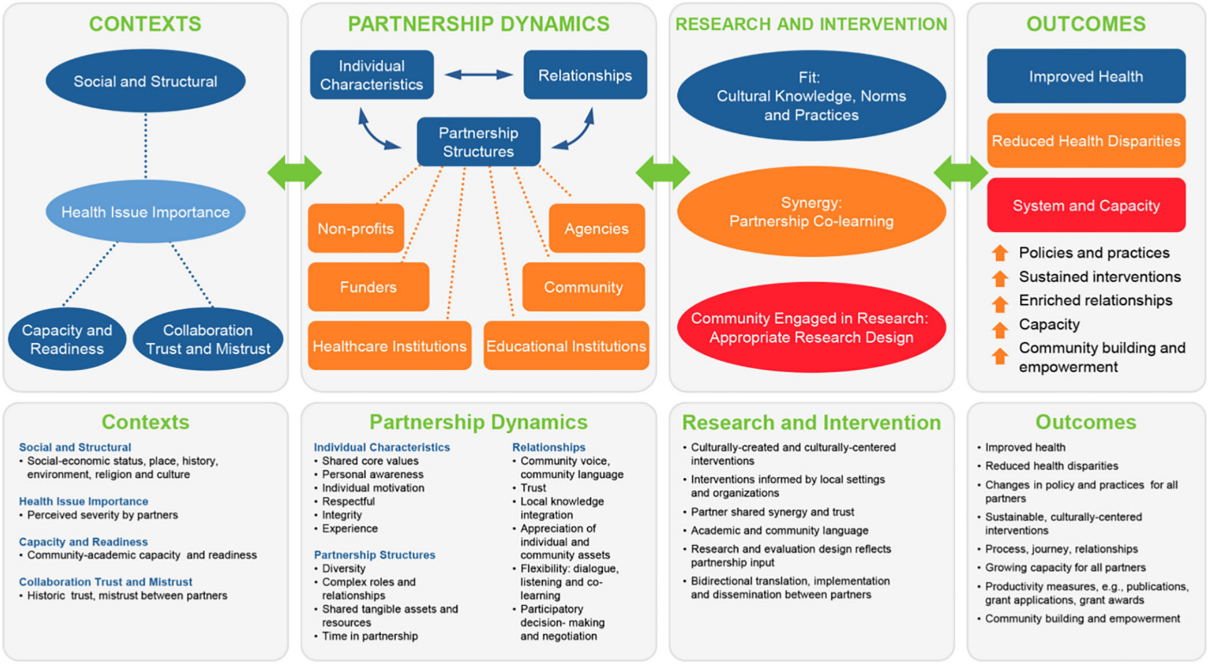

FIGURE 2
RHCP CBPR conceptual model (18).

Lessons learned for sustaining a CBPR partnership

RHCP community and academic partners have learned many lessons on sustaining a CBPR partnership over the last 18 years. Most of these lessons have been born of finding ways to overcome key and frequently faced challenges. First, community-based organizations and advocacy groups engaged in CBPR work are often small, with limited administrative infrastructure, budget and personnel. Yet, these small groups can reflect community voice with grassroots authenticity that is more difficult to emulate in larger organizations. This lack of community infrastructure can be a barrier to consistent engagement, even when these projects are relevant to the communities they serve. Similarly, rapid transitions in leadership and personnel among partnering organizations can lead to a change in partnership relational dynamics, affecting both ongoing and future engagement in CBPR. To overcome these challenges, flexibility in project timelines, both in processes and outcomes, is important, while actively seeking to identify upcoming challenges and brainstorming solutions together. This includes intentional agreement about meeting times and forecasting of competing priorities, holidays, and community events that may impact project timelines. Furthermore, succession planning, meeting alternates, having more than one key person in a community organization, and structural governance help to ensure continuity and reduce the risk of fracturing longitudinal relationships.

RHCP has also experienced challenges to sustainability of academic partners. Despite the rapid growth of CBPR approaches in the US (33), investigators with interest in CBPR often do not appreciate the investment in time (often in "off" hours) and relationship building. For those who are accustomed to traditional research approaches, this focus and commitment can seem time consuming, with results long in coming. In our experience, despite a strong initial interest in becoming an RHCP academic partner, only a relatively few invest in making this a large component of their careers. More intensive investment at the partnership level and institutional level in the small number of investigators dedicated to making CBPR the foundation of their career may be more fruitful than investing in loose ties to CBPR in academic settings.

As noted above, funding is often project based, leaving no specific support for administrative and partnership infrastructure. Frank and open discussions among all partners around funding and finances is critical for trust-building and sustainability. Commitment by partners in RHCP has ensured that engagement continues throughout, including during "dry spells" when there is limited funding, taking these opportunities to continue with capacity building for both community and academic partners. This commitment is often a testament to the level of investment both community and academic partners have to their communities and the mission of RHCP. Furthermore, advocacy is needed to ensure institutional support of CBPR infrastructure to promote sustainability.

Conclusions

RHCP is an 18-year CBPR partnership that works to address issues of health promotion among immigrant and refugee populations in Southeast Minnesota with extended networks throughout the US. The partnership has taken a circuitous research agenda that reflects community priorities and capacities with shared values informed by its CBPR principles, operating norms, and conceptual model. Challenges are encompassed by the tension between project-based funding and the needs of a social, longitudinal infrastructure that transcends individual projects. Long-term translation of partnership successes have resulted in sustainable, community-led change.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Addressing institutional and community barriers to development and implementation of community-engaged research through competency-based academic and community training

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Introduction: The National Center for Advancing Translational Sciences (NCATS) focuses on reducing barriers to effective translational research that rapidly translates science to clinical and community interventions to improve individual and community health. Community-Engaged Research (CEnR) plays a crucial role in this process by bridging gaps between research and practice. It effectively generates bi-directional knowledge and communication by engaging patients and communities throughout the translation research process. Skills development, however, is critical to enable investigators and communities to establish successful partnerships in research. While there are many independent CEnR education programs nationally, few curricula are mapped to identified domains and competencies.

Assessment of current community engagement educational frameworks and competencies: We located three comprehensive efforts to identify CEnR domains and competencies that we aligned to inform development of our curriculum, which we then mapped to these competencies. The first, undertaken by the NCATS Joint Workgroup on Researcher Training and Education and Community Capacity Building (JWG) was developed to assess training opportunities for academic researchers and community partners to increase their capacity to meaningfully engage collaborators in translational research. The JWG identified curricula, resources, tools, strategies, and models for innovative training programs and community engagement in all stages of research. It also conducted a gap analysis of deficiencies in available resources. Using Competency Mapping, they developed a framework for curriculum mapping that included eight domains, each with two to five competencies of knowledge, attitudes, and skills. The second aligned community-engaged research competencies with online training resources across the CTSA consortium, while the third was focused on Dissemination and Implementation training.

Actionable recommendations: Further informed by a conceptual model to advance health equity, we have adapted and integrated these components into a set of modules designed to educate and empower investigators, trainees, students, and community partners to engage in effective CEnR.

Discussion: This curriculum fills an important gap in our workforce development and helps to meet needs of our community partners. Following program evaluation and validation, we will offer the curriculum for use and further evaluation by other groups interested in using or adapting it for their own programming.

KEYWORDS

community-engaged research (CEnR), community-based participatory research (CBPR), competency-based training, increasing capacity, education to action

1. Introduction

Community-engaged research (CEnR) includes the target community as part of the research, where community is defined as a group of individuals affiliated by geographic proximity, health conditions, or other unifying traits or interests commonly shared (1, 2). Translational and clinical research that incorporates the voices of affected communities increases the likelihood of sustaining successful partnerships, developing and implementing successful interventions, and of disseminating those interventions within the community (3). CEnR provides an insider's perspective often missing from traditional research structures and is recognized as critical in bridging gaps between research and practice, thus enhancing translational results (3). However, to truly engage communities in research in meaningful, ethical, and equitable ways necessitates understanding the relationship of research and researchers to communities and acquiring the skills to enable successful engagement. Additionally, understanding the barriers to practicing effective CEnR is required so that they can be properly addressed to ensure effective CEnR is being practiced and upheld. Researchers and their community partners often need extensive training to be able to solicit and integrate community input effectively. Therefore, we created a model to address overcoming institutional and community barriers preventing successful engagement in addition to a CEnR educational training that will be implemented at our institution, which is based upon current offerings from across the Clinical and Translational Science Award (CTSA) Consortium. The primary objectives of this manuscript are to synthesize three comprehensive efforts to identify a framework for CEnR domains and competencies, align and integrate those identified domains and competencies to inform development of our proposed CEnR training, and to offer a model that assists in breaking institutional and community barriers to achieving effective CEnR. This model integrates recent work on domains and competencies which we aligned to suggested action steps identified by community leaders working with the National Academics of Sciences, Engineering, and Medicine (NASEM), CTSAs, and other institutions. This model was created to help assist in addressing institutional and community barriers that inhibit successful community engagement prior to its start. The purpose of this manuscript is for potential users to adopt or build upon our findings and offerings to enhance their own programming.

To this end, the Joint Workgroup on Researcher Training and Education and Community Capacity Building (JWG) was developed by the National Center for Advancing Translational Sciences (NCATS) to assess training and education opportunities for academic researchers and community partners that would increase their capacity to meaningfully engage collaborators in translational research. The Joint Workgroup identified pragmatic curricula, resources, tools, strategies, and models for innovative education and training programs and community engagement in all stages of research (4). It also compiled a database of existing training curricula and conducted a gap analysis of deficiencies in available resources. They then engaged in a comprehensive Modified Delphi Technique for CEnR Curricula Competency Mapping, which resulted in a final framework for curriculum mapping that included eight domains, each with two to five competencies of knowledge, attitudes, and skills (4). Through competency mapping, the committee identified the strongest and most comprehensive CEnR curricula as well as those that require strengthening. The Workgroup identified emphasis on the following competencies: community and stakeholder engagement, cultural and population diversity, translational teamwork and partnerships, cross-disciplinary training, and scientific and collaborative communication. They also identified relative deficits in the competency domains of leadership, regulatory support and knowledge, and ethics and responsible conduct of research.

In addition to the domain competency deficits identified by the JWG in their gap analysis, further barriers to competency-based community-engaged research were discussed in *Principles of Community Engagement*, developed by a task force that included members from the CTSA Consortium's Community Engagement Committee, the National Institutes of Health, Agency for Toxic Substances and Disease Registry, and Centers for Disease Control and Prevention. The five identified barriers included: "engaging and maintaining community involvement; overcoming differences between and among academics and the community; working with nontraditional communities; initiating a project with a community and developing a community advisory board; and overcoming competing priorities and institutional differences" (5). Furthermore, a qualitative study conducted by North Carolina Translational and Clinical Sciences Institute, the CTSA institution at the University of North Carolina at Chapel Hill (UNC) identified five fiscal and administrative barriers and facilitators to conducting community-engaged clinical and translational research. Those barriers are as follows: "level of partnership equity; partnership collaboration and communication; institutional policies and procedures; level of familiarity with varying fiscal and administrative processes; and financial management expectations" (6). This CTSA, the task force, and the JWG share a common vision to improve human health by transforming research and teaching environments to enhance the efficiency and quality of clinical and translational research (5, 6). However, operationalizing that vision requires developing an integrated framework suitable for training new generations of translational and clinical researchers interested in participating in community-engaged research (7). Establishing this framework will entail addressing the competency deficits and institutional and community barriers through vetted and appropriate competency-based CEnR training and education.

Although many community-engagement education and training programs have been developed in recent years, few curricula are mapped to identified domains and competencies, and fewer still are designed to address institutional and community barriers to effective training in CEnR. However, many outstanding curricula have been developed that effectively address these competencies. Our Community-Engaged Research Curriculum draws from and builds upon such programs of excellence, including those from the Meharry-Vanderbilt Community Engaged Research Core of the Vanderbilt Institute for Clinical and Translational Research (8); the University of New Mexico's Center for Participatory Research (9); the Tufts Clinical and Translational Science Institute's *Building Your Capacity: Advancing Research through Community Engagement* (10); the Scripps Translational Science Institute's *Toolbox for Conducting Community-Engaged Research* (11); and the University of Arkansas for Medical Sciences Translational Research Institute's *The Community Scientist Academy Toolkit* (12). Our modules are designed to serve our local community by educating and empowering faculty, students, and community partners in community-engaged research. To date, no community-engaged research curriculum has been implemented at the University of Texas Medical Branch that meets the needs of all parties who play a significant role in community-engaged research (e.g., IRB members, academic investigators, and community-based research partners). This curriculum thus fills an important gap in our workforce training offerings. Following program evaluation and validation, we will offer the curriculum for use and further evaluation by our sister research Centers and other groups interested in using or adapting it for their own programs. Moreover, the model we propose later in this manuscript was created to assess identified institutional and community barriers that limit or prevent engaging in successful CEnR. The model represents a process describing how to address these barriers in the development and implementation of CEnR and CEnR trainings. While the model follows the domains and competencies of our specific training identified by the JWG as exemplary, it can be adapted/adopted by other research centers or institutions that wish to strengthen their own programming through use of these suggested action steps. During the development stage of our training, we designed this model to ensure we were taking the necessary action steps to break such barriers. This allowed us to strengthen the design of our CEnR training and identify deficient areas in the training that need further improvement based on both institutional and community needs.

1.1. Brief overview of our CEnR training

The intent of our CEnR curriculum is for participants to better understand community-engaged research and to utilize the information provided in the modules to enhance their skills and confidence in CEnR. The curriculum will be offered to all individuals wishing to expand their knowledge on the topic of community-engaged research. The program's ultimate goal is to strengthen clinical and translational research while improving population health and overall quality of life. It also seeks to improve both health services and public health practice and to positively impact community and environmental norms and behaviors. Participants who complete this educational training will leave with improved skills, behaviors, and attitudes toward communities through community empowerment, stronger community-university trust, and a better understanding of community engagement in terms of research and public health. The CEnR Educational Program is a 6-module curriculum that will be covered over the course of 6 weeks delivered in a classroom setting. The curriculum will address eight community-engaged research domains: Community and Stakeholder Engagement; Cultural and Population Diversity; Translational Teamwork and Partnerships; Leadership; Cross-Disciplinary Training; Scientific and Collaborative Communication; Regulatory Support and Knowledge; Ethics and Responsible Conduct of Research. The objectives of each module following and addressing the community-engaged mapping domains can be found in Table 1. Successful completion of the training will entail the following:

- Completion of all six modules.
- Active participation in class discussions and group exercises.
- Completion of required readings, videos, and case studies.
- Completion of pre- and post-test assessments.

However, we also encourage participation in singular modules for those who wish to further their skills in a certain area. Upon completion, participants will have gained a better comprehension of community-engaged research, how to create strong partnerships, their specific role within community-engaged research, and much more including but not limited to skills such as leadership, decision making, accountability, financial responsibilities, and effective communication.

2. Assessment of current community engagement educational frameworks and competencies

In developing our curriculum, the competency domains we identified as key were derived from the JWG community-engagement educational framework along with other community-engaged research competencies identified through assessment of online training resources across the CTSA consortium (13), which were further informed by a framework developed for Dissemination and Implementation training (7). We carefully considered these comprehensive efforts, aligned and integrated competencies where suitable, and adapted them for our use to address institutional and clinical barriers for successfully participating in and improving translational research. Such efforts to strengthen preexisting programming and align competencies and goals are consistent with the overall mission of clinical and translational science to improve population health through effective community-engaged research (14).

TABLE 1 CEnR domains and competencies offered in this CEnR training derived from the NCATS joint workgroup.

Mapping domains	Competencies: Knowledge, attitudes and skills
1. Community engagement and scientific and collaborative communication	Articulate principles of community and collaborator engagement
	Demonstrate how to engage communities and other partners in research
	Benefits and challenges of community engagement
	Facilitate group discussions, promotion of health and community literacy (i.e., context, needs, values and perspectives of engaged community) and multicultural communications
	Develop and implement a communication plan to share research findings with partners and those impacted by the research
2. Cultural and population diversity	Social determinants of health in individuals and communities
	Cultural competency vs. humility vs. sensitivity
	Health disparities vs. health equity vs. equality of outcomes
	Benefits and challenges of cultural and social variation relating to research
3. Translational teamwork and partnerships	Building and sustaining inter- and/or multi-disciplinary teams
	Advocating for, facilitating and reconciling multiple points of view
	Building and sustaining community and academic partnerships from research teams
4. Leadership and cross-disciplinary training	Identify potential key collaborators to participate in community-academic partnerships to address significant health issues and disparities
	Effectively lead collaborations with academics, communities and other partners
	Recognize institutional and community context of CEnR and partnerships
	Clarify each team members' responsibility through research process
	Develop and manage budget and other resources (e.g., volunteers, meeting space, etc.)
	Formulate study questions and determine outcomes to be assessed
	Advance various models of peer engagement in research (e.g., advisory, employment, formal partnership, etc.) and their value to different phases of translational research spectrum
	Use narrative-based (i.e., qualitative) and numbers-based (quantitative) methods to identify significant health issues

(Continued)

TABLE 1 (Continued)

Mapping domains	Competencies: Knowledge, attitudes and skills
5. Regulatory support and knowledge	Meet expectations for IRB and community review of research projects and process
	Identify proven processes to establish agreements regarding ownership and dissemination
6. Ethics and responsible conduct of research	Understand all ethical dimensions of CEnR and mutual benefit for all research partners and affected community
	Identify approaches and tools to evaluate and improve the collaborative process

In delineating our curriculum's domains and competencies, we adapted the JWG domains and competencies but concentrated them to better fit the needs and requirements of our community and institution. We also focused more intently on the three deficient competency domains revealed by the JWG's gap analysis. In our curriculum, two of the three deficient competency domains the JWG identified are addressed in a learning module devoted to regulatory support and knowledge and ethics and the responsible conduct of research. Based upon their connectivity, the remaining deficient competency domain, leadership, was combined with cross-disciplinary training. Doing so is supported by a study concluding that practical actions on fostering cross-disciplinary research are closely linked to leadership and teamwork that should be planned and implemented at research team and institutional levels (15).

The second comprehensive effort we identified aligned CEnR competencies with online training resources across the CTSA consortium (13). This study cataloged publicly accessible online community-engaged research resources from CTSAs and mapped these available resources to CEnR competency domains (13). They identified eight community-engaged competency domain definitions and characteristics, including: knowledge and perceptions of CEnR; personal traits necessary for CEnR; knowledge and relationships with communities; training of those involved in CEnR; CEnR methods; CEnR program evaluation; resource sharing and communication; and dissemination and advocacy. In aligning these domains with those of the JWG, we adopted a practical approach, i.e., considering the role of particular competencies as they relate to training. Many of the core competency domains were highly correlated with those of the JWG, and where different, we modified our curriculum to reflect both. For example, by definition the identified domain of knowledge and perceptions of CEnR was conceptually close to our own of community engagement and scientific and collaborative communication. Both address the basic principles and concepts integral to understanding and performing community-engaged research (i.e., value of CEnR, history of CEnR, CEnR communication, CEnR approaches). We followed this same process in aligning the rest of our competency domains. One slight deviation was related to the domain of personal traits. While we wholeheartedly agree that personal traits are highly influential in capacity for effective relationship building and partnerships, we chose to focus on development of skills that can be taught, modeled, and learned, while emphasizing the importance of self-evaluation and self-reflection.

The third model we considered was focused primarily upon Dissemination and Implementation training. This conceptual framework identified detailed competencies for researchers participating in community-engaged dissemination and implementation (CEDI) and maps these competencies to domains (7). Shea et al. developed this conceptual framework for CEDI competencies identifying attitudes, knowledge, and behaviors necessary for carrying out the principles of community engagement (7). While mapping their competencies based on the community engagement principles as defined by the National Institutes of Health (NIH), they used a nominal group technique (NGT) approach to determine the competencies for conducting CEDI. They identified 40 competencies mapped to nine domains reflecting the attitudes, knowledge, and behaviors for researchers conducting CEDI research (7). This framework was highly useful in that it contributed content based upon a researcher's readiness to participate in community-engaged research, a key aspect of the educational process and essential for its success. While the focus on community engagement dissemination and implementation research is a more specific approach than our own, we found that it, too, was quite similar to the domains and competencies identified by the JWG. As with those of the Piasecki et al. (13) model, where there were differences, we incorporated content to address both.

After carefully examining the three comprehensive efforts, we used various methodologies to align and integrate their domains and competencies in establishing our own. We conducted a thematic analysis to analyze the qualitative data each comprehensive effort uncovered in their study. This five-step process included: familiarization, coding, generating common themes, reviewing themes, and defining themes. Following this method, we investigated all CEnR components to detect, analyze, and report repeated patterns found within the three comprehensive efforts observed. This allowed us to map, identify, and condense similar domains and competencies to establish a final framework. This framework intends to reduce redundancies in current literature and bridge gaps in domain competency mapping. Using this approach in aligning CEnR domains and competencies across the CTSA Consortium allowed us to produce contextual, real-world knowledge about the social structures, behaviors, skills, and attitudes required for carrying out effective CEnR. The methodology of the three comprehensive efforts we examined were compiled from interviews, observations, and existing data. As touched on previously, the JWG used a modified Delphi technique to identify deficits in their domain competency mapping. In contrast, the Shea et al. study used a nominal group technique approach to identifying their domains and competencies. After careful review of the processes each effort used, we performed a summary analysis that collates the key domains and competencies of each source. We have taken this approach because the three comprehensive efforts under review have a similar structure. This finally led us to our last strategy of aligning the CEnR domains and competencies of our training, in which we examined word repetition, indigenous categories, key words in contexts, and used a compare and contrast approach to determine similarities and differences in related themes. After aligning the three efforts, our final framework was devised and can be observed in Table 1. Table 1 represents the domains and competencies offered in our CEnR training that were adopted from the JWG and identified as exemplary. The only modifications made to these domains and competencies, besides condensing them to meet needs of our institution, were concentrating on the domain deficits the JWG identified and revealed in their gap analysis. To ensure that we focused more intensely on these domain deficits and further address them in our training, we aligned similar domain themes identified by the other comprehensive efforts. The final resource we used to inform our curriculum was the National Academies of Sciences, Engineering, and Medicine's (NASEM) Leadership Consortium: Collaboration for a Value and Science-Driven Health System (2). This group created a conceptual model to advance health equity through transformed systems for health. This model identifies concepts and metrics that can be used to assess the extent, process, and impact of community engagement and also illustrates the dynamic relationship between health equity and health system transformation. The model further examines opportunities to assess community engagement and the potential impact it could have on health and healthcare policies, including factors such as inclusion, diversity, and health equity (2). For this reason, we used this framework to inform meaningful community engagement in our curriculum but modified it to appropriately address the institutional and community barriers to developing and implementing effective community-engaged research training. We followed the same process and methodology in designing this model, focusing on the eight foundational standards the NASEM Leadership Consortium identified:

- Define what should be measured in meaningful community engagement, not what is currently measured.
- Be sufficiently flexible to measure engagement in any community.
- Define health holistically.
- Allow the community to see itself in or identify with the language, definitions, and context.
- Embed equity throughout the model.
- Emphasize outcomes of meaningful community engagement.
- Present a range of outcome options for various stakeholders.
- Communicate the dynamic and transformative nature of engagement.

The NASEM conceptual model and our model are similar in that they both address meaningful community engagement; however, the NASEM model is designed to advance health equity through transformed systems for health, whereas our model addresses action steps to breaking institutional and community barriers to effectively develop and implement successful community-engaged research training. As observed in Figure 1, our model centers around the five community and institutional barriers identified in the *Principles of Community Engagement* (5) and the five fiscal and administrative barriers and facilitators identified by the CTSA institution at UNC at Chapel Hill. The model centers around these 10 community and institutional barriers that prevent achieving effective CEnR. From there the model branches off into six circles, each containing our identified domains (i.e., community engagement and scientific and collaborative communication; cultural and population diversity; translational teamwork and partnerships; leadership and cross-disciplinary training; regulatory support and knowledge; and ethics and responsible conduct of research) that were obtained from the JWG's domain competency mapping. These six domains are individually addressed in our community-engaged research training, each making up one learning module. Each circle consists of one of the six domains our curriculum addresses, and within each circle are action steps, each consisting of two to four proposals to help break these institutional and community barriers. The action steps have been aligned with the six domains and their mapped competencies in order of presentation during training. We used a categorization methodology to align these action steps to the objectives of each domain. These action steps have been integrated in our training through various examples and through the content each learning module contains. We conducted an analysis of the qualitative information in which the modules include and differentiated them by certain classes. By accounting for these community and institutional barriers to implementation and development of CEnR training, we hope to ensure the practice of successful and effective CEnR, thus improving translational science and population health outcome. We find these identified action steps essential to breaking institutional and community barriers, and successfully implementing community-engaged research training. The model and recommended actions steps are further addressed, synthesized, and explained in the next section of this manuscript.

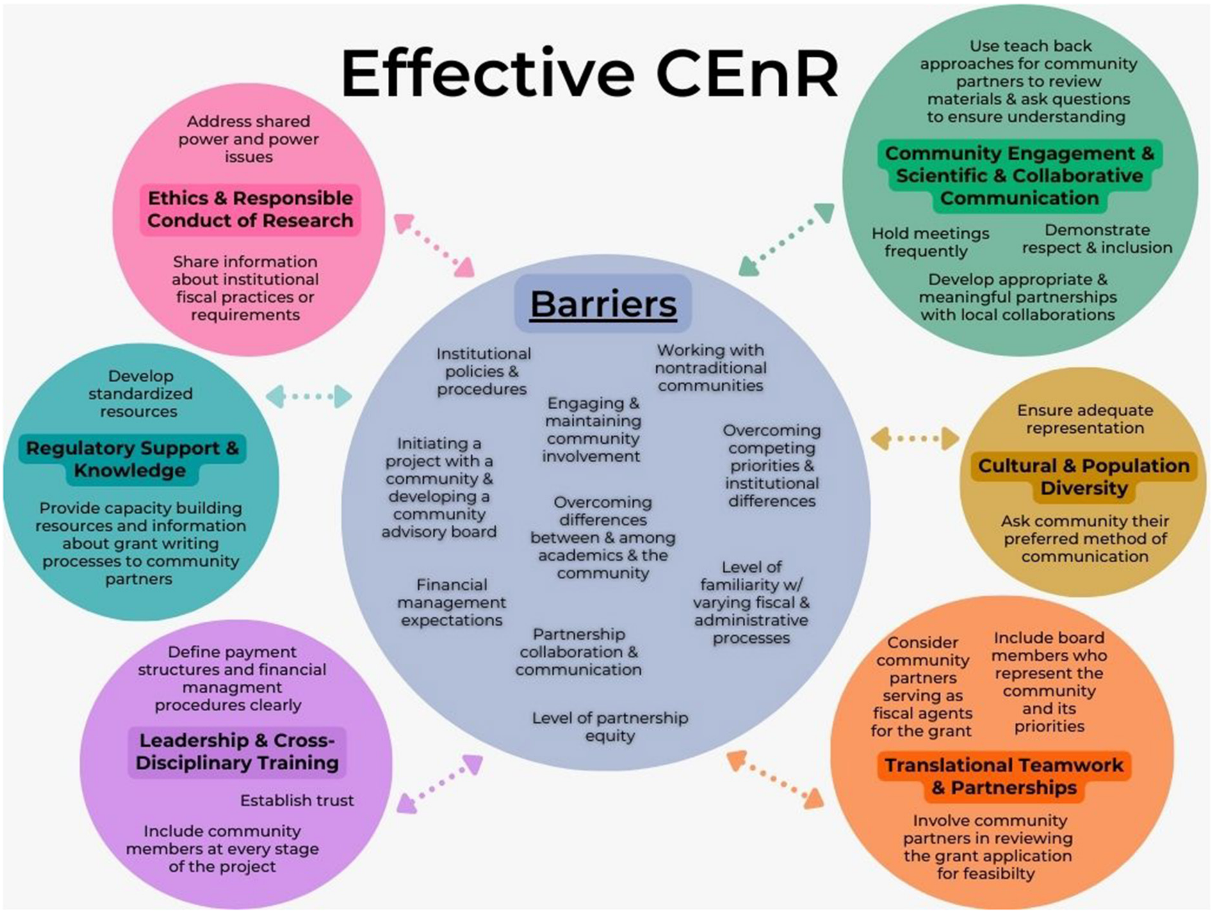

FIGURE 1
Breaking institutional and community barriers to achieve effective CEnR.

3. Actionable recommendations

In addressing barriers to effective CEnR and CEnR training, to successfully engage in effective CEnR necessitates having a strong understanding of the institutional and community barriers that prevent successful engagement from occurring. Without addressing these impeding barriers, acquiring the necessary skills, behaviors, and attitudes required for effective participation in CEnR may not be attainable. To this end, we created a conceptual model that demonstrates a process of executing specific action steps to overcome these barriers hindering successful community engagement. The key contribution of our model is to provide emphasis on identified community and institutional barriers. To our knowledge, no model exists that demonstrates a process to break such barriers while integrating CEnR domains and competencies for training. While the model follows the domains and competencies of our specific training identified by the JWG as exemplary, it can be adapted by other research centers or institutions that wish to strengthen their own programming by adopting these suggested action steps and applying them to their own domains and competencies. The model presented was created to help facilitate our CEnR training in the development and evaluation of our domains and competencies. As previously mentioned, the barriers addressed in this model stem from the five community and institutional barriers identified in the *Principles of Community Engagement* (5) and the five fiscal and administrative barriers and facilitators identified by the CTSA institution at UNC at Chapel Hill. We combined and included these ten barriers because we believe each barrier is unique and an important impediment contributing to preventing successful CEnR. The 10 barriers to effective CEnR and CEnR training in this model include (5, 6):

- Engaging and maintaining community involvement.
- Overcoming differences between and among academics and the community.
- Working with nontraditional communities.

- Initiating a project with a community and developing a community advisory board.
- Overcoming competing priorities and institutional differences.
- Level of partnership equity.
- Partnership collaboration and communication.
- Institutional policies and procedures.
- Level of familiarity with varying fiscal and administrative processes.
- Financial management expectations.

To better understand our proposed model, the barriers, and the suggested action steps to break these barriers aligned to CEnR domains and competencies, we created a table (Table 2) that provides firsthand examples as to where in our CEnR training these barriers have been addressed and the necessary action steps to address them in doing so. The intent of this conceptual model is to highlight newly discovered barriers while integrating recent work conducted by the JWG and other CSTAs on CEnR domains and competencies. The major distinction between the conceptual model and the table is that the conceptual model demonstrates the necessary action steps required to address these identified barriers found within each domain, while, in contrast, the table describes how our training accounts for these barriers and where in our training it addresses how to overcome them. For instance, to address the barrier of meeting “financial management expectations,” which the domain of “leadership and cross-disciplinary training” addresses, the suggested action steps to overcome this barrier would be to define payment structures and financial management procedures clearly and ensure strong financial involvement of principal investigators. To achieve these action steps while also breaking this barrier, in our training we describe the process of developing a budget, including an example budget, and have incorporated community member compensation guidelines that the CTSA Collaboration/Engagement Domain Task Force identified. Without describing and providing these examples within our training modules, addressing these institutional and community barriers cannot be done successfully. The suggested action steps can only be done if the content in the modules demonstrates how to accomplish achieving this. In addition to using a categorization methodology to align our domains to these 10 institutional and community barriers, we also independently reviewed and analyzed them using a Rapid Assessment Process (RAP). We use this approach to facilitate key themes among their corresponding competencies and objectives. We chose this approach because of time-sensitivity and because the topic of CEnR is rapidly evolving.

Prior to creating our community-engaged research training, we examined the suggested recommendations for future improvements from the models we adapted. Suggestions included improving efforts across the CTSA consortium for navigating community-engaged research online information, materials, and resources; increasing access to CTSAs’ publicly online CEnR coursework; and establishing standardized nomenclature. Other recommendations include establishing a gold standard for community-engaged research for CEnR domains and competencies across the CTSA consortium while reducing redundancies (13). In aligning these frameworks to build our own, we experienced this challenge firsthand. While we have established a program that will work well for our purposes and will hopefully be of use to others, it is not and was not intended to be a gold standard. However, development of a true gold standard remains necessary to optimize an effective community-engaged research training that could be widely adopted across CTSAs and other similar research entities with a need for effective CEnR training. This will ensure consistency across programs and that trainees completing programming will have similar abilities in taking the field.

Shea et al. suggested developing a community-engaged dissemination and implementation/ community-engaged (CEDI/CE) research readiness survey, based on their proposed domains and competencies (7). This readiness survey is to accurately measure a researcher’s attitudes, willingness, and self-reported ability for acquiring the knowledge and performing the actions necessary for effective community engagement (7). We found their framework highly useful in building and designing our curriculum. We adapted their suggestion to employ a community-engaged research readiness survey into our pre-and-posttest assessments to gauge and evaluate all participants’ knowledge and readiness in practicing effective community-engaged research. They also emphasized the importance of training on how to establish and maintain effective research/community partnerships and included a level of granularity in their competencies that was lacking in other models. We were able to include specific suggestions throughout our curriculum, particularly related to capacity and relationship building.

The JWG Domain Task Force’s final report for NCATS identified four recommendations for further work and research. The four recommendations include (4):

1. Promote access to existing curricula, support the maintenance of the community-engaged research curricula inventory, and ongoing availability of resources provide curricula accessibility through online, searchable platforms.
2. Use the identified curricular gaps from the JWG’s gap analysis, those deficits being the competency domains of leadership, regulatory support and knowledge, and ethics and responsible conduct of research, to encourage the development of additional curricula that addresses these deficiencies.
3. Encourage NCATS to disseminate the JWG report and its findings extensively.

TABLE 2 Addressing institutional and community barriers to achieve effective CEnR.

Barrier	Mapped domain	Action steps	Examples in training
Engaging and maintaining community involvement	Community engagement and scientific and collaborative communication	Develop appropriate and meaningful partnerships with local collaborations; Demonstrate respect and inclusion	The nine principles of community engagement; timeline of project; scope of project
Overcoming differences between and among academics and the community	Leadership and cross-disciplinary training	Include community members at every stage of the project; establish trust	Bridging the gap between academia and community; team members responsibility planning
Working with nontraditional communities	Cultural and population diversity	Ensure adequate representation; ask community their preferred method of communication	Communication planning; diversity and inclusion measures; Social Determinants of Health
Initiating a project with a community and developing a community advisory board	Translational teamwork and partnerships	Include board members who represent the community and its priorities	Guidelines for collaboration, 5-step process for initiating CEnR project; logic model; advisory
Overcoming competing priorities and institutional differences	Ethics and responsible conduct of research	Address shared power and power issues	Organizational chart of designated roles; managing expectations; IRB review
Level of partnership equity	Translational teamwork and partnerships	Involve community partners in reviewing the grant application for feasibility; consider community partners serving as fiscal agents for the grant	Sharing in decision making; involvement in grant writing; shared data agreement
Partnership collaboration and communication	Community engagement and scientific and collaborative communication	Use teach back approaches for community partners to review materials and ask questions to ensure understanding; hold meetings frequently	Memorandum of Understanding; timelines; roles
Institutional policies and procedures	Ethics and responsible conduct of research	Share information about institutional fiscal practices or requirements	Review of institutional policies regarding research; procedure plan
Level of familiarity with varying fiscal and administrative processes	Regulatory support and knowledge	Develop standardized resources; provide capacity building resources and information about the grant writing process to community partners	Community partner toolkits; list of requirements; technical support network for administrators
Financial management expectations	Leadership and Cross-Disciplinary Training	Define payment structures and financial management procedures clearly; ensure strong financial involvement of principal investigators	Developing budget; community member compensation guidelines

4. Encourage stakeholders and community partners to collaborate with the CTSA hubs to develop new programs addressing the diverse and changing needs of community partners and academic researchers.

Based upon the models and their suggestions for future improvement, we developed our own CEnR framework and selected the supporting curriculum, which is geared toward a broad-based audience including investigators, students, trainees, and community partners. We mapped our curriculum to the domains and competencies in a series of six modules that will be covered over the course of 6 weeks. The training addresses the eight community-engaged research domains identified by the JWG, supplemented by additional competencies included in the Shea et al. (7) and Piasecki et al. (13) models. The eight domains include: Community Engagement; Cultural and Population Diversity; Translational Teamwork and Partnerships; Leadership; Cross-Disciplinary Training; Scientific and Collaborative Communication; Regulatory Support and Knowledge; Ethics and Responsible Conduct of Research. The domains are covered in the six modules, each which provides training in two to eight competencies (see Table 1). Within the curriculum, the competency domains of leadership, regulatory support and knowledge, and ethics and responsible conduct of research have been further addressed, defined, and developed to fill this competency gap.

4. Discussion

Community-engaged research and supporting training efforts are greatly increasing, providing opportunities for increased collaborations across CTSA hubs and other research institution partners in these endeavors. Current independent

CEnR education programs and educational offerings propose conceptual frameworks that identify the components and principles of community-engaged research, but few are mapped to identified domains and competencies or focus on addressing institutional and community barriers. Although some frameworks and trainings are available for building and assessing partnerships between community collaborators and researchers, few describe a process for translating research into practice (7). In addition, the available community-engaged research domains and competencies identified by the JWG and other online training resources across the CTSA consortium must be further tailored to the diverse and changing needs of academic researchers and community partners (4). The University of Texas Medical Branch has not previously implemented a community-engaged research curriculum that primarily focuses on all parties involved in community-engaged research (i.e., investigators, trainees, students, and community partners). Thus, this CEnR curriculum fills an important gap in our workforce and helps meet the needs of multiple community partners and investigators. This curriculum not only identifies all facets of successful community-engaged research and provides a process for translating research into practice, but also outlines the attitudes, knowledge, and skills required for effective CEnR. The content of this training focuses on the research process, community involvement, sustainability of partnerships, research ethics, study design, budget and grant funding, communication planning, and skills development to establish successful collaborations in translational research. It is intended to simplify participation in research for community members, foster strong partnerships, and provide opportunities for open dialogue between researchers and community members.

The model presented herein was created to address institutional and community barriers to effectively develop and implement successful community-engaged research training. However, this model is only one key component of the work needed to ensure these barriers are being properly addressed and that effective CEnR training takes place. Testing this model is essential for evaluating its effectiveness and understanding the most appropriate context and circumstances for its use. Future work should consider integrating CEnR resources and supporting development of standardized curricula for community-engaged research education and its use in translational science. There is still a pressing need for better access to such resources and navigability remains problematic (13). There is also inadequate publication of CEnR literature and limited data related to the core competencies necessary for successful scholarship in community-engaged research (7, 13). Additionally, extreme variations exist in the methods and quality of literature concerning best practices in community-engaged research training, and further research is needed to establish universally accepted competency domains. Steps should also be taken to ensure the adoption of common definitions and language. For example, in our curriculum we have opted not to use the term *stakeholder*, given its potential to offend some tribes and tribal members and its avoidance is now recommended by the Centers for Disease Control and Prevention as a best practice (18, 19). The next step for this CEnR curriculum is to implement it at the University of Texas Medical Branch following program evaluation and validation. This curriculum will be offered for use and further evaluation by our partners and other groups interested in using or adapting its content in their own educational programming.

4.1. Limitations

It is necessary to understand this community-engaged research training is designed and oriented to meet the needs of our desired institution and community. It must also be understood that this curriculum is ongoing and needs to be continuously updated and improved as new evidence and research emerge. It is imperative to note that this community-engaged research curriculum requires further evaluation of the efficacy and acceptability of the curriculum at the individual, community, and institutional levels (16). The future direction of this community-engaged research training primarily focuses on facilitator satisfaction, ease of implementation, and institutional and community adoption/acceptance.

5. Conclusion

Optimally, addressing institutional and community barriers to effective CEnR will help advance community-engaged research and CEnR training across the CTSA Consortium. Understanding this complex relationship is key to improving the quality of the clinical and translational research enterprise. To our knowledge, no CEnR training exists that integrates recent work on domains and competencies aligned to specific action steps that aim to break institutional and community barriers. Our findings highlight the importance of equitable processes for establishing the necessary skills, behaviors, and attitudes for effective community engagement. Synthesizing these three comprehensive efforts led us to identifying a framework for CEnR domains and competencies that will help to reduce redundancies in current resources and offerings. We then aligned and integrated the domains and competencies to inform development of our CEnR training. We hope that other users can replicate our work or build upon it using a similar methodology. Lastly, we hope that other research institutions will use our model to help overcome the identified community and institutional barriers hindering successful CEnR. Conceptual models are designed, in part, to be utilized as a guiding instrument for advancing science. Conceptual modeling is a framework that is initially used in research to outline the plan of action or to present an idea or thought (17). When conceptual models are developed in a sensible, logical way, they provide a rigor to the research process (17). To our knowledge, no widely used model exists with a purpose of breaking institutional and community barriers while integrating CEnR domains and competencies for training. As demonstrated in the model we designed to address these barriers, we aligned suggested action steps identified by community engagement leaders from across the country working within the CTSAs, NASEM, and other institutions (see Figure 1). We hope that potential users will adopt or improve it for their own programming. Community-engaged research trainings have the capacity to strengthen scientific and translational research while improving population and community health. However, to maximize their effectiveness and ensure consistency in our national programming, integration of efforts and adoption of common metrics is essential. Therefore, the model presented in this manuscript is a key contribution to understanding how to consider, address, and break these institutional and community barriers preventing effective CEnR.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

CH contributed heavily to the educational curriculum upon which the manuscript is based and to the writing of the manuscript and synthesized the educational frameworks into ours. KB co-authored the manuscript in its entirety, contributing heavily to its framework, construction, and revision. LH as educational program director, critiqued the framework, contributed to the authorship, and editing of the paper. SC was responsible for the concept of the paper and contributed significantly to its writing and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Embracing context: Lessons from designing a dialogue-based intervention to address vaccine hesitancy

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Dialogue with people who are vaccine hesitant has been recommended as a method to increase vaccination uptake. The process of cultivating dialogue is shaped by the context in which it occurs, yet the development of interventions addressing vaccine hesitancy with dialogue often overlooks the role of context and favors relatively fixed solutions. This reflexive paper shares three key lessons related to context for dialogue-based interventions. These lessons emerged during a participatory research project to develop a pilot intervention to create open dialogue among healthcare workers in Belgium about COVID-19 vaccination concerns. Through a mixed methods study consisting of in-depth interviews, focus group discussions, and surveys, we engaged healthcare workers in the design, testing, and evaluation of a digital platform featuring text-based and video-based (face-to-face) interactions. The lessons are: (1) what dialogue means, entails, and requires can vary for a population and context, (2) inherent tension exists between helping participants voice (and overcome) their concerns and exposing them to others' ideas that may exacerbate those concerns, and (3) interactional exchanges (e.g., with peers or experts) that matter to participants may shape the dialogue in terms of its content and form. We suggest that having a discovery-orientation—meaning to work not only inductively and iteratively but also reflexively—is a necessary part of the development of dialogue-based interventions. Our case also sheds light on the influences between: dialogue topic/content, socio-political landscape, population, intervention aim, dialogue form, ethics, researcher position, and types of interactional exchanges.

KEYWORDS

dialogue, COVID-19, vaccine hesitancy, dialogue-based intervention, digital intervention, participatory research, public health intervention

1. Introduction

The COVID-19 pandemic raised awareness of the necessity of dialogue for addressing vaccine concerns (1–7). Considered an effective approach for overcoming vaccine hesitancy (8), dialogue is an important way to learn how context, such as the evolving crisis in relation to local socio-cultural and practical complexities, shapes COVID-19 vaccine hesitancy (9, 10). Accordingly, some interventions [e.g., (1, 3, 11–15)] have focused on using dialogue to understand and respond to people's vaccination concerns, with the aim of increasing uptake.

Attending to context can also reveal how to effectively cultivate and ultimately scale dialogue within a population. Intervention efforts to create dialogue spaces to address COVID-19 vaccine hesitancy, however, are limited in the ways they consider and incorporate context (1, 3, 11–15). Relatively fixed approaches and solutions are implemented, reducing the opportunity to understand what could better generate dialogue in evolving contexts. For example, in Knight et al.'s (1) "linear" approach to developing "therapeutic dialogues" that address "the most common vaccine concerns" (p. 99), the COVID-19 pandemic and vaccination context appears as a factor shaping the content of participants' concerns but not as a factor shaping the intervention process itself (e.g., the type/form of dialogue).

From our experience designing and implementing a pilot dialogue-based intervention for addressing COVID-19 vaccine hesitancy, we share three critical lessons that emerged from embracing context. This was a participatory research project to cultivate open dialogue among Belgian healthcare workers (HCWs), which was conducted from November 2021 to March 2022. At the time the project started, there were 1,380,343 confirmed cases of COVID-19 and 26,224 deaths in Belgium (16), significant for a population of 11.5 million (17). The national COVID-19 vaccination campaign kicked off on December 28, 2020 with a prioritizing scheme that began with the residents of nursing homes and HCWs (18). During our project, polarization (in Belgium and globally) was evident between supporters and opponents of the COVID-19 measures, including vaccination (19, 20). The Belgian government's proclamation of mandatory vaccination for HCWs occurred just before the start of our study (21), and this was followed by the last Delta-wave, then the first Omicron-wave (16), which further burdened HCWs. Later, the deadline for mandatory vaccination was postponed until summer 2022 (22) and then eliminated (23), soon after our study concluded. Through a reflexive account, we shed light on the complexities of developing our intervention in this polarizing, evolving context.

Our international, interdisciplinary research team had studied vaccine hesitancy in Flanders, Belgium for a year prior to this project, during which time we had documented polarization online on social media. We had observed "unspoken vaccine hesitancy," the phenomenon where "health professionals [both vaccinated and not vaccinated] often do not voice their vaccine-related concerns, particularly to colleagues, due to the institutional and societal pressures to vaccinate" (p. 1) (24). That led us to launch this study.

2. Our project and intervention design

Our project aimed to mitigate "unspoken vaccine hesitancy" among HCWs through learning how to create open dialogue in a group with varying vaccine sentiments. We saw the intervention as a way to contribute to building vaccine confidence, even though it was not about resolving specific vaccination concerns. To maximize the potential for HCW engagement—given the polarization concerning mandatory vaccination and the pressures of this period for them—we chose to use a digital (online) platform to allow them to engage anonymously and asynchronously.

We conducted in-depth interviews (1-h) and focus group discussions (2-h) with 74 healthcare workers from Flanders and Wallonia (recruited through purposive sampling) to understand three key topics: their COVID-19 vaccination perceptions and concerns, what they experienced as the atmosphere of vaccine discussions, and what they saw as essential features of a safe space for open dialogue among HCWs. The methodology for that, the characteristics of those participants, and the findings about the first two topics, can be found in our previously published paper (25), while this paper focuses on the third topic. Most of these exchanges took place before the launch of the platform, and thus they were not only a source of input into the design of the platform but also a source of potential platform users. Research team members held weekly meetings to discuss findings. Detailed meeting notes from these exchanges were also used as source material for our analysis. Transcripts of focus group discussions and in-depth interviews and meeting notes were imported into Nvivo (QSR international) and coded thematically.

A text-based platform offers users the opportunity to engage with each other asynchronously. At the time of the intervention, offering only a non-text or live platform would have made it extremely difficult to recruit and coordinate with HCWs, given the strain of the pandemic and also the variation in healthcare professions (e.g., their work demands or hours).

For rapid benchmarking, five prominent text-based social media and instant messaging platforms were selected, based on robustness of features for online dialogue and/or popularity: Facebook groups, Reddit, Discord, Slack, and WhatsApp. Criteria for evaluation included the following, which easily eliminated most of the platforms: ease of access and use for users, anonymity from users, flow of conversation (synchronous vs. asynchronous), possibility of sharing links, ease of doing polls and surveys, future value for user, possibility to validate an information sheet (regarding the research process and rules for open dialogue), possibility to extract data, and possibility to delete platform content after closing the project. Although less widely used in Belgium, Discord (https://www.discord.com) offered integration of voice-based and text-based options, as well as the greatest level of anonymity; users could join with a "secondary" identity and sign up with simply an email address that would stay hidden from others. To make our final decision, we asked some focus group participants about Discord vs. Slack. We ultimately selected Discord. To address lack of familiarity and give people a sense of what they might be signing up for, our invitation letter described why we chose Discord and linked to a short orientation video (that we created in both Dutch and French) with basic guidance on how to orient oneself in the platform and where to engage in dialogue.

Our Discord server *Platform for Vaccine Dialogue* was launched with a general channel for questions about Discord. A few other initial channels were for discussion topics and rules of conduct; these channels were available in Dutch and in French. Both languages are the main official languages spoken in the regions in which the HCWs needed to work. All project activities were offered in both languages to be inclusive, by giving participants the flexibility to communicate in their language(s) of choice. A feature of Discord that was also valued by the team was that Dutch and French were available as languages in the user's settings.

The platform was active from January 13 to February 21, 2022. To recruit users, we invited participants from the focus group discussions and interviews that had already taken place, and we also issued an open invitation to other HCWs and healthcare institutions. Twelve HCWs anonymously joined the Discord server. To provide food for dialogue in the server, we conducted social media analysis and posted the results weekly (e.g., sharing a word cloud with the most used hashtags from Belgian Twitter users' vaccination-related tweets that week, both in Dutch and French). As is common with online groups, a smaller subset (five users) actively posted and/or reacted to others. From the later focus group discussions, we learned that some members were reading the posts but not actively engaging.

In the Discord server, we also announced opportunities for face-to-face dialogue sessions that were prescheduled group video calls, offered separately in Dutch and French. Ten HCWs joined the group video calls during that time, half in each language.

We conducted short, Google form-based, pre- and post-intervention surveys to obtain feedback on how participants experienced different activities in this project. The pre-intervention survey was sent to all participants of the focus groups and interviews that had already taken place and to all platform users when they joined; we had 53 respondents. After the platform closed, the post-intervention survey was sent to all participants we had contact with throughout the project, not just to platform users; we had 29 respondents (including nine Discord users and five group video call participants). Roughly half of those respondents (15 out of 29) indicated they had participated in at least two project activities (i.e. focus group discussions, interviews, text-based platform, group video calls). Among those who had not joined the platform, the most frequently cited reason for non-participation was lack of time.

The seven members of our research team who were directly involved with participants regularly reflected (individually and collectively) on their experiences throughout the research and intervention design process. This was documented in weekly and *ad hoc* memos, from which the following three lessons were drawn.

3. Lessons

3.1. What dialogue means, entails, and requires may vary. (Re)Determine how the population can be (re)engaged in dialogue in an evolving context.

We had hypothesized that for open dialogue, participants would need to firstly feel safe by having an anonymous identity (i.e., not having their faces, names, and voices revealed to others) and knowing that the platform they enter would be respectful toward all speakers. We envisioned a text-based digital platform with minimal monitoring (e.g., to prevent hate speech) to be the most suitable kind of space for this. We discovered, however, that we would need to expand our approach and understanding of what open dialogue means, entails, and requires.

During the pre-intervention design period, we referred to this platform as a "safe space for dialogue" when speaking to participants; one of the first surprises was that this term could have a negative connotation. This inverted our notion of "safety." Some participants critically asked who was really meant to be protected by these safe spaces. For them, the idea of holding private, small group discussions, centered around anonymity and confidentiality, might be less about offering a safe space for them and more about protecting the broader public from their viewpoints and ideas. For example, one participant said he considered these safe spaces as "discussions in a cellar" away from others. This led us to avoid the term "safe space" when naming our platform. Although safe spaces have garnered significant attention in the academic and activist domains (26), our results highlight how divergent understandings of this concept may drive some people away from engaging in dialogue.

Some participants had safety-related concerns that were not only about having anonymity but also about having protection from perceived untrustworthy information. They were concerned about being exposed to perceived "unscientific" content or other posts on the text-based platform that they did not consider to be "evidence-based." For vaccine-confident participants, a safe space meant being able to block out misinformation or disinformation and knowing that there would be fact-checking of all posts.

Safety-related concerns also extended beyond the immediate digital space. Most participants described a safe space as a place where individuals could share their thoughts without fearing consequences, which meant knowing who would own and have access to their input and data. This was especially important because of the perceived risk of expressing their views (e.g., potential repercussions in the workplace when exposed).

What drew participants to our research project was the opportunity for more meaningful or authentic forms of dialogue, even if that meant less anonymity. In a polarizing context, people may be inhibited from speaking openly, but also they may have not had opportunities to have the quality of dialogue that they would make time to engage in. While vaccine hesitant participants who leaned toward pro-vaccination valued a text-based platform they could consult for reliable information, the more hesitant participants placed greater value on synchronous dialogue *via* video-based interactions, in other words, a face-to-face digital platform. For those participants, face-to-face was considered safer, because it does not enable trolling as a text-based platform does (27). Furthermore, it would allow them to see each other, to see emotions, and to evaluate the quality, intensity, and perceived trustworthiness of what others were sharing. Although having an anonymous identity was highly important, several participants still preferred face-to-face dialogue as long as they could safely use pseudonyms. Some of these participants even considered an in-person group meeting to be a safer space than a digital platform, as they believed that identities and written text could leak more easily through online engagement. Due to the Delta and Omicron waves, we could not expand to in-person interactions, but we were able to invite users to engage in group video calls (with cameras being voluntary). Based on post-intervention interviews and survey results, we concluded that text-based dialogue was not as successful as we had anticipated and that "live" face-to-face dialogue had made a bigger impact on users.

3.2. The cultivation of open dialogue entails a tension between helping participants voice and overcome their concerns (e.g., about vaccination) and exposing participants to others' ideas that may exacerbate those concerns. This is the paradox of open dialogue that must be adaptively navigated.

Our aim was to cultivate open dialogue that would not only give voice to diverse viewpoints but also more specifically, give voice to healthcare workers as a way to help them overcome their concerns. However, with open dialogue, there was also a risk of creating an echo chamber of narratives that might prevent the intervention from possibly contributing to building vaccine confidence, another aim of our project. This occurrence is what we call the paradox of open dialogue. In pre-intervention focus group discussions, when we encountered instances where healthcare specialists monopolized the dialogue with no pushback from other participants, the team had to reflect further on the meaning of open dialogue and the limits of free speech.

Monitoring and moderating dialogue is one way to navigate this paradox, but it is not straightforward. Because some users (particularly vaccine skeptical ones) might perceive the space as being an extension of institutional sources of information (e.g., World Health Organization) or as being another platform for debunking alternative views, we had to recognize that too strict management of the dialogue might discourage them from openly voicing their views. For vaccine hesitant HCWs, having a rule where people had to listen and respect each other's opinions brought relief. Being allowed to post articles about concerns that are usually interpreted (on other platforms) as misinformation also meant a great deal to them.

Our preparation for navigating the paradox on the text-based platform included: (1) sharing rules of conduct with users and (2) close monitoring to address imbalanced dialogue. Additionally, our risk mitigation options included, for example, recruiting more participants to help balance the dialogue and using the face-to-face dialogue sessions to address any behavioral issues observed in the text-based platform. This means that the management of a safe digital space may require drawing on different types of resources as needed, which requires ongoing attention and flexibility.

For our face-to-face dialogue sessions, navigating the paradox meant: (1) excluding the healthcare specialists who had previously hijacked the focus group discussions, which inhibited dialogue and (2) selecting a professional facilitator who generated dialogue through structured debate. The facilitator we recruited used the deep democracy approach to group dialogue and conflict management (28), which was recommended by some of our participants. The debate question was centered on the mandatory vaccination of HCWs, making use of polarization in that there were two sides. Each participant (including our team members who attended) was asked to give arguments for both sides, in order to collectively cultivate empathic dialogue.

As researchers, we hesitated to play both sides of the debate, primarily due to the potential impact that we—as researchers giving arguments against vaccination—might have on hesitant HCWs. In one session, our team members declined to give arguments against vaccination. In another session, our other team members fully participated, and this appeared to be appreciated by their participants and facilitator.

3.3. Interactional exchanges (e.g., with peers or experts) that matter to participants may shape the dialogue in terms of its content and form. Uncover what is relevant to participants.

In our context of vaccination among HCWs, the level of expertise or power was a key characteristic of exchanges that shaped how participants wanted to engage in dialogue and with whom (29). Notably, several participants called for what we would characterize as an "epistemically vertical" exchange, in that they were requesting information and guidance from experts. Not all participants, however, would consider a space to be safe if there was the presence of an expert (or someone who thinks they know better or who has the "official answer"). And for others, experts were seen as listeners who could make a difference; for example, some participants wanted to be heard specifically by scientific experts or others with authority, such as policymakers. Hierarchy among HCWs can also matter, for example, when doctors or specialists made strong claims and other HCWs did not push back. Reflecting a more "epistemically horizontal" exchange, some participants spoke of other HCWs as peers and preferred a facilitated dialogue among peers; they further suggested that peers be screened for their willingness to engage in dialogue.

We considered how we might incorporate all these different types of exchanges, but due to the short duration of the platform, we ultimately chose not to engage scientific experts. We believed that this could have exacerbated asymmetries in expertise and power, which would have required more time for adaptation, as the notion of an "expert" can vary based on the participant and interaction context.

Not surprisingly, a moderator or facilitator—representing a more "neutral" exchange—mattered to participants too. As researchers, we aim to preserve a certain "neutral" and trusting relationship with participants throughout the process. The polarizing nature of the topic—and thus the potential for unintentionally producing a context of "right" or "wrong" information that could shape people's vaccination decisions—pushed the team to have a clear strategy about its role. For example, if we had specifically taken on the role of an expert while conducting interviews, then the combination of asking participants for their views and sharing our "expert" view could have damaged our own epistemic position in the research process. We did not feel that we could or should serve as experts who provide "the truth" or "the right" information, because we recognized that what can be considered information vs. misinformation is not always clear.

Participants did not want to enter a space where they were to be persuaded to be pro-vaccination, but they did appreciate us posting weekly results of our social media analysis. We were careful about how we framed the posts, in order to avoid conveying our pro-vaccination stance or influencing participants in unanticipated

TABLE 1 Recommendations for more context-sensitive dialogue-based intervention design.

Recommendations for intervention organizers	Application to the topic of vaccine hesitancy
In exploring user needs during the pre-intervention design stage, be open to understanding the multiple ways in which participants may understand key concepts such as "safe dialogue" (and any related concerns)	In cases where participants need to feel safer to engage or want more meaningful dialogue, explore how their understandings of these concepts translate into viable formats for dialogue. If possible, work with participants to explore how to handle dialogue "risk factors" that shape context, such as the participation of those seen as having polarizing views or "expert" views. Other factors may include pressures to comply to directives in the workplace or hesitancy to share their concerns
Consider whether and how multiple dialogue-based interventions could be implemented, in order to reach a larger population and be more adaptive to different (and dynamic) needs	Because the framing of an intervention and its goals may not work for all participants (e.g., those who might not trust public health institutions), multiple interventions with distinct goals may need to be implemented to allow for different contexts for dialogue. For example, one intervention may explicitly aim to address information concerns while another cultivates empathy and allows for meaningful discussion
Formally integrate reflexive practices into the intervention design process, through making the time and space to discuss and respond to the emerging relationship between organizers and participants, on an ongoing basis or at key points in time	As concerns about vaccine hesitancy have been well-documented in literature, use this knowledge as a starting point to reflect on the influences and roles of the organizers. If possible, provide participants with opportunities to share not just their experience engaging in dialogue but also their experience relating to the organizers, in order to adapt to their context in a timely manner

ways. We became sensitized to this very early on, when some participants pointed out the pro-vaccination bias that they could detect in our pre-intervention survey questions (which used closed questions and a Likert scale for quantitative evaluation).

4. Discussion

Our case contributes a more dynamic and contextualized view to literature on addressing vaccine hesitancy with dialogue (30) and vaccine hesitancy among HCWs (31). We gained a sense of how highly contextualized and adaptive the development process for dialogue-based interventions needs to be, if we are to seriously orient to participants (e.g., not see them as simply being "users" with preferences but as also being shaped by situated meanings, paradoxes, and types of exchanges) and if we are to make use of digital platforms, which cannot equally serve all stakeholders. We do not suggest that our specific adaptations are necessarily solutions for other interventions, but rather that our adaptations reflect the need to design dialogue-based interventions with our three context-related lessons in mind.

We also suggest that having a discovery-orientation—meaning to work not only inductively and iteratively but also reflexively (e.g., where researchers are attuned to their own challenges, open to learning about their own role in shaping context, and exploring their capacity to adapt with participants)—should be a necessary part of the development of dialogue-based interventions and possibly also a part of the ongoing intervention (32, 33). Such reflexivity is lacking not only in dialogue-based interventions but also in digital health interventions (30, 34). In both types, the recursive relationships between researcher and context and between researcher and participants tend to go unacknowledged, except through mentions of researchers' limitations. What seems to run counter to a discovery-orientation is the growing interest in an approach that sits at the intersection of both dialogue-based and digital interventions: chatbots (13–15, 35, 36). Even though chatbots are considered promising, easily scalable, and adaptable, they are limited in how they can respond to rapidly-changing vaccination concerns and emotional statements (15) and thus, how they can incorporate context and cultivate dialogue. Furthermore, chatbots might not serve populations for whom authenticity of dialogue and safety of data are key requirements for engagement.

Our specific case demonstrates the importance of maintaining a discovery-orientation not only through offering three key lessons but also through shedding light on influences between: *dialogue topic/content* (i.e., COVID-19 vaccination), *socio-political landscape* (i.e., COVID-19 "infodemic," fifth wave of infections nation-wide, and mandatory vaccination for HCWs), *population* (i.e., HCWs in Belgium with varying degrees of vaccine hesitancy/confidence), *intervention aim* (i.e., "safe space" for dialogue), *dialogue form* (e.g., digital, text-based, face-to-face), *ethics* (e.g., anonymity, risk of offline impact, risk of increasing vaccination concerns), *researcher position* (i.e., pro-vaccination stance, "neutral" project role, rules moderator, source of expertise or "truth"), and *types of interactional exchanges* (e.g., with healthcare peers/experts, co-workers, institutions, scientific experts, facilitators, research team). These linkages are avenues for future research. Juggling these considerations and feeling more constrained about what we could say to participants about our own views or concerns, we were also caught up in a form of "unspoken hesitancy" (24). We could not simply cultivate dialogue "from the outside" but were intertwined in the process and thus were cultivating it "from the inside."

To advance practice, we offer three specific recommendations for how dialogue-based interventions can embrace context, and we elaborate on how these apply to the specific topic of vaccine hesitancy (Table 1). These recommendations reflect our conclusion that researchers, public health stakeholders, and other organizers should continue developing dialogue-based interventions and digital interventions in inductive and participatory ways, but with greater attention to how their own roles in an evolving context are shaping dialogue, participants, and the intervention process itself.

Data availability statement

The datasets presented in this article are not readily available because they are composed of full transcripts of several thousand words each, which even when anonymized could lead to the identification of participants. Requests to access the datasets should be directed at: the Institutional Review Board at the Institute for Tropical Medicine (Antwerp, Belgium) at irb@itg.be.

Ethics statement

The studies involving human participants were reviewed and approved by the Institutional Review Board of the Institute of Tropical Medicine (ITM) Antwerp and the Social and Societal Ethics Committee (SMEC) of KU Leuven. The patients/participants provided their written informed consent to participate in this study.

Author contributions

LH, CG, CVR, HL, TG-V, KPG, and NV conceptualized the project. LH, SD, HD, TN, CVR, LB, and CG conducted the research and investigation process. NV, TG-V, KPG, and HL provided oversight and leadership. TN first drafted the manuscript. LB reviewed the literature used in this paper. TN, LB, LH, CVR, CG, SD, NV, TG-V, KPG, and HL contributed to reviewing and editing of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

LH, NV, TG-V, KPG, CG, CVR, SD, TN, LB, and HD declare receiving a grant by Fonds Wetenschappelijk Onderzoek (FWO-Research Foundation—Flanders), to conduct social listening of vaccine concerns in Belgium and receiving funds by the Vaccine Confidence Fund to conduct a study on healthcare workers vaccine sentiments and to foster vaccine dialogue in Belgium. HL reports receiving a grant by MacArthur Foundation to address inequalities in COVID-19 recovery, by J&J to listening to public concerns around COVID-19, from UNICEF to carry out Social Media Listening of vaccine concerns in Central and Eastern Europe and by Merck on Research on Vaccine hesitancy among health care providers in 15 countries.

Publisher's note

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From the national to the local: Issues of trust and a model for community-academic-engagement

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Inequities in health and health care in the United States have persisted for decades, and the impacts on equity from the COVID-19 pandemic were no exception. In addition to the disproportionate burden of the disease across various populations, the pandemic posed several challenges, which exacerbated these existing inequities. This has undoubtedly contributed to deeply rooted public mistrust in medical research and healthcare delivery, particularly among historically and structurally oppressed populations. In the summer of 2020, given the series of social injustices posed by the pandemic and highly publicized incidents of police brutality, notably the murder of George Floyd, the Association of American Medical Colleges (AAMC) enlisted the help of a national collaborative, the AAMC Collaborative for Health Equity: Act, Research, Generate Evidence (CHARGE)[1] to establish a three-way partnership that would gather and prioritize community perspectives and lived experiences from multiple regions across the US on the role of academic medicals centers (AMCs) in advancing health and social justice. Given physical gathering constraints posed by the pandemic, virtual interviews were conducted with 30 racially and ethnically diverse community members across the country who expressed their views on how medical education, clinical care, and research could or did impact their health experiences. These interviews were framed within the context of the relationship between historically oppressed groups and the COVID-19 vaccine clinical trials underway. From the three-way partnership formed with the AAMC, AAMC CHARGE participants, and 30 community members from racially and ethnically diverse groups, qualitative methods provided lived experiences supporting other literature on the lack of trust between oppressed communities and AMCs. This led to the development of the Principles of Trustworthiness (PoT) Toolkit, which features ten principles inspired by community members' insights into

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[1] The AAMC Collaborative for Health Equity: Act, Research, Generate Evidence (CHARGE), a national collaborative of health equity scholars, practitioners, and community partners cultivates health equity through partnerships with communities, families, patients, and sectors outside health care to advocate for structural and policy change and address factors that contribute to a community's health. For more information, visit aamc.org/CHARGE.

how AMCs can demonstrate they are worthy of their community's trust[2]. In the end, the three-way partnership serves as a successful model for other national medical and health organizations to establish community engaged processes that elicit and prioritize lived experiences describing relationships between AMCs and oppressed communities.

KEYWORDS

health equity, community engagement, trustworthiness, healthcare, social justice

Introduction

The lack of public trust in medical research and healthcare delivery by historically oppressed groups is one of the most significant obstacles facing medical institutions today. Equally important are the root causes for this distrust amongst historically oppressed people, which have contributed to longstanding health and healthcare inequities (1). The COVID-19 pandemic has exacerbated these inequities and reminds us that to effectively address inequities experienced by communities that have historically been oppressed, we must first have relationships with those communities predicated on trust (2).

Academic medical centers and their partners must co-develop more authentic community-engagement strategies to build trust and ultimately facilitate effective health equity action (3). Furthermore, these strategies must acknowledge the present and historical incongruence of health and healthcare experiences between majority and minoritized groups.

In the United States, the evidence of injustices against communities of color, including those directly impacting health, supports the use of qualitative methods to study the lived experiences of these groups as they encounter healthcare systems (4, 5). The use of qualitative methods presents one of the best options for exploring whether and how structural racism, as a set of social processes and relationships, triggers biological mechanisms that impact the health of historically and structurally oppressed groups[3]. Given the value of lived experiences in elucidating social processes and issues resulting from historical and present-day structural barriers, qualitative methods are an effective pathway for developing community-academic partnerships to improve community health (6).

In 2020, the Association of American Medical Colleges (i.e., "AAMC team") revised its 2015 process of developing annual toolkits that explore how academic medical centers engage and work with members of oppressed groups.[4] Here, we illustrate the 2020 process used during the COVID-19 pandemic describing how the AAMC built trust across multiple regions with community members of racial and ethnic groups by working through a nationally organized third party known as AAMC Collaborative for Health Equity: Act, Research, Generate Evidence (CHARGE). By implementing community-engaged practices through an intermediary organization, AAMC was able to use qualitative methods across several local regions to successfully capture the lived experiences of community members that make up the CHARGE service areas. This three-way partnership between the national organization and multiple communities facilitated through an intermediary group ultimately produced narratives on mistrust representative of stories from historically oppressed groups and produced the toolkit entitled Principles of Trustworthiness (PoT).

The three-way partnership is a replicable and scalable model for other AMCs to elicit and prioritize widespread community insights in a virtual environment. Additionally, inspired by approaches but distinct from other existing partnership models, this process was facilitated by a national, multidisciplinary health equity network (7). This work amplifies concepts and frameworks about building the trustworthiness of AMCs among oppressed communities shared in the pre-COVID-19 literature, such as making long-term commitments, bi-directionality, and humility (8, 9). Thus, the process sets a unique precedent by establishing community-engaged practices that moved from the national level through a third-party organization down and across multiple local regions to elicit lived experiences from racial and ethnic community members that highlighted relationships between AMCs and groups that experienced historical and ongoing inequities during the COVID-19 pandemic.

Methods

The AAMC team set the vision and goals of the initiative, identified partners that could recruit members of historically and structurally oppressed groups, and managed the logistics

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[2] For more on the PoT toolkit, see aamc.org/trustworthiness.

[3] Chapter co-author Lauri Andress' public health website (placeandhealthwv.com) is a qualitative epidemiological profile of inequities using stories, narratives, and images to portray the lived experiences of historically marginalized groups that lie behind the past and present-day rates of death and disease reported in one region of the US.

[4] The development of toolkits began in 2015 with video recorded interviews from a single region soliciting their perspectives on how medical education, clinical care, and research can and should respond to social injustice and the social determinants of health. The resulting videoed interviews were used to frame a conversation during the annual AAMC meeting.

TABLE 1 Geographic location of Principles of Trustworthiness Toolkit partners.

	AAMC team	AAMC CHARGE collaborators	Community members
Total number of participants	5	9	30
Institution/region	Washington, DC	**Baylor University** Houston, Texas **Children's National Hospital** Washington, DC **Christiana Care Health System** Wilmington, Delaware **Fayetteville State University** Fayetteville, North Carolina **George Washington University** Washington, DC **The Ohio State University** **Medical Center** Columbus, Ohio **Readily Apparent** Austin, Texas **UCLA CTSI Community Engagement Research Program and Kaiser Permanente Bernard J. Tyson School of Medicine** Los Angeles, California **The University of Texas, Galveston** Galveston, Texas	**West:** Los Angeles, California Sante Fe, New Mexico **Midwest:** Columbus, Ohio Pittsburgh, Pennsylvania **South:** New Orleans, Louisiana Fayetteville, North Carolina Austin, Texas Galveston, Texas Houston, Texas **East:** Washington, DC Wilmington, Delaware

and coordination of all project components, including engaging all partners.

Establishing the team and logistics

Given official in-person gathering guidelines and restrictions posed by the COVID-19 pandemic, the AAMC CHARGE, a national collaborative of health equity scholars, practitioners, and community partners, was enlisted to produce the 2021 toolkit.

The AAMC team requested applications for interested AAMC CHARGE participants (i.e., "collaborators") with community engagement and qualitative research experience who could recruit and conduct semi-structured video interviews with local community members from across the US that had lived experiences based on membership in an oppressed group. Following the application review period, 13 collaborators were selected. Given scheduling conflicts with a few of the initially selected collaborators, the last team of collaborators consisted of nine individuals from varying organizations/institutions and regions of the country (Table 1). Before beginning the toolkit development process, the AAMC team worked to coordinate IRB clearances for some of the collaborators as required by their institutions.

A 1-h mandatory virtual training session was held for all collaborators to learn more, ask questions, and offer modifications about the project, its goals, and the process for conducting the interviews and submitting files. Each institutional team selected one person as the designated interviewer and was provided a shared Dropbox folder, which contained the following:

- Training materials for interviewers.
- Interview guide.
- Consent forms, including certified Spanish translation.
- IRB approval documentation.
- Technical configuration for optimizing and standardizing Zoom recording quality.
- Detailed Instructions for all processes.

The AAMC team chose Dropbox as a standard filesharing tool and Zoom as the preferred video recording platform due to their low cost and high accessibility across operating systems and devices.

Community participant recruitment, interviews and analysis

While there was no universal method for recruiting interviewees, the project relied on CHARGE collaborators' extensive regional community relationships across the US. As a result, the recruitment criteria tasked CHARGE with recruiting interviewees of at least 18 years of age from racial and ethnic groups of any gender, socioeconomic status, geographic location, or educational level.

Collaboration across the national regions that came from CHARGE collaborators, geographical distances, and digital work and information environments presented unique challenges and constraints posed by COVID-19 pandemic social distancing and safety requirements. Thus, collaborators conducted most interviews virtually.

Given the potential of varying access to technology, information was provided for interviewees to sign consent forms *via* free smartphone apps such as Adobe Fill and Sign. Digital photos of signed hard-copy audio and video consent forms were also accepted and taken by either the interviewee or the collaborator. Interviewees could participate in the interview *via* smartphone, tablet, or computer *via* the free Zoom app. Collaborators used a 12-question interview guide that members of the AAMC team developed to conduct individual, semi-structured, virtual interviews with community members from each of their local regions (Supplementary material 1). The interview guide included open-ended questions to explore the community members' perspectives about how community, clinical care, medical education, and research make individuals and communities healthier. The guide was based on the 2015 interview guide co-developed by the AAMC team, the University of Maryland Medical Center, Johns Hopkins University, and their community partners. In 2015, that team sought to understand the Baltimore community's perspective on how academic medicine, across its research, clinical, and educational missions, could address local social injustice. For the 2020 iteration, we revisited that guide and shifted the focus from local injustice to the broader issue of trust in our medical and scientific institutions and communities.

After the interviews, collaborators used standardized nomenclature for saving files, uploaded all materials into their institution's respective Dropbox folder, and notified the AAMC team *via* email within 48 h of conducting an interview. A $25 gift card (either by email or a physical card sent *via* US mail, according to interviewee preference) was sent directly to the participant within 24 h of AAMC being notified. In addition, the de-identified interview audio was submitted to a transcription service. Hyperlinks to all documents (video files, separated audio tracks, consents, transcripts, and contact information for interviewees to receive gift cards) were compiled into a single spreadsheet listed by participant name. This spreadsheet was accessible only to the AAMC team to protect the interviewees' privacy.

The AAMC team used open coding to develop codes from the review of transcripts and then refined codes with a subsequent review during a series of multiple close readings during virtual meetings to discuss the key themes which emerged from the interviews (10). As part of the data analysis, the AAMC team and the collaborators selected and organized relevant interviewee quotes to appear in a professional 10-min video montage. These quotes, including their respective timestamps, were ordered and categorized according to subthemes to develop the "storyboard" for the video. The AAMC team contracted with an external pre-identified video production company to edit the interview footage accordingly. The company developed consecutive video cuts for review until a final version was approved. To ensure collaboration throughout this process, the AAMC team, collaborators, and community members remained connected through regular email communication and virtual calls, during which project updates were shared, and there were opportunities for revision. Additionally, during these exchanges, the collaborators relayed their and community members' feedback on the different cuts of the video and other components of the resulting toolkit. The AAMC team moved forward with the final products once a general consensus was met with all partners.

Simultaneously, once all community interviews and analyses were completed, the AAMC team worked with a self-selected subset of collaborators to develop a brief evaluation survey that gathered more detail about the nine collaborators' strategies to recruit interviewees and conduct their interviews. The survey was approved by AAMC and administered *via* Google Forms.

Results

The AAMC effort resulted in the following outcomes: (1) formation of a three-way partnership between the five Association of American Medical College (AAMC) team members, nine AAMC CHARGE collaborators, and 30 diverse community members from across the nation with racial and ethnic backgrounds (Table 1) and (2) the co-development of the PoT Toolkit (Table 2, Supplementary material 2–4).

The AAMC CHARGE collaborators served as a liaison between the AAMC and the 30 racially and ethnically diverse local community members from regions across the US. The collaborators used snowball sampling to recruit community members *via* email and word of mouth based on previous relationships between CHARGE collaborators and specific community organizations.

The collaborators conducted 28 virtual and two in-person interviews regarding clinical trial participation in the setting of the COVID-19 vaccine trials that were underway at the time. The interviews yielded 14 h and 51 mins of video footage, with an average of 30 mins per interview. The AAMC conducted the initial data analysis and shared with all partners the primary unifying and paramount theme of trustworthiness that emerged from the interviews[5].

For the evaluation of the partnership, nine CHARGE collaborators completed a survey that assessed their reflections and level of satisfaction with the toolkit development process and three-way partnership. Collaborators reported that it was essential to recruit participants with whom they had previously developed a trusted relationship, defined as a reliable, respectful, meaningful, and bidirectional collaboration where parties co-learn and evolve together.

Additionally, collaborators were very satisfied with the establishment, process, and final product of the three-way partnership, the PoT toolkit. Further collaborators reported satisfaction with the AAMC's vision for the initiative, facilitation

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[5] "Trustworthiness" is defined as being worthy of confidence or being responsible, safe, and secure (https://www.merriam-webster.com/dictionary/trustworthiness). Accordingly, trustworthiness is defined in relation to its amplification of the core principles of community engagement, including bi-directionality, shared governance, and inclusivity.

TABLE 2 Description of principles of trustworthiness toolkit components.

Component	Description
10 principles of trustworthiness	1. The community is already educated; that's why it doesn't trust you 2. You are not the only experts 3. Without action, your organizational pledge is only performance 4. An office of community engagement is insufficient 5. It doesn't start or end with a community advisory board 6. Diversity is more than skin deep 7. There's more than one gay bar, one "Black church," and one bodega in your community 8. Show your work 9. If you're gonna do it, take your time, do it right 10. The project may be over, but the work is not
Recorded videos and video guide	Principles of Trustworthiness Community Video, featuring footage from interviews with community members, and The Principles of Trustworthiness Orientation Video. The video guide offers suggestions for how to use each video
Interactive discussion guide	Includes pre-work for facilitators, and a series of steps for engaging audiences in interactive discussions about the Principles of Trustworthiness
Community engagement action guide	Includes a series of activities to assist in moving the 10 Principles of Trustworthiness from concept to action
Community engagement reflection guide	Includes a series of questions for personal self-reflection or as a tool to help one's organization reflect upon all 10 Principles of Trustworthiness

of meetings, communication about recruitment logistics and conducting interviews with participants, and data analysis. Moreover, they were delighted with the way feedback and perspectives of all parties were incorporated into each stage of the initiative and reported that they were very likely to engage in future efforts of this collaboration. One collaborator stated that the "team used a completely collaborative approach that is rare to find in academic medicine [...] it was a privilege to be a part of." Collaborators thought their final product would impact academic institutions' engagement with diverse community stakeholders. Another collaborator noted, "The voice of the community partnered with the AAMC reputation will be critical in engaging medical centers to engage and learn more about this work [...] I believe in the goals of the collaboration to effect change."

Discussion

In the end, the unique, three-way partnership is exemplary of a comprehensive approach that other AMCs can emulate to elicit and prioritize community insights and lived experiences from community members. While the initiative was conceived and led by the AAMC, we utilized a partnered approach throughout the entire process, from design to dissemination of the Principles of Trustworthiness Toolkit. Additionally, our partnership process led to the co-creation of content that adds to existing literature demonstrating why and how historically marginalized communities lack trust in academic healthcare institutions that aim to serve the public (8, 9). While the theme of distrust among marginalized communities and the 10 Principles of Trustworthiness are not novel concepts, the outcomes of this project amplify the evidence showing an increased interest in the topic during the COVID-19 pandemic. Further, the PoT Toolkit also serves to build on, support, or provide recommendations that further that trustworthiness as a foundation for effective community engagement (11, 12). Finally, guidance was provided for any organization and all stakeholders within AMCs, including, but not limited to, healthcare providers, public health officials, and researchers, to recognize the elements required to move beyond merely building trust and becoming *trustworthy* to its local community partners.

Limitations

Despite its innovation, this process had limitations. Though we were able to recruit diverse collaborators and community members from different regions of the country, our sample size was small, and our results may need to be more generalizable. Our study was also limited in that access to broadband and technology (including those living in rural areas) was a critical component of community member participation and thus may have excluded some under-resourced populations, further limiting the generalizability of this study. This also impacts the validity of the product, particularly given the challenges posed by the COVID-19 pandemic for those without broadband access. Finally, due to logistical barriers, we needed to formally assess community members' satisfaction with or reflections on the recruitment and partnership process. Though we received overwhelmingly positive feedback indirectly from CHARGE collaborators, a structured evaluation of participating community members' perceptions would have bolstered the validity of the process and product.

Future implications

Moving forward, the sustained three-way partnership model will allow for future collaborations with stakeholders that facilitate the refinement and effectiveness of community-academic partnerships that seek to address historical issues of mistrust between AMCs and groups who have been historically marginalized.

Further, in addition to the usefulness of the Toolkit, the PoT remains a hallmark of the Center for Health Justice's work and enjoys ongoing interest and adoption. The AAMC Center for Health Justice is continuing investment in the PoT and has planned implementation, evaluation, and dissemination activities for 2023 and beyond. Further, to address some of the study's limitations, it will be critical to share the toolkit with those community members who did not have broadband internet to validate its ability to represent the lived experiences, beliefs, and circumstances of under-resourced groups. There may also be an opportunity to conduct a similar study post-pandemic with in-person interviews to increase sample inclusivity, as well as disseminate an evaluation of the existing toolkit and partnership by participating community members. Moreover, the PoT Toolkit can be used by AMC leaders to set aside dedicated time to have facilitated discussions within their communities of healthcare providers, researchers, and community stakeholders/members. These discussions will allow all involved in unpacking the principles to explore how they uniquely come to life locally and determine what actions might be taken to demonstrate trustworthiness. Ultimately allowing for enhanced relationship building with broad coalitions, the ability to track lessons learned, and highlighting the importance of health leaders co-creating and sustaining multi-sector community partnerships with the explicit mission to improve population health.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The human subjects' research described in this Innovation Report was approved by American Institutes for Research's Institutional Review Board IRB00000436 on 8/14/20, project EX00530. The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

PA and KS conceived the original idea and helped supervise the project. KS and OC spearheaded the development of research materials while LA, EA, DT, SM, SG-W, and ML carried out the research. OC and SP oversaw logistics related to research implementation. OC, SP, PA, and KS spearheaded the analysis. All authors discussed the results and contributed to the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1068425/full#supplementary-material

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Represent: A community engagement roadmap to improve participant representation in cancer early detection research: An Oregon case study

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Introduction: While authentic and sustained community involvement in the research process is critically important to making new technologies and interventions effective and socially acceptable, there is uneven participation across sociodemographic, racial, and ethnic communities in many research areas, including cancer early detection research. Currently, 18% of cancer in the United States impacts Hispanics and Latinos, this population accounts for <10% of research participants. Understanding barriers and facilitators to cancer early detection research is imperative to the ultimate success of this research. Therefore, the objectives of this study were to: understand Hispanic and Latino community perspectives in participation in cancer early detection research; and identify sustainable and mutually beneficial approaches to community engagement and involvement.

Methods: The Oregon Case Study, led by Oregon Health & Science University's Community Outreach, Research and Engagement (CORE) in partnership with colleagues at Vocal, a partnership between Manchester University NHS Foundation Trust and the University of Manchester and Cambridge University, adopted a participatory research approach to better understand participation in cancer early detection research from the perspectives of Oregon's Hispanic and Latino community members. We implemented two evidence-based community engagement models, the Community Engagement Studio and the Community Readiness Assessment Model. Using a facilitated format prescribed by each community engagement model, community members helped us to answer two research questions: (1) What methods help us increase participation of underrepresented communities in cancer early detection research?; and (2) How can we build trust between researchers and underrepresented communities within cancer early detection research? Quantitative (i.e., descriptive statistic) and qualitative (i.e., thematic analysis) analytic methods were used to measure and assess community knowledge, leadership, beliefs, and resources regarding participation in cancer early detection research.

Results: A total of 36 Hispanic and Latino community members participated in the two community engagement models. We identified three emergent themes pertaining to participation in cancer early detection research that include: low-level awareness of cancer early detection research and opportunities for research participation, structural barriers to research participation, and uncertainty of the benefits of research participation.

Conclusion: Our approach, using two evidence-based community engagement models, yielded valuable insights about perceptions of research participation for Hispanic and Latino community members. These findings, synthesized into three key themes, led to actionable recommendations to increase research participation.

KEYWORDS

cancer early detection, research participation, underserved and unserved populations, community engagement, cancer early detection research

Background

While it has often been said that cancer is a non-discriminate killer, the reality is that in Oregon and the country as a whole, individuals from geographic and racial/ethnically underrepresented groups are disproportionally affected by certain types of cancer (1). Cancer is the leading cause of death among Hispanic or Latino people in the USA, accounting for 20% of deaths (2). In 2021, there were an estimated 176,600 new cancer cases and 46,500 cancer deaths among Hispanic & Latino people in the United States (3).

The best approach to reducing cancer mortality for all population groups is through effective strategies for cancer prevention and control. New technologies that are developed through cancer early detection research are one of the most promising approaches to reducing the cancer burden and saving lives (4). However, for these technologies to reduce cancer deaths in a significant and meaningful way they must work for everyone.

Participation from people from all racial and ethnic groups is crucial in translational clinical research, biorepositories, observational studies, and clinical trials (5). Suboptimal participation rates among populations that have been historically underrepresented in cancer clinical trials, including Hispanic and Latino people, are a major obstacle to the effectiveness of cancer early detection technologies developed through research (6, 7). Between 2019 and 2021, while the number of people identifying as Not Hispanic who participated in National Institutes of Health funded research rose from 87.3 to 91.1%, the percentage of participants identifying as Hispanic fell from 9.7% in 2019 to 9.3% in 2021 (8). Stated another way, Hispanic and Latinos represented 18% (60.6 million) of the U.S. population in 2019, but make up <10% of participants in federal cancer and drug studies (3, 8, 9). The historical and current underrepresentation of minority participants in clinical trials could reduce cancer early detection and treatment effectiveness. Without adequate representation in cancer clinical trials, researchers are less likely to develop approaches or new early detection technologies that are acceptable to and work best for minority populations, including the Hispanic and Latino population, the largest ethnic minority population in Oregon (10).

Goals of this investigation

The objectives of this case study were to: (1) understand Hispanic and Latino community perspectives in participation in cancer early detection research; and (2) to identify sustainable and mutually beneficial approaches to community engagement and involvement. This project was guided by two questions: (1) How can all communities be included in cancer early detection research?; and (2) How can trust be built between cancer early detection researchers and communities?

Methods

This study was a collaboration among the University of Cambridge, Vocal, a partnership between Manchester University NHS Foundation Trust and the University of Manchester, the University College London, and Oregon Health & Science University Knight Cancer Institute in Oregon, U.S.A. The multidisciplinary research team brought together expertise from social anthropology, community health, epidemiology, public health, and community engagement/public and patient involvement and engagement (PPIE).

We implemented two evidence-based community engagement models the Community Engagement Studio (CES) (11–13) and the Community Readiness Assessment Model (CRAM) (14). Both models position community members as experts and active members in every step of the process. Importantly, implementation of these models were guided by principles of compensating participants for the time and expertise, meeting the community where they are, (i.e., go to the community), and being inclusive through use of the community's preferred language. Both models are described in detail below in our description of data collection activities. We elected to implement two participatory community engagement models with community representatives to develop a deep understanding of barriers and facilitators to participation in cancer early detection research among individuals in the Hispanic and Latino community (10). This approach also enabled us to identify mutually beneficial approaches to build trust and social acceptability of cancer early detection research participation by understanding individual level attitudes and community level support.

Participants

Participants were recruited from two regions in Oregon, (i.e., Central Oregon and the Willamette Valley). Two community partners led recruitment activities using a purposive sampling approach. Potential participants were approached by two community organizations *via* email, text, and phone describing the study and inviting their participation. To be eligible, participants self-identified as Hispanic or Latino and reside in Oregon. All participants received financial compensation in acknowledgment of their contributions to this study.

Data collection

Two CES and one CRAM were implemented within a four-week period in the spring of 2022. The CES model is a facilitated conversation between identified community "experts" and the scientist (11–13). The model intentionally engages the focus population as community experts in giving them a voice to communicate with the researcher their experiential knowledge of their community, understand barriers and challenges to participating in research, identify potential ethical concerns, and provide firsthand insight into cultural and linguistic preferences (11). A structured 2-h facilitated discussion, the CES is a conversation between with community members, researcher, a facilitator, and a notetaker. The CES is an opportunity for the researcher to receive feedback from their population of interest on the relevance and feasibility of their research as shown in Figure 1.

We conducted two CES sessions within a two-week period using a virtual, web-based platform. Our partnering organization recommended the virtual format to increase participation by alleviating transportation barriers and COVID transmission concerns. Prior to the CES sessions, members of the research team met with a CES project lead with OHSU's Community Outreach, Research, and Engagement (CORE) team who provided consultation and guided them through a CES planning process, including logistical planning and the development of a 10-min presentation describing to orient CES participants to the REPRESENT project. The CES project lead also coordinated with a community partner who recruited participants and hosted both CES sessions. Both CES sessions were conducted in Spanish. Logistical planning, led by the CES project lead, involved training a bilingual OHSU CORE collaborator to facilitate the CES sessions, developing a plan to record both CES discussions, and training two bilingual notetakers who were employed by the community partner. Both sessions were video and audio recorded. Two notetakers attended each session. Notes were taken in English and given to the CES project lead who synthesized the notes in a summary report that was provided to the research team in English.

The Community Readiness Assessment model (CRAM) is a structured approach to understanding and enumerating how ready a community is to engage in different interventions, in this case, readiness to provide community wide support and buy in for cancer early detection research. Developed at the Tri-Ethnic Center at Colorado State University and revised in 2014, the CRAM involves community in every step of the process including recruitment, interviewing and analyzing the data, interpreting the results, and identifying next-steps (14). For this project, the CRAM consisted of 36 interview questions addressing the community's knowledge of efforts, leadership, community climate, knowledge of issue and resources regarding participation in cancer early detection research (Figure 1). Participation in cancer early detection research was defined as participation in ethically approved studies dedicated to understanding risk factors for developing cancer, developing new clinical tests to detect cancer early, or assessing how well current early detection tests work.

The same structured interview guide was used in all of the interviews. Bilingual, (i.e., Spanish and English) members of the Hispanic and Latino community conducted all of the interviews virtually, either by phone or a web-based platform including Zoom, and were compensated for their time. All interviewers received training *via* webinar and were sent handouts by email. A PhD researcher provided support *via* phone (call and text) and email throughout the data collection time period.

The interviews ranged from 30 min to 1-h. The interview guide included both open ended questions, as well as Likert-scale and quantitative (i.e., number between 1 and 10) assessments. Participants were given the option to conduct the interview in Spanish or English. All interviews were audio recorded, transcribed verbatim, and translated from Spanish to English by a certified translation service prior to scoring and qualitative analysis. Scoring of the interviews occurred in person with all members of the research team, our community partner, and all community members who conducted the interviews. Everybody involved in the scoring process underwent a 30-min, OHSU-developed training, including community research ethics. All community members who were a part of the interview process were compensated for their time.

Data analysis

CES data were analyzed using thematic analysis, a qualitative descriptive approach to identifying, analyze, and report patterns in the data (15). Common themes were identified across the four sets of CES notes, (e.g., two note takers documented each CES session).

Quantitative and qualitative methods were used to analyze CRAM data. Quantitative analysis using an anchored rating scale system from the CRAM community readiness handbook was used to score the CRAM interviews. Four researchers and four community members came together in a physical space to analyze the 12 interviews. The process lasted a full day, including introductions, informal conversations, training, analysis, lunch, and reflection.

Each content area, (i.e., knowledge of efforts, leadership, community climate, knowledge of issue and resources) of the interview was analyzed and scored separately. The final outcome from the assessment is a "score" for each of these five areas, as well as a combined score. The combined score connecting all five areas informs about the overall level of engagement or community capacity and guide recommendations for "next steps", whereas each area's score informs where to start.

All CRAM interview questions were first "scored" independently by one researcher and one community member. The two scorers then sat together to compare scores across each area for each interview they went through. If scores differed with only one point, then the average was recorded as the final score. If score discrepancies where larger than 1 "point", then they negotiated consensus by reassessing they answers and reflecting on bias and interpretation. In the majority of cases, scorers reported having identical scores or being within 1 point from each other. This process ensured validity, but also fidelity as potential cultural differences in the interpretation of the transcript were discussed and settled.

Qualitative analysis was initiated in parallel with the quantitative scoring of the CRAM interviews, and completed by two coders consisting of a researcher and an intern at a later date. During the CRAM scoring, all participants had the interview transcripts as paper copies. As they read through the transcripts and assessed a score, they also highlighted passages and quotes that felt important or justified a score. The highlighted quotes were collected into a spreadsheet. A research intern also read through the interviews

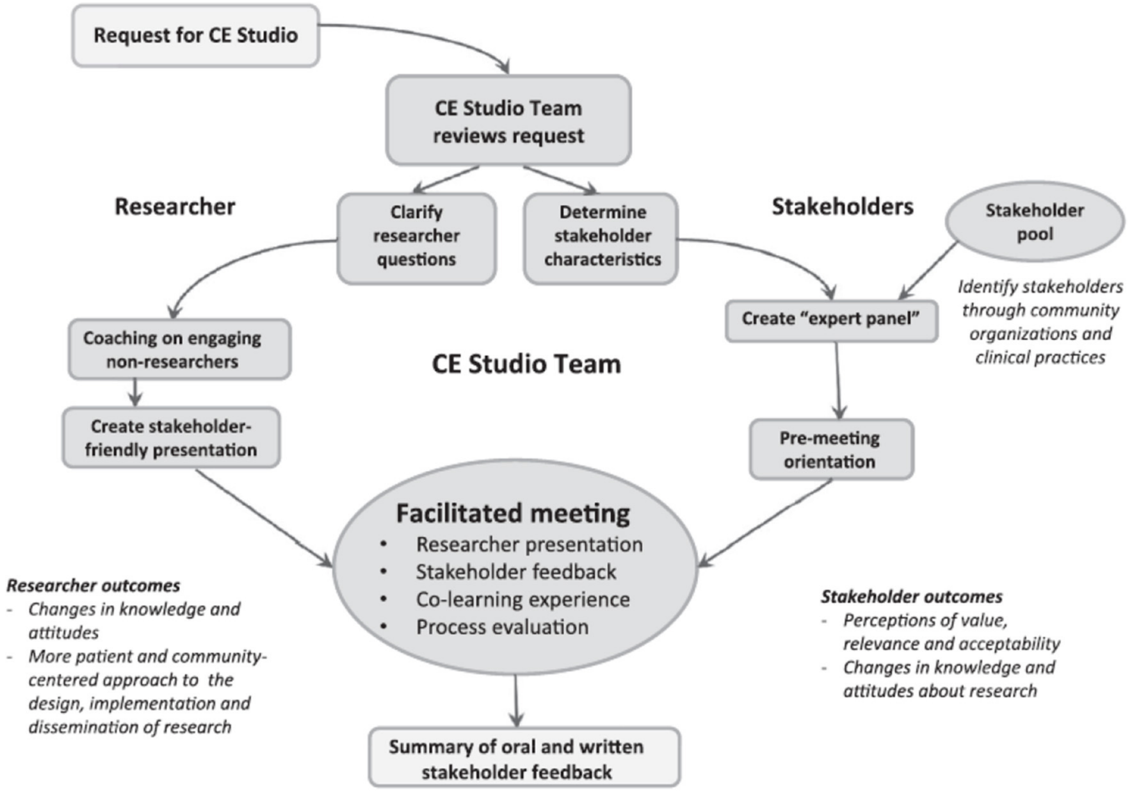
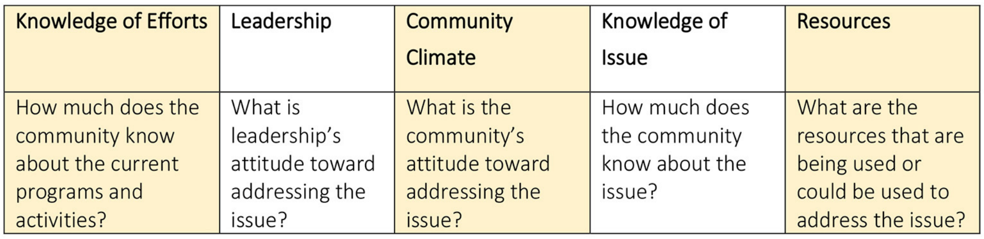


FIGURE 1
Community engagement studio framework implementation (11).



Knowledge of Efforts	Leadership	Community Climate	Knowledge of Issue	Resources
How much does the community know about the current programs and activities?	What is leadership's attitude toward addressing the issue?	What is the community's attitude toward addressing the issue?	How much does the community know about the issue?	What are the resources that are being used or could be used to address the issue?

FIGURE 2
CRAM participation in cancer early detection research assessment content areas.

and extracted mentions of places/organizations, as well as specific barriers and opportunities which had not been highlighted as part of the quantitative analysis using a thematic analysis approach. Each theme aligned with the dimensions of the CRAM, (i.e., knowledge and efforts, leadership, community climate, knowledge of issue, and resources) (Figure 2). We relied on the CRAM handbook's suggested Strength, Weaknesses, Opportunities, and Threads (SWOT). Framework (16) to identify strength, weaknesses, opportunities, and threads within each theme to report results to the community in a format which aligns closely with the overall CRAM method. Our approach to data collection and analysis is shown in Figure 3.

Results

We conducted two CES sessions and one CRAM over a 4-week period in the spring of 2022. A total of 34 individuals participated in the two community-engagement models, with 18 participating in the two CES sessions and 16 were involved in the CRAM. Participants characteristics are shown in Table 1.

CES and CRAM qualitative results

We synthesized CES and CRAM results and identified three key themes pertaining to participation in cancer early detection research. They include: (1) low-level awareness of cancer early detection research and research participation opportunities; (2) structural barriers to research participation; and (3) uncertainty of the benefits of research participation.

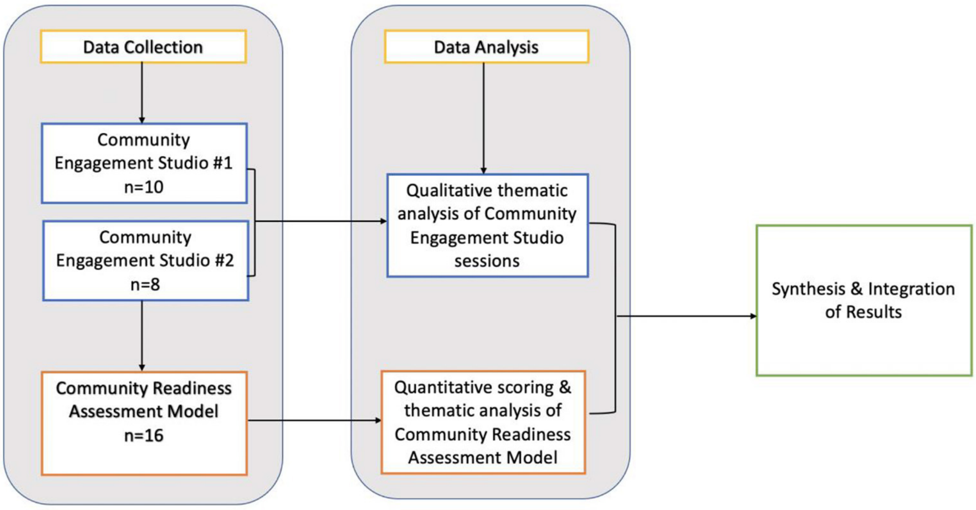


FIGURE 3
Data collection and analysis process.

TABLE 1 Participant characteristics.

Characteristic	CES	CRAM
Number of participants	18	16
Hispanic or Latino	18 (100%)	16 (100%)
Age		
Persons 25–40 years	4 (22%)	–
Persons 40–65 years	10 (55%)	–
Persons > 65 years	2 (11%)	–
Missing Data	2 (11%)	–
Gender		
Female	11 (61%)	10 (63%)
Male	7 (39%)	6 (37%)
Number of interviews	–	12
Number of interviewers	–	4

Low levels of awareness of cancer early detection research

We found a general lack of understanding of the meaning of the term cancer early detection and low levels of awareness about cancer early detection research. None of the participants identified prior or existing efforts for the Latino community to participate in cancer early detection research.

- "Because I think that in general, the Latino community is not aware of the available studies. If they are not aware of the available studies, then they aren't interested either, whether the Latino population is being taken into account or not." (CRAM Respondent #11)

Participants also stated their preference for being unaware of a health condition or disease diagnosis as there was a general feeling of hopelessness regarding ways to act on such information. From the qualitative analysis of CES and CRAM interview transcripts, we deduced that the low-level awareness about cancer early detection is mostly driven by residents' competing priorities to provide for themselves and their families, coupled with struggles to access healthcare, and high out-of-pocket costs for health care services from being uninsured or underinsured.

- "My community is living to survive not to live." (CES Respondent #1)
- "I think that the Latino community in general is more focused on meeting other needs or has priorities in other areas, like primary care, and also economic issues and how to meet their basic needs first and foremost." (CRAM Respondent #4)

Hispanic and Latino community members were not aware of any efforts to engage their community in cancer early detection research. Importantly, none of the participants identified prior or existing efforts for the Latino community to participate in cancer early detection research. While some participants recognized that their community's participation in cancer early detection research is important, other believed that research is only for people who are already sick.

- "These issues are certainly important and they know that research of this type can bring long-term benefits. But specific knowledge of what benefits they could bring, like what treatments are going to improve life expectancy…those things are not known at the community level." (CRAM Respondent #9)

Structural barriers to participation

Our study also identified several structural barriers, both individual-level and system-level, to research participation. Cultural differences, including language barriers were specifically noted as a challenge. Participants reported that research conducted in a language other than their primary language was a barrier to their

TABLE 2 CRAM community assessment results.

	Knowledge of efforts	Leadership	Community climate	Knowledge of issue	Resources
Mean	1.25	2.42	3.46	2.29	2.54
Range	1–3	1–4	3–4.5	1.5–4	2–3
SD	0.58	1.18	0.50	0.78	0.50

TABLE 3 Stages of readiness.

Knowledge of efforts	Leadership	Community climate	Knowledge of issue	Resources
1	2	3	2	2
Stages of readiness				
No awareness	Denial/resistance	Vague awareness	Denial/resistance	Denial/resistance
Community has no knowledge about local efforts addressing Latino participation in health-related research	Leadership believe that participation in cancer early detection research may be a concern in the community, but have shown no motivation to act	Community members believe that participation in cancer early detection research may be a concern in the community, but is not seen as a priority.	Only a few community members have knowledge about cancer early detection research, and there may be misconceptions	There are limited resources available to address Latino participation in cancer early detection research.

participation. Others reported inaccessible, complicated language used in research documents, including consent documents, as another notable factor. In addition to language barriers, CES participants shared that health is a private matter and expressed feelings of discomfort with sharing information and being a part of research about their health. System-related factors identified by participants included limited flexibility to take time off work, cost considerations, (i.e., lost wages from time off work), lack of access to health care services, and concerns related to health insurance coverage, or lack of coverage. These concerns are consistent with published literature on barriers to underrepresented population group's participation in cancer clinical trials (5, 6, 17).

We learned that cancer is a very charged term, causing fear with some who equate a cancer diagnosis with a death sentence. We found that many Hispanic and Latino community members do not seek preventative care out of fear or lack of affordable treatment options. Having limited access to healthcare likely influences this community's reluctance to participate in clinical research.

- "You might say the word "biopsy" but what I hear is that I am going to die. It will be expensive, and I'm going to die. I am going to suffer." (CES Respondent #9)
- "Fear of knowledge [...]I think a lot of times women are scared of what they might find out." (CRAM Respondent #7)

Uncertain benefits of participation

We found that the benefits of participation in cancer early detection research were unclear among participants in our sample. They believed that research studies they might come across are not for them and therefore self-selected to opt out, even if they were eligible. This, we understood, was due to three reasons. Firstly, participants reported that low confidence in their English language abilities. This, combined with a lack of cultural familiarity or negative experiences interacting with providers, made them feel that they would not be understood or that nobody would help them. Secondly, the burden of participation in cancer early detection research was identified as a significant barrier. Specifically, taking time off work to participate in clinical research was equated with loss of income for hourly-wage workers. Perceptions of burdens of participation did not outweigh the benefits. Third, there were concerns about confidentiality in research studies. Some participants were undocumented, and others lacked a social security number. Considering this, they expressed worry about how the personal data required for research participation could be shared across institutions signaled a potential threat and harm.

CRAM quantitative results

A total of 12 interviews were conducted by 4 bilingual community members over a 4-week period. Out of the 12 interviews, 9 were conducted in Spanish and 3 in English. Interviews conducted and transcribed in Spanish were translated into English for analysis by a certified translation service.

The overall score average across all 5 areas for all 12 interviews was 2.39. The results were calculated by taking the mean of each area. We also assessed the range and calculated standard deviations for each of the five areas (Table 2). Following the CRAM methodology, the mean results in each content area are all rounded down.

We found limited awareness about cancer early detection research efforts among CRAM participants in our sample. An overall score of 2.39 suggests Hispanic and Latino community members residing in Oregon's Willamette Valley have limited knowledge, attitudes and resources to address participation in cancer early detection research (Table 3). This level of readiness was expressed as incomplete information about research, low prioritization because of competing demands, scarce resources to deal with the issue, and limited understanding of early detection cancer research.

Discussion

The objectives of this study were to: (1) understand Hispanic and Latino community perspectives in participation in cancer early detection research; and (2) to identify sustainable and mutually beneficial approaches to community engagement and involvement. We identified three key themes: (1) a general low-level awareness of cancer early detection research and research participation opportunities; (2) structural barriers to research participation; and (3) uncertainty of the benefits of research participation.

Our results suggest that limited knowledge about how to participate in clinical research was coupled with limited effort among researchers to engage with the Hispanic and Latino community. When studies and research are not shared with the Hispanic and Latino community, members don't know about their existence, or know that they are underrepresented in clinical research. Our results revealed that Latino and Hispanic individuals in our sample were open to participating in cancer early detection research, but they needed to: (1) be informed of research opportunities; and (2) know more about what participation entails, including the benefits of their involvement.

Further, it is necessary to raise awareness and knowledge among community members more broadly regarding the uneven rates of Hispanic and Latino participation in cancer early detection research and share opportunities for research participation. This can be accomplished by identifying networks and establishing partnerships with community-based organizations that are invested in cancer research and support efforts to increase knowledge and awareness among their members. Collaborating with stakeholders and community leaders to support the effort through strategic communication is also likely to have an impact. Many organizations hold community events. When readiness levels are low, these events could present an opportunity for face-to-face delivery of information and a space to ask and have questions answered. A small presentation, or informal talk by a community leader and researcher will draw attention to this issue and is an opportunity to provide benefits unrelated to cancer early detection research to attendees. Our findings support the position that participation in cancer early detection research should be mutually beneficial, especially in the context of limited resources and barriers to healthcare. Such an approach would help to increase cancer awareness and help to dispel the belief that a cancer diagnosis is a death sentence. This approach is also an opportunity for researchers to better understand community needs and priorities as well as build relationships.

Our participants gave insight into several potential barriers to cancer early detection research participation. The most common reasons they cited were language barriers, a lack of flexibility to take time off work, and cost considerations, (i.e., lost wages from time off work). Language barriers can be easily alleviated by researchers intentionally communicating in multiple languages and in a manner that is accessible, easily understandable, and void of overly complicated terminology. The concept of surviving vs. living was identified by Hispanic and Latino community members in our sample and may be a unique obstacle to participation in cancer early detection research for this population. Work and income related barriers are a particularly significant obstacle for clinical research participation in a population where many are focused on survival and have competing priorities (18). Many people in Oregon, including some Latino and Hispanic community members, encounter challenges in accessing the health care system, making health prevention sometimes unfeasible. This may be because people are uninsured or underinsured and have significant out-of-pocket costs for health care services. Hispanic men and women continue to be the least likely to have health insurance of any major racial or ethnic group (2). Further, there is limited knowledge of where and how to access primary are and prevention health care services and a self-described lack of awareness of how to navigate a complex health system to receive follow-up care. The literature suggests Latino and Hispanic individuals are less likely to have a primary care provider or usual source for health care compared to non-Hispanic Whites, 25 vs. 17%, respectively (2). These barriers likely influence an individual's priorities and attitudes toward participating in research.

Based on the findings, we would recommend the benefits of participating in clinical research must be meaningful enough to balance the aforementioned barriers, including lost wages from missing work. To mitigate this and other participation barriers, researchers should strive to identify and remove barriers. For example, as part of the study's design, funding and planning logistics for follow-up care for those who participate in early cancer detection research is essential, especially if the study population has limited access to healthcare. Also, financial incentives for research participation help to deter the economic burden of participation by making up for a potential loss of income from time off work, transportation, or childcare costs. Financial incentives have proven to be successful in facilitating research participation (19, 20).

Our study has a few limitations. This was a pragmatic study implemented in a real-life setting. A real strength of our approach was that the community engagement activities were delivered in Spanish. This enabled the team to recruit those that might not otherwise have participated. However, the decision to promote cultural familiarity by offering two language options brought a limitation. Our community partner hosting the CES sessions were unable to include members of the research team that did not speak Spanish. Moreover, the translation of certain experiences might not have accounted for contextual nuances. We learned that translation is essential to hear from communities that usually do not participate in early detection cancer research. Yet, we must ensure that translation goes beyond the words provided on leaflets, including contextual nuance and keeping the integrity of experiences throughout the research process so that everyone can fully participate.

Community engagement and collaboration is at the heart of any successful research. Using two evidence-based community engagement approached, we identified low-levels of awareness of cancer early detection research and research participation opportunities, structural barriers to research participation, and uncertainty of the benefits of research participation. These themes are likely influential drivers of underrepresentation of Hispanic and Latino community members in cancer early detection research. The actionable recommendations we propose are aimed at meaningfully engaging Hispanic and Latino individuals in research by removing participation barriers through trusting, reciprocal relationships between researchers and community members so that research participation is mutually beneficial.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

Material preparation and data collection and analysis were performed by JC, IA, CJ, HT-U, and CPC. The first draft of the manuscript was written by JC. All authors have read and approved the final manuscript. All authors contributed to the study conception and design.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Faith-based health screenings for Marshallese adults living in the Republic of the Marshall Islands: Study design and results

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Introduction: Striking health disparities exist in the Republic of the Marshall Islands (RMI). The RMI has one of the highest age-adjusted type 2 diabetes mellitus (T2DM) rates in the world (23.0%) compared to global (9.3%) and United States (US; 13.3%) rates. We conducted health screenings including clinical indicators of T2DM and hypertension among Marshallese in the RMI.

Methods: Screenings were conducted at 20 churches on Majuro Atoll. Participants completed questionnaires and biometric data collection assessing glycated hemoglobin (HbA1c), blood pressure, and body mass index.

Results: Screenings included 528 participants and showed a high prevalence of T2DM, obesity, and hypertension. One-third of participants were referred to the non-communicable disease clinic. The percent of adults in this study with T2DM-indicative HbA1c (48.5%) is higher than observed at the national level (23.0%).

Discussion: Results highlight the need for non-communicable disease-related programs in the RMI.

KEYWORDS

Republic of the Marshall Islands, Native Hawaiian and Pacific Islanders, type 2 diabetes, hypertension, community-based participatory research, faith-based organizations

Introduction

The Republic of the Marshall Islands (RMI) is part of the United States (US) Affiliated Pacific Islands (USAPI) through a Compact of Free Association (COFA) (1). The RMI is made up of 29 atolls and five isolated islands in the North Pacific Ocean, about halfway between Hawaii and Australia, with a population of ∼80,000 (2). Although research in the RMI is limited, the available data demonstrates striking health disparities including a high rate of type 2 diabetes mellitus (T2DM) (3–6). The International Diabetes Foundation has ranked the RMI with one of the highest age-adjusted T2DM rates in the world (23.0%) (7) compared to lower rates in the US (13.3%) and globally (9.3%) (7, 8).

Health disparities in the RMI are linked to historical trauma experienced by Marshallese, resulting from testing of nuclear weapons on the atolls by the US (9, 10). Between 1946 and 1958, the US military tested numerous nuclear weapons, resulting in the exposure of Marshallese to significant levels of radiation (9, 10). Due to the contamination of the RMI from nuclear testing, the Marshallese transitioned from a diet sourced through local farming and fishing to a diet reliant on highly processed commodity foods imported from the continental US and a more sedentary lifestyle (9–13). Further, American scientists conducted research on the Marshallese people in an attempt to understand the effects of nuclear fallout;

however, this research was conducted without consideration of language differences or informed consent, creating distrust in outside researchers (9, 10).

The long-term objective of the study team is to understand and address the epidemic of T2DM in the RMI in collaboration with the Ministry of Health and non-governmental organizations in the RMI. The purpose of this study was to conduct health screenings as part of a needs assessment that included clinical health indicators of T2DM and hypertension among Marshallese living in the RMI, as well as diabetes self-management knowledge and behaviors for Marshallese previously diagnosed with T2DM. The main aims of the health screenings were to: (1) conduct a needs assessment to understand the current prevalence and severity of T2DM in faith-based organizations in the RMI; and (2) identify the barriers to T2DM treatment and self-management in the RMI. The findings from the health screenings will be utilized to inform future T2DM and other non-communicable disease related programs in the RMI. Health counseling was provided to all participants, and referrals to health care providers were arranged for those participants with screening results out of the normal/healthy range.

Study design

Community-based participatory research

This study utilized a community-based participatory research (CBPR) approach, which promotes equitable and ethical research (14–17). The use of a CBPR approach is important given the historical trauma experienced by the Marshallese people, including the nuclear weapons testing conducted in the RMI by the US military and the resulting unethical research on Marshallese exposed to nuclear fallout (9). CBPR engages community partners, honors their unique contributions at all stages of research, and ensures Marshallese cultural knowledge informs the process (18).

Community partners

A community advisory board that included seven members from our community partners in the RMI led the assessment. Community partners included the RMI Ministry of Health and Human Services (MOHHS), the Marshallese Educational Initiative (MEI), and Kora In Jiban Lolorjake Ejmour (KIJLE; approximately translated to "Women for Health"). The MOHHS has been designated by the RMI's Constitution as the state health agency and is vital to researchers appropriately implementing research activities in the RMI (19). The study team has built a strong working relationship with MOHHS and has full time staff with a dedicated office space in MOHHS. MOHHS worked closely with the study team to develop the study protocol and received weekly updates on study activities and progress. The study team collaborated with the MOHHS non-communicable disease (NCD) team to provide counseling at each screening event for all participants. Participants who needed further care were referred to the NCD clinic with scheduled appointments provided by NCD providers at screening events.

MEI is a non-profit organization that promotes cultural, intellectual, and historical awareness of the Marshallese people; MEI is headquartered in Springdale, Arkansas with outreach in the RMI. KIJLE is a non-profit women's group, which collaborates with the MOHHS to engage the community in public health initiatives. KIJLE is important to maintaining cultural congruence during implementation as they represent the matriarchal leadership of the RMI.

Study setting

The study was conducted in 20 churches located on Majuro Atoll. Churches play an important role in Marshallese culture; prior needs assessments in Arkansas have shown that 96.5% of Marshallese adults report regular church attendance (20). Most of the health screenings were done inside the church buildings; however, due to limited room at some locations, a few set up the health screenings at an outside location. In all cases, the study team arranged the counseling tables away from the general screening area for privacy. The study team worked with the churches to ensure rooms were available for glycated hemoglobin (HbA1c) testing to ensure the testing kits could remain temperature controlled.

Study team

The study team was comprised of the principal investigator and several co-investigators who have prior experience conducting research studies with Marshallese participants in the US and the RMI. The study manager has 15 years of community health and research experience and is a native of the RMI. The study manager previously relocated to the RMI and was responsible for the management of all local community health workers (CHWs) who served as research staff during this study. Local CHWs and research staff completed Collaborative Institutional Training Initiative Human Subjects research training, training on Health Insurance Portability and Accountability Act of 1996 privacy requirements, blood borne pathogen safety training, trainings in biometric data collection, and study-specific trainings. At least six data collectors and one MOHHS NCD provider were present at every data collection event.

Church and participant recruitment

CHWs and community advisory board members assisted with recruiting churches to participate in the health screenings. Additional recruitment efforts included announcements on the local radio station, through text messaging, and through invitations

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Abbreviations: BMI, body mass index; BRFSS, Behavioral Risk Factor Surveillance System; CBPR, community-based participatory research; CHW, community health worker; COFA, Compact of Free Association; HbA1c, glycated hemoglobin; IRB, Institutional Review Board; KIJLE, Kora In Jiban Lolorjake Ejmour; MEI, Marshallese Educational Initiative; MOHHS, RMI Ministry of Health and Human Services; NCD, non-communicable disease; RMI, Republic of the Marshall Islands; T2DM, type 2 diabetes mellitus; US, United States; USAPI, United States Affiliated Pacific Islands.

extended to non-participating churches who inquired about participation after hearing of the health screenings taking place elsewhere. When a church was identified as being interested in participating, the study team would meet with the pastors face-to-face to present information about the needs assessment and its recruitment goals. Once a church agreed to participate, town hall style question and answer sessions were used to inform and recruit individual participants. Additionally, the health screenings were advertised *via* postings on local websites, social media, and study flyers. Potential participants were advised of the time commitment involved in the health screening and were invited to participate in other scheduled screenings if they were unable to stay for the full screening event.

Eligibility determination

The study team captured biometric and survey data on individuals who met the inclusion criteria and consented to participate in the study. Participant inclusion criteria included: (1) self-identified as Marshallese and (2) over 18 years of age.

Consent

Previous research with the Marshallese community has highlighted Marshallese participants' desire for a simplified consent process and the preference for verbal discussion of study requirements (21). Therefore, as the health screenings were considered a minimal risk study, a waiver of consent documentation was requested and granted by the University of Arkansas for Medical Sciences Institutional Review Board (IRB #262557). The study information sheet was provided to participants in Marshallese, and plain language was used to increase understanding. Participants were allowed time to read or have a CHW read the information sheet to them. Participants were encouraged to ask any questions they may have had. All participants received a paper version of the study information sheet in Marshallese for their records. Participants verbally acknowledged consent prior to data collection.

Remuneration

Remuneration was provided to all participants who consented to take part in the study. Participants were given $10 as compensation for their participation. Individuals who wanted to receive a health screening but declined the opportunity to participate in the study were provided a screening free of charge but did not receive compensation.

Methods and analysis

Data collection

All data collection staff had previous experience collecting biometric and survey data in the RMI. REDCap was utilized to store and manage data (22). To prevent/minimize missing data, REDCap includes a missing data report in the Quality Assurance tool which allowed for convenient quality assurance validation and monitoring, as well as prompt collection of missing data. All of the instruments used in the study were chosen collaboratively with Marshallese stakeholders and have been translated into Marshallese and validated with Marshallese participants. The research team has used these same questions with more than 1,000 Marshallese participants in multiple studies (23, 24).

Biometric data

The biometric data collection was completed by qualified, trained research staff and was carried out using standard infection, prevention, and control practices. Waste was disposed of in a safe manner in accordance with MOHHS instructions. Biometric measures collected included HbA1c, weight, height, and blood pressure. HbA1c was collected *via* finger prick using aseptic techniques and analyzed using PTS Diagnostic's A1CNOW+ point-of-care HbA1c tests. Participants' weight (without shoes) was measured to the nearest 0.5 pound using a calibrated digital scale. Height (without shoes) was measured to the nearest 0.25 inch using a stadiometer. Body mass index (BMI) was calculated using collected height and weight [(weight in pounds*703)/(height in inches^2)]. Systolic and diastolic blood pressure was measured using a digital blood pressure device with the participant seated, arm elevated, and cuff placed at approximately heart height. Categorical blood pressure (normal, pre-hypertension, stage 1 hypertension, and stage 2 hypertension) were informed by the American Heart Association standards (25). Pulse pressure was calculated by subtracting the diastolic from the systolic blood pressure value (26). All individuals who participated in the health screening received a paper copy of their biometric results.

Survey data

After consent was provided, participants took a short 10-min survey before or after the health screening. The survey instrument included questions adapted from the Behavioral Risk Factor Surveillance System (BRFSS) survey (27). All survey documents were translated into Marshallese and were self-administered or interviewer-administered, depending on the preference and/or literacy level of the participant. Due to past findings from research with Marshallese communities in the RMI and Arkansas, the length of the survey was reduced from prior studies to ensure accurate responses and to reduce participant burden.

Analysis

Descriptive statistics, including means and standard deviations for continuous variables and frequency and percentages for categorical variables, are used to report the results of the health screenings. Descriptive statistics are provided for demographic and biometric data. The analysis was completed using STATA 17 (28).

Results

Sample

Five hundred and twenty eight (528) Marshallese adults participated in the health screenings. Due to issues and delays with the supply chain (in some cases, supplies took more than a month to arrive from the US with unreliable tracking data), only 450 participants were able to have their HbA1c tested during the screenings. Table 1 presents the demographics of the sample and the results of the health screenings.

Demographics

The sample was predominately female (61.9%) with a mean age of 43.4 years (± 15.1 years). Just over one-third (35.2%) of the participants were between the ages of 45 and 64. The majority of participants either had some high school education (32.8%) or were a high school graduate (25.2%).

Biometrics

HbA1c

The mean HbA1c of the sample was 7.2% (± 2.5%). The majority of the sample had an HbA1c indicative of glucose dysregulation; 17.8% had an HbA1c indicating prediabetes (5.7–6.4%) and 45.3% had an HbA1c indicating diabetes (≥6.5%).

Weight and BMI

The mean weight of the sample was 168.3 lbs. (± 38.3 lbs.), and the mean BMI was 31.4 ± 6.8. The majority of participants were either overweight (25.7%) or obese (56.8%).

Blood pressure and pulse pressure

The sample had a mean systolic blood pressure of 118 mmHg (± 19 mmHg) and a mean diastolic blood pressure of 73 mmHg (± 11 mmHg). Just over a third (36.2%) had blood pressure indicative of prehypertension, 8.1% had blood pressure indicative of stage 1 hypertension, and 3.8% had blood pressure indicative of stage 2 hypertension.

The mean pulse pressure of the sample was 45 mmHg (± 14 mmHg). Forty-three (43.4%) percent had an elevated pulse pressure (40–49 mmHg), and 14.2% had a high pulse pressure (≥50 mmHg).

Referrals to medical care

Over a third (34.8%) of participants were referred to the NCD clinic with scheduled appointments with a health care provider.

Dissemination plan

Throughout previous work with the Marshallese community, the study team has found that individual in-person meetings, as well as church meetings, town hall meetings, using infographics, and using plain language summaries, are the culturally preferred methods for dissemination of study results (29). Individual participant results were shared with participants during the diabetes health screening events.

Study staff will provide a summary of the results back to the Marshallese community utilizing existing community partnerships. Culturally and linguistically appropriate infographics and summaries will be created and used as flyers and posters to be distributed or displayed at community events. Flyers and/or posters will also be available in a digital format for posting on Facebook or other social media platforms.

To ensure participant confidentiality is maintained, aggregated de-identified results will be shared with the congregations at participating churches. Aggregated de-identified results may also be shared in town hall style events hosted by community partners; town hall meetings will be announced through social media, newspaper, and radio. A summary of the results will be provided in a formal report and presentation to the RMI MOHHS. Additionally, results of this study will be used for academic presentations, posters, or publications.

Discussion

In this study, Marshallese adults from 20 churches on Majuro Atoll in the RMI were invited to participate in diabetes health screenings. This report describes the recruitment strategies and study protocol and provides the results of the biometric data. The data from our study will inform our future research addressing health disparities in the RMI, especially those related to cardiometabolic diseases including diabetes and hypertension.

The results of the screenings show a high prevalence of diabetes, obesity, and hypertension among the participants in the study. The percent of screened adults with an HbA1c indicative of diabetes in this study (45.3%) is even higher than the diabetes prevalence observed at the national level (23.0%) (7). This is also higher than the proportion found in similar health screenings for Marshallese adults conducted in northwest Arkansas (38.4%) (24). These results provide evidence of the health disparities faced by the Marshallese living in the RMI and highlight the need for further diabetes and other non-communicable disease-related programs in the RMI. Although the rate of non-communicable disease among the participants in the health screening study was high, we were able to assist over 180 people in setting up appointments with non-communicable disease providers.

Historical trauma experienced by Marshallese, resulting from testing of nuclear weapons on the atolls by the US, has long been linked to the health disparities the small island nation faces today (9, 10). Between 1946 and 1958, the US military tested numerous nuclear weapons, resulting in the exposure of Marshallese to significant levels of radiation (9, 10). Following these tests, American scientists conducted research on the Marshallese population in an attempt to understand the effects of nuclear fallout without any consideration of language differences or informed consent, creating distrust in outside researchers (9, 10). Given the long history between the US and the RMI, it is important

TABLE 1 Participant demographics and biometrics.

	Obs	*N* (Mean ± SD)	% of Sample	Range
Sex	527			
Female		326	61.9	–
Male		201	38.1	–
Education	527			
Never attended		4	0.8	–
Elementary		98	18.6	–
Some high school		173	32.8	–
High school graduate or GED		133	25.2	–
Some college or technical school		86	16.3	–
College graduate		33	6.3	–
Age (continuous)	528	43.4 ± 15.1		18–83
Age (categorical)	528			
18–24		72	13.6	–
25–44		217	41.1	–
45–64		186	35.2	–
>65		53	10.0	–
HbA1c (continuous)	450	7.2 ± 2.5%		4.1–14.1%
HbA1c (categorical)	450			
Normoglycemic (≤5.6)		166	36.9	–
Pre-diabetes (5.7–6.4)		80	17.8	–
Diabetes (≥6.5)		204	45.3	–
Weight (in pounds)	525	168.3 ± 38.3		85.8–311.2
BMI	525	31.4 ± 6.8		17.2–58.8
BMI (categorical)	525			
Underweight		6	1.1	–
Normal weight		86	16.4	–
Overweight		135	25.7	–
Obese		298	56.8	–
Systolic blood pressure (mmHg)	528	118 ± 19		82–211
Diastolic blood pressure (mmHg)	528	73 ± 11		44–119
Blood pressure (categorical)	528			
Normal (<120/80)		274	51.9	–
Pre-hypertension (120–129/<80)		191	36.2	–
Stage 1 (130–139/80–89)		43	8.1	–
Stage 2 (≥140/≥90)		20	3.8	–
Pulse pressure (mmHg)	528	45 ± 14		12–119
Pulse pressure (categorical)	528			
Normal		224	42.4	–
Elevated		229	43.4	–
High		75	14.2	–
Advised to seek medical care regarding results	526			
No		343	65.2	–
Yes		183	34.8	–

Only valid percentages shown. Percentages may not total 100 due to rounding.
SD, standard deviation; GED, graduate equivalency degree; HbA1c, hemoglobin A1c; BMI, body mass index.
HbA1c only completed for 450 participants due to supply chain issues.

for our research team to develop a trusting relationship with the Marshallese community.

In 2011, members of the research team became increasingly aware of the significant health disparities of the Marshallese community in northwest Arkansas and began meeting with Marshallese community members, Marshallese community organizations, and Marshallese churches with the goal of setting a community-driven research agenda using a CBPR approach (30). The research team conducted field work to gain a better understanding of Marshallese history and culture, and community members were invited to share their history, stories, and perspectives on health and research (30). Members of the Marshallese community were asked to join with the research team to review secondary data from the Census, Behavioral Risk Factor Surveillance System (BRFSS), Arkansas Department of Health Vital Records, and needs assessments conducted in 2004 and 2010 by the local hometown health coalition and community foundation (30). Through this work, Marshallese community members asked the research team to focus their efforts on addressing the high rates of T2DM in the community.

As part of developing the work on T2DM in Arkansas (later adapted for the RMI setting), the lead investigator brought together a diverse interprofessional research team and engaged 31 Marshallese community stakeholders, including patients, family members, and health care providers to select and adapt an appropriate intervention to address the high rates of T2DM with community support. The Marshallese stakeholders included patients with T2DM, family members of people with T2DM, and community health care providers. Representatives from Marshallese community-based organizations, the Marshallese Consulate, and Marshallese churches were included and represented patients, caregivers, and their organizations. Discussions were conducted both in English and in Marshallese and a bilingual translator provided interpretation. The use of the Marshallese language increased comfort and shifted the power of gaining knowledge and sharing information to the Marshallese stakeholders. Using the native language was important both to the research team and to the Marshallese stakeholders given the historical trauma experienced by Marshallese people and the distrust in American scientists it created. Further, as part of our efforts to build trust with the Marshallese community in Arkansas, we included a native Marshallese physician, Marshallese nurses, and additional Marshallese staff as part of the research team. At the urging of the Arkansas-based Marshallese stakeholders, we have worked diligently to bring our efforts to address T2DM to the RMI. Overall, because of the long-standing relationship with, and support from, the Marshallese community in Arkansas, Marshallese community organizations, and the RMI MOHHS, we have been able to successfully adapt our studies and health screenings to benefit Marshallese living in the RMI; without the support and involvement of Marshallese people, these efforts would not be possible. These relationships have been, and will continue to be, a vital part of our work with the Marshallese community in the US and the RMI; this study is one of several our research team has conducted in partnership with Marshallese communities in the US and the RMI dating back to the original conversations in 2011 (24, 30–37).

The health screening study was instrumental in highlighting the barriers to study administration in the RMI. Biometric data collection was not without its difficulties. Due to issues and delays with the supply chain (in some cases, supplies took more than a month to arrive with unreliable tracking data), only 450 participants were able to have their glycated HbA1c tested during the screenings. Maintaining the correct temperature for the A1CNOW+ test kits was difficult in churches without air conditioning, and special care was needed to ensure ice packs and coolers were available as needed to maintain the test equipment. Electricity was not always reliable, which limits the potential screening equipment that can be utilized during studies. Further, although churches play an important role in Marshallese life, there are limitations given the sheer number of events and activities that utilize these spaces. The study team did encounter some difficulties with utilizing churches for data collection. On occasion, the start time of the health screenings were delayed or ultimately rescheduled due to needing to have the buildings unlocked or due to another event taking place at the church.

There are limitations to consider when interpreting the findings. The convenience sample limits the ability to generalize the results, and due to a lack of community-level data, no direct comparisons of the study sample can be made to the general population of Marshallese living in the RMI or abroad. The sampling method also limits comparisons to other studies. Moreover, some participants in the screenings may have been aware of potential health conditions and, therefore, may have been more likely to agree to participate in the study. Finally, we recognize BMI is a problematic measure. Marshallese participants are often uncomfortable with having research staff measure their waist and/or hip circumference, which limits the options of determining weight-related risk factors.

Despite these limitations, we were able to provide health screenings to over 500 Marshallese adults. The aims of this study were 2-fold: (1) to conduct a needs assessment to understand the current prevalence and severity of diabetes within faith-based settings in the RMI and (2) to identify the barriers to T2DM treatment and self-management among members of faith-based organizations in the RMI. The data we have collected will help us to meet these aims and will position the research team and our community partners well to address the needs of Marshallese adults in the RMI.

Data availability statement

The deidentified data underlying the results presented in this study may be made available upon reasonable request from the corresponding author, PM, at pamcelfish@uams.edu.

Ethics statement

This study involving human participants was reviewed and approved by the University of Arkansas for Medical Sciences Institutional Review Board. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

JA, BR, and PM: study conception and design. JA, BR, GO'C, WB, and PM: data collection. JA, BR, PM, and PM-K: analysis and interpretation of results. JA, BR, GO'C, WB, SR, PM, and PM-K: draft manuscript preparation. All authors reviewed the results and approved the final version of the manuscript.

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Conflict of interest

PM-K was employed by Iakwe Home Health LLC.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Family listening/circle program: The experience of community action projects to promote family and community wellness in three tribal communities in New Mexico

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Introduction: The Family Listening/Circle Program (FLCP) is a community-based participatory research (CBPR), culture-centered, intergenerational family strengthening program that was co-developed in partnership with the University of New Mexico's Center for Participatory Research (UNM-CPR) and three tribal communities (Pueblo of Jemez, Ramah Navajo, and Mescalero Apache) in New Mexico. The Family Listening/Circle Program brings together fourth and fifth graders, their parents, caregivers, and elders to reduce risky behaviors associated with the initiation of substance use among the youth, and to strengthen family communication and connectedness to culture and language as protective factors.

Methods: The tribal research teams (TRTs) from each community worked with UNM-CPR to co-create, pilot, implement, and evaluate the tribally-specific FL/CP curricula centered in their own tribal histories, language, knowledge, visions, and actions for the future. A key component of the FL/CP involved the planning and completion of community action projects (CAPs) by participating families. During the final session of the program, the families present their community action projects on poster boards, with children leading the presentations. The TRTs and UNM team document narratives of what was shared and learned by the families.

Results: The CAPs provide an empowerment and community benefit focus based on Paulo Freire's philosophy that people can become agents of change if they identify and work on issues that are important to them. The community action projects are also centered in Indigenous values and practices of reciprocity, responsibility, and being active members of the community.

Discussion: The CAPs added unique contributions to the Family Listening/Circle Program as the participants' learnings were strengthened when they had the opportunity to give back to their communities. The CAPs were important to document as they illustrated the potential range of effectiveness with their capacity to empower participants to address challenges within their communities, strengthen cultural norms and values, and improve the wellbeing of community members.

KEYWORDS

community-based participatory research, Indigenous community-engagement, culture centered intergenerational prevention program, community action project, empowerment, American Indian

Introduction

Research with American Indian/Alaska Native (AI/AN) communities has increasingly turned to community-based participatory research (CBPR) approaches to reduce inequities and strengthen wellness among AI/AN populations. Tribal oversight and participation in research have grown in the past two decades to counter historic abuses of "helicopter" research, negative stereotyping, and disregard for community knowledge and participation. Tribes now expect and demand the benefits of studies, including ownership of data and authority over publication. In the last decade, guidelines specific to AI/AN communities have been more defined, with recognition of tribal sovereignty and use of the term *Tribal Participatory Research* (1–4); or *Indigenized Research* (5–8).

In New Mexico (NM), three American Indian tribes came together to engage in a National Institutes of Drug Abuse/National Institutes of Health (NIDA/NIH) funded R01 5-year CBPR research study with the University of New Mexico Center for Participatory Research (UNM-CPR) to evaluate the effectiveness of the Family Listening/Circle Program (FL/CP), a culture-centered and evidence-based intergenerational family prevention program. This collaborative research has been a long-term commitment and partnership which has sought to honor tribal direction and ownership of research through multiple NIH funding cycles (9–12).

The Family Listening/Circle Program brings together fourth and fifth graders, their parents, and elders to reduce risky behaviors associated with the initiation of substance use among the youth, and to strengthen family communication and connectedness to culture and language as protective factors. A key component of FL/CP involves the planning and completion of community action projects (CAPs) by families, which provide an overarching empowerment and community benefit focus. The premise of community action projects is centered on Indigenous values and practices of reciprocity, responsibility, and being active members of the community. Drawing from Paulo Freire's liberatory listening/dialogue/action educational methodology (13), community action project ideas emerge from listening to youths' concerns about their community, engaging them in dialogue with their families for support, and creating collective actions that empower them toward community improvement (14–17).

While AI/AN communities are particularly at risk for health disparities, facing high rates of intergenerational trauma, as well as structural inequities, such as high unemployment, they also have significant cultural and language strengths to inform research. Much evidence demonstrates that connection to history, land, language, traditional food, and cultural practices have a positive impact on Indigenous health (18–20). With Indigenous culture inextricably linked to land and place, a collectivist sense of community and self emerges that can promote healing from discrimination and negative trauma from assimilative policies (7, 21, 22).

Connection to culture and community can also facilitate civic participation (23, 24). There is evidence that these connections may decrease stress, increase adaptive psychosocial resources and reduce the likelihood of negative outcomes (such as anti-social behaviors) in the long term (16, 25). In Australia, the most commonly used definition of health for Indigenous peoples states that health is "not just the physical wellbeing of an individual but is the social, emotional and cultural wellbeing of the whole community" (17), nurturing relational restoration *via* worldviews across body, place, self, family, community, past and future generations (7).

An additional concept of culture-centeredness proposes that for interventions to be effective and sustainable, they must recognize culture not just as a set of beliefs, but as people's agency, voice, and power to direct the changes needed in their community (2, 26). Shared principles include the right of Native peoples to base research in their own knowledge and priorities, and to participate in research processes based on dialogue, longer timeframes, decolonized methodologies, culture-centered interventions, and recognition of tribal diversity (18, 27–29). Multiple governance mechanisms, such as tribal or intertribal IRBs, tribal research committees, tribal councils, and other leadership oversight, have begun to codify these benefits and principles (30–32).

The Family Listening/Circle Program has embraced this comprehensive understanding of culture by advancing the research practice of calling community advisory committees to be called *Tribal Research Teams* (TRTs), to honor tribal community partners' equal status as co-researchers (9, 33). The TRTs have worked together with UNM-CPR for over 14 years to co-create, pilot, and now implement three tribal-specific Family Listening/Circle Program curricula, based on their own tribal histories, language, knowledge, visions, and actions for their future. The authors for this article included six tribal partners (Jemez Pueblo, Ramah Navajo, Mescalero Apache), two from each of the three tribal communities (two teachers and four service providers) and four from the academy, two co-principal investigators (Navajo and Jewish), one Native co-investigator researcher (Jicarilla Apache) who is leading the writing team and an international graduate student (Nepalese). We started this article at a bi-annual meeting with the tribal partners and UNM team brainstorming ideas, which became an iterative and active process, sharing and discussing working drafts at numerous meetings.

For this article, we first present the background of each tribal community and their long-term research partnership with UNM-CPR, which has ranged between 14 to 20 years. Secondly, we summarize the CBPR process to co-develop three evidence-based and tribal/culture-centered family curricula with blended Indigenous theory and Western behavior change theory, rather than being simply a "tailored" program. Thirdly, we showcase the community action projects that demonstrate how children and parents deepened their involvement within their community and culture to become advocates and change agents. Finally, we end with results, limitations, and recommendations for other intervention programs, interested in incorporating cultural-centeredness, empowerment, and community action projects to promote health equity and community health.

Community-based participatory research

The UNM Center for Participatory Research was founded on CBPR principles, defined "not simply as a community outreach strategy but rather a systematic effort to incorporate community participation and decision making, local theories of etiology and change, and community practices into the research effort” [http://cpr.unm.edu/index.html, (32, 34, 35)]. The tribal community partnerships were initiated individually between UNM-CPR and each tribe. This grew into a collective collaboration, focused on the co-implementation and testing of a culture-centered intervention through the shared NIDA grant (2009–2014), facilitating three tribal-specific Family Listening/Circle Programs with common curricular elements, even as each tribe retained its own cultural knowledge, history, and values. The Family Listening/Circle program works with elementary children to strengthen resiliency and increase protective factors, such as cultural identity, language, anger management, and communication, to hinder alcohol and substance abuse initiation. According to the literature (36–38), youth that delays the first initiation of alcohol and substances are more likely to not experiment or develop addictions to alcohol or substances. The three communities, all committed to improving the lives of Native children and families, represent New Mexico’s three dominant tribes of Pueblo, Navajo, and Apache. Figure 1 provides a map with the locations and representation of tribes in New Mexico.

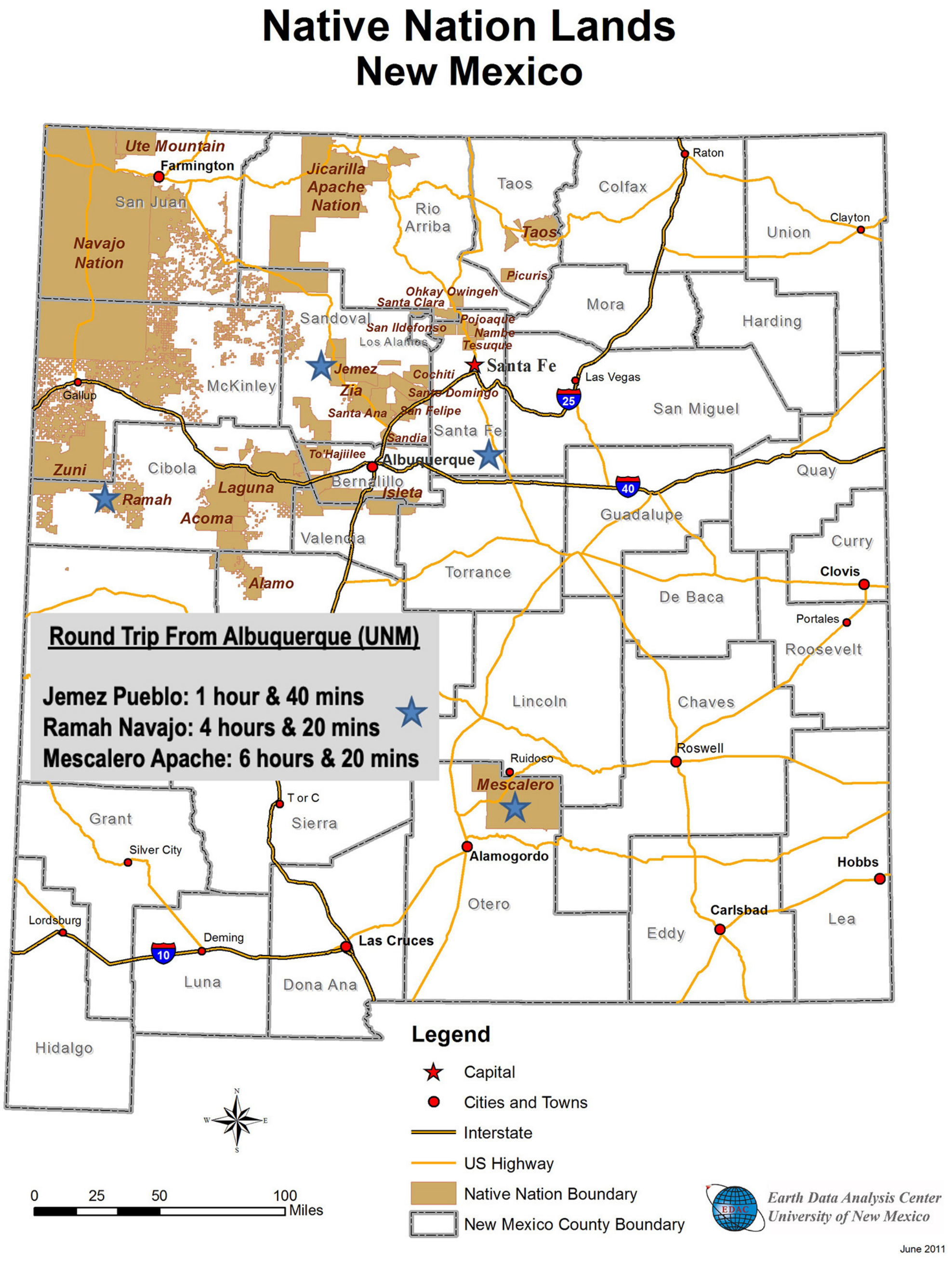

FIGURE 1
Map of New Mexico tribes and location of three tribal community partners.

Pueblo of Jemez

The Pueblo of Jemez is a federally-recognized tribe traditionally known as *Hemish of Walatowa* located 1-h northwest of Albuquerque, with community members living in a single village known as Walatowa and encompassing over 89,000 acres of land. Of the ∼3,400 tribal members, 58% live in Walatowa (http://www.jemezpueblo.org) (39) and are the only Towa-speaking community, with language fluency, last surveyed in 2006, was 80% across all generations (40). To address language, the Tribal Council passed a resolution in December 2012 to convert their Head Start Program to full language immersion and in 2016 the Walatowa Head Start Language Immersion Program was completed. Jemez was the first tribe to charter two schools under the NM Charter School Law: San Diego Riverside Charter School was established in 1999 and the first on tribal lands, Walatowa High Charter School, the first Native high school chartered in 2002 and the second on tribal lands. Both schools are unique in that they were approved by Tribal Council resolution to exist as state-funded public charter schools on tribal trust lands with language and culture-based curriculum and programs at the core of both charters, locally determined with strong community and tribal input. In 1999, Jemez also took over its health care system from the Indian Health Service and broadened its focus to include prevention programs focused on healthy traditional foods (i.e., growers' market, nutrition classes) and physical exercise (i.e., running and cycling clubs) (10).

The Pueblo of Jemez and UNM-CPR partnership was initiated in 1999 and has since collaborated on four CBPR research studies. The first in 1999 from the Centers for Disease Control and Prevention (CDC), the "Community Voices" research study partnership ran from 1999 to 2003 and identified cultural strengths and community capacities as a means of understanding social capital in an indigenous context (41). Based on the "Community Voices" recommendations, the partnership successfully obtained a Native American Research Center for Health III (NARCH) pilot grant (2005–2009) to co-develop a culture-centered family intervention to reduce child risk factors using Hemish cultural strengths (10, 12). Building from an existing Anishinabe curriculum (http://www.ppsi.iastate.edu/american-indian-prevention) (42), the Jemez community advisory committee expanded its membership to include elders, who provided history and language knowledge for re-centering the curriculum in Hemish culture. After 2 years of development, the Hemish of Walatowa Family Circle Program (FCP) curriculum was finalized and piloted with two family cohorts. Poised for larger testing of FCP, Jemez joined the successful R01 NIDA application for their third and largest collaborative research study. With other collaborative initiatives, the community advisory committee redefined itself as a Tribal Research Team (TRT) to own co-researcher status (9). Transitioning to TRT signified that tribal community partners were no longer in an "advisory" role; they were active and engaged researchers directing the project to meet their community needs. See TRT timelines for the evolution of their partnership at http://cpr.unm.edu/research-projects/flcp/historical-timelines.html.

Ramah Band of Navajo

The Ramah Band of Navajo is located in Western New Mexico 2.5 h west of Albuquerque. Ramah Navajo encompasses over 170, 000 acres and is one of three non-contiguous satellite reservations of the main Navajo Nation Reservation and is located in a "checker-board" area based on the fact that the land status in and around Ramah Navajo includes tribal trust lands, individual American-Indian allotments, privately-owned, and state lands (i.e., Bureau of Land Management). Hundreds of Ramah Navajo community members were forcibly removed in the 1860's "Long Walk" by the U.S. Government and lands had to be reclaimed throughout the 1940's (43). Not until 1955 was Ramah Navajo officially recognized as a Chapter, one of 110 local governing bodies of the Navajo Nation (www.ramahnavajo.org) (44, 45). Ramah Navajo was the first tribal community in New Mexico to exercise self-determination and established its own educational system in the 1970's, under Public Law (PL) 93–638. At the same time, the Ramah Navajo School Board (RNSB) was established as a non-profit to oversee the new tribal school and in 1978 RNSB expanded its role to run its own clinic and health and social services department from the Indian Health Service (11, 44). Today, Ramah Navajo's enrollment is estimated at over 3,500, with over 400 students from Head Start through 12th grade enrolled in the local school.

The Ramah Navajo and UNM-CPR partnership began in 2000 and has since collaborated on four research studies. The first study was a CDC grant received by the Albuquerque Area Indian Health Board (AAIHB), to increase cervical and breast cancer screening in the community of Ramah Navajo. Based on that experience a second study was obtained, a NARCH I (2001–2005) focused on the creation of a comprehensive community profile to assess community capacity as well as historic losses and a range of health, education, and community issues (46, 47). This study was guided by what was called the Ramah Navajo Advisory Board to guide the community capacity dimensions, focusing on youth, elders, sense of community, culture, communication, women, and leadership (31). Data analysis from 250 households led to findings, similar to Jemez's Community Voice's findings, that cultural preservation was highly valued, but concerns remained about language loss and family communication breakdown.

The next research grant for Ramah Navajo was the NARCH III pilot grant (2005–2009), collaboratively with Jemez, to co-create their family curriculum (i.e., Family Listening Program) grounded in their culture and language context. Piloting of their FLP was overseen by the Ramah Navajo Advisory Committee (RNAC), similar to the council established in their first study. The RNAC conducted one pilot with 10 families (10), and based on the very positive experience, Ramah Navajo joined the R01 NIDA application for their third research study. Similar to Jemez, the RNAC redefined itself to what was called as a Tribal Research Team (TRT) to own their co-researcher status, with their partnership timeline showing their evolution (http://cpr.unm.edu/research-projects/flcp/historical-timelines.html).

Mescalero Apache tribe

Mescalero Apache is a federally-recognized tribe with more than 5,000 enrolled members located in south-central Sacramento Mountains, 3 h south of Albuquerque. The reservation was established in 1873 and covers 440,000 acres. There are three tribal sub-bands, Mescalero, Chiricahua, and Lipan Apache, and the language spoken is Southern Athabaskan. Four sacred mountains are within Mescalero's homelands: The Sierra Blanca, Guadalupe Mountains, Three Sisters Mountain, and Oscura Mountain Peak. A leader in Native American sovereignty issues in water rights and business, Mescalero Apache hosts several tribal enterprises, i.e., Ski Apache, Inn of the Mountain Gods Resort and Casino, Mescalero Forest Products, Mescalero Gas Company, and Mescalero Apache Telecom (www.mescaleroapachetribe.com) (48). The Mescalero Apache School, kindergarten to 12th grade (K-12), is operated by the Bureau of Indian Education with about 550 students enrolled. Before 1995, Mescalero Apache had only a day school for elementary students and middle and high-school students were required to commute to neighboring non-Native communities. Under the late Tribal President Wendell Chino, the current K-12 school was built with the first graduating class in 1996. Health services are still provided under the Indian Health Services. In 2009, Mescalero Apache entered into a research partnership with UNM-CPR and has since collaborated on two NIH-funded research studies. The FLP was the first tribally-directed culture-centered prevention program to target youth before substance abuse experimentation (49).

Mescalero Apache learned of the Family Listening Program through a NARCH III presentation to the Albuquerque Area Indian Health Board (AAIHB) which was the administrative center for the NARCH projects in New Mexico. In that meeting, one of the AAIHB advisory members was from Mescalero and she regularly heard the reports about the Family Listening/Circle Program with Jemez Pueblo and Ramah Navajo. The advisory member then requested that FLP be brought to her community and with approval from her Tribal Council, UNM-CPR and Mescalero Apache co-submitted, and received NARCH V pilot funding from 2009 to 2014 to create their family curriculum (i.e., Family Listening Program) grounded in Mescalero Apache history, values, and knowledge. Mescalero Apache established its own community advisory committee, yet midway through the grant changed to a TRT (49). The TRT was able to pilot their family program twice and based on their experience joined the R01 NIDA application for their second research study. Similar to Jemez and Ramah Navajo, the Mescalero Apache partnership timeline can be viewed at http://cpr.unm.edu/research-projects/flcp/historical-timelines.html.

Methods

Through a CBPR process, the FL/CP curriculum was co-developed with each tribe incorporating their own cultural teachings, histories, and community learnings into their unique tribally-centered curriculum, while retaining similar indigenized cognitive-behavioral evidence-based strengthening family components across all curricula. While supporting external validity through shared components, each tribal research team was able to integrate their own teachings and make the Family Listening/Circle Program their own. Each tribal community contracted a local community artist to design distinctly different program logos, illustrations, and images meaningful to their community and significant cultural teachings. The curriculum also includes an empowerment focus based on the philosophy of Paulo Freire (13), that individuals/families can become agents of change if they identify and work on issues that are important to them (50). This empowerment perspective incorporated sessions for children, parents, and elders to create their own visions, identify community challenges, and choose a community action project to address community challenges. Children were given cameras or used their camera phones to create a photovoice documentation of their CAPs, sharing their photos to promote further community dialogue (51, 52).

While each curriculum is unique, they follow the same structural format that begins with prayer, followed by dinner, traditional introductions (clan, Indian name, or welcome) with practice in their tribal language, a review of home practice, main content experiential exercises (often in separate children and adult groups), group dialogue, journaling, and wrap-up with a small incentive. The first six sessions of the curriculum are grounded in teachings specific to each tribe and incorporate cultural introductions, cultural foods, families eating together, relationships (clanship, kinship), core values, cultural family roles, ancestral lineages of the people, phases of life, cultural responsibilities and ceremonies linked to those phases, and visions for the community. Sessions 7–12 include indigenized cognitive-behavioral exercises that help strengthen communication, help-seeking, anger management, problem-solving, exploring discrimination while highlighting the beauty in differences, positive relationships, empowerment, and building social support within community networks. Table 1 provides an outline of the curriculum sessions, objectives, and introduction example.

The Family Listening/Circle Program is implemented in each tribal community by trained community TRT facilitators. Facilitators have included teachers, behavioral health staff, prevention specialists, public health educators, parents, and elders. The facilitators were instrumental in helping families plan, organize, and implement their CAPs. The TRT facilitators let families know the goal of the CAP is to contribute to community improvement without the expectation of solving huge community problems. Families were encouraged to envision projects that were feasible within the timeframe of the program. Program participants had the flexibility to complete their project either as an individual family or as a group of families. The community action projects are introduced in session five and six when program participants discuss their community visions and the challenges they see in their community. As children and families identify community challenges, the facilitators help them think through potential solutions to address their concerns.

Ideas about addressing challenges from the children included: picking up trash; gathering items for ceremonies; doing food and clothing drives; bridging gaps between themselves and elders; substance abuse awareness; and ways in which they could give back to their communities. Based on these discussions, the families were asked to select an area of improvement in the community they would like to address and they develop a plan of action

TABLE 1 Family listening/circle program curriculum.

FL/CP curriculum sessions, objectives and introduction example	
Session 1: welcoming - Welcome participants to Family Listening/Circle Program and reflect on values - To review the guidelines and goals of the program over the next 12 weeks *“The FLP/CP is to support healthy families and learn our culture and language. Some activities we’ll do include sharing a meal, discussing topics with your family, and developing a community action project*	**Session 7: community challenges** - To identify areas of concern in the community - To identify people and groups who can support our efforts to improve the community through community action projects *“Session seven will help us identify challenges we face as a community and to begin exploring solutions. We will discuss what challenges we could address through a community action project”*
Session 2: tribal history (Part I) - To increase knowledge and pride in tribal community history and strengths as a people - To help build and strengthen tribal identity *“We will learn our tribal history and how our customs and traditional ways are passed on through families. Knowing our history and where our people came from can create a sense of pride in who we are. Our people have lived through much struggle and joy”*	**Session 8: communication, help seeking, and problem solving** - To learn how to communicate better, to seek help, and problem solve - To learn how to talk about emotions and reinforce emotional reactions using tribal community values *“Session eight will address communication, asking for help, and problem-solving using role playing and skill building scenarios”*
Session 3: tribal history (Part II) - To increase knowledge and pride in tribal community history and strengths as a people - To help build and strengthen tribal identity *“We will learn our tribal history and how our customs and traditional ways are passed on through families. Knowing our history and where our people came from can create a sense of pride in who we are. Our people have lived through much struggle and joy”*	**Session 9: recognizing types of anger and managing anger** - To understand anger as a normal emotion - To identify factors that contribute to anger - Learn ways to manage anger using cultural values *“We will discuss what anger is and where it comes from and learn how anger can be harmful to our health. We will discuss how to manage anger in a healthy way”*
Session 4: my family - To reflect on family, community, and cultural strengths and practice active listening - To learn about respectful and positive communication *“We will explore ways to communicate to bring family together to learn, discuss, and make decisions in a respectful way. We will practice listening to one another* and *will learn about our family trees”*	**Session 10: being different and positive relationships** - To understand that differences make us unique, not unequal as human beings - To challenge stereotypes and appreciate diversity - To understand the value of recognizing our own biases and how they affect our actions *“We will talk about being different and finding our strengths in differences. We will discuss how to have respectful conversations among diverse groups”*
Session 5: tribal way of life - To recognize the importance of role models at home and in the community - To learn important cultural roles and responsibilities with each phase of life *“Our way of life can reflect what you believe in, values your family practice, language spoken, or the daily habits/activities practiced in our community”*	**Session 11: building social support** - To identify supportive people in participants’ lives - To learn how to build a support system - To build pro-social and pro-active peer support *“In this session we will focus on building and strengthening our social support. Social support means identifying people we trust and who we can count o.”*
Session 6: our vision - To engage in community visioning - To create a personal vision for the future - To begin discussing community action projects *“In this session we will practice creating a personal and community vision for our future. We will discuss ways we can give back to our community through a community action project”*	**Session 12: making a commitment and community project presentations** - To conclude the 12-week program and share community projects and lessons learned - To evaluate the program *“This session will conclude our 12-week program. Everyone will share their community action projects and highlights of the program”*

to complete their community action project by the end of the program. The FL/CP program provides funding to support the families’ community action project efforts. As part of the R01 CBPR research study, each Tribal community received its own budget to support running the FL/CP program (staff time, food, supplies, incentives, etc.), paying facilitators, and implementing the community action projects. The Tribal community PIs and TRTs determine the budget for the CAPs and they help the families stay within budget. However, the majority of the CAPs had minimal costs, mainly for supplies such as trash bags, paint, and tools.

The families plan out their CAPs through the last six sessions with guidance and support from the TRT facilitators. When the CAPs were implemented varied among the communities and families, particularly if the CAPs were completed by individual families or as a group. However, generally, the CAPs were completed within several weeks after the eleventh session of the curriculum. The twelfth session is held after the families complete their CAPs, as the last session provides time for families to present their community action projects on poster boards, with children leading the presentations. The TRTs and UNM team document what was shared and learned by the families.

Results

Pueblo of Jemez

After four waves of implementation of the Family Circle Program, four cycles of CAPs were completed, with families tending to engage in individual family CAPs. Examples include:

one family deciding to clean up the path from their home to their child's school. Even though the cleanup day was very windy, the children still wanted to complete the project, highlighting how upset children were about the trash being thrown onto community roads and their willingness to be out in harsh conditions for the cleanup. Another family decided to update the community bulletin board, a place where community events were posted. The board had many old flyers, but after the cleanup, the board received an updated look with current information. Another family decided to collaborate with the Jemez Department of Planning and Transportation to post a speed limit sign on a community road, which had increased traffic where children played. After posting the sign, a community member commented, "Yes, I have seen several [speed limit signs] in several places that were not there before," implying a much-needed change in the community.

Other examples of CAPs included the cleanup of the village plaza after a Feast Day event, the cleanup of neighborhoods, and the posting of speed limit signs near school zones. The TRT and community members have seen families involved in CAPs become empowered through their participation. One community member stated, "It [CAPS] is to improve community life, so I think that's a good way to start teaching them [children] about stuff like that, it's really important." In each year of the last session of the program, Jemez community and tribal council members have been invited to the presentations and families have showcased their CAPs, which children conducted in their Towa language.

Ramah Navajo

Program families in Ramah Navajo have tended to come together as a group to organize and implement their CAPs. For example, during one wave of program implementation, the participants decided to conduct a group cleanup of the community fitness trail, which had been neglected for years. Families initiated the planning, spoke on the local radio, and created flyers to invite community members to join in the cleanup effort. In the planning, a unique collaboration was formed between the Tribal Security, Health Promotion and Education, and the radio station to accomplish the project. 2 years later, the fitness trail is still being maintained and used by community members.

During another year, some participants conducted individual CAPs, driven by individual child interests; and others teamed up for a group Elder Food Drive. Often students have big ideas for their projects, which require more funding for completion. However, the facilitators assist in the narrowing of the projects to assure realistic and achievable goals. In the last year of the FLP funding, the CAPs goal to empower students was reached when students presented their project at the Ramah Navajo Chapter House. One of the high school student interns who was hired to assist in the Family Listening Program was encouraged to run for the Ramah Navajo Queen Contest, a platform that allows students to address community concerns. The intern won the competition and was able to give voice to the FLP children by sharing community needs, enabling her to work toward strengthening community bonds, while improving her communication skills and instilling Ramah Navajo pride and identity.

During another year families came together and hosted an event to collect donations (clothing, household items) to distribute to families in need in their community. With substantial donations, after families came and took items they needed, leftover items were donated to the Social Services Program. Another group of families focused their CAP on promoting positive messages for the community. The families created signs with positive messages and placed them at intersections for people to see. The families created the signs to get people thinking about drug and alcohol use. The resiliency-based messages at the different intersections stated, "Doing good does you good," "Love your family, NOT alcohol!" and another quote that addressed methamphetamine use.

Mescalero Apache

In Mescalero, four CAPs were completed, with grant funding providing support for supplies and equipment. During the first round of planning, the first group of families opted to complete a group CAP to lessen the burden on individual families. Through a consensus process, the families decided to clean up several local lake recreation areas. They created hand-painted signs that asked community members to keep the lake clean and not litter, with signs posted in picnic areas. Photos were taken with the children proud of their artistic contribution to the community. The TRT stated that they heard community members say they were happy to see the signs posted around the lake. To date, only one sign was vandalized but the other signs remain in good condition. A TRT member stated, "This shows that the community appreciates and values the meaning of the signs." For the second family cohort which took place under winter snowy mountain conditions, the families sought a community action project inside. From the brainstorming of ideas during the FLP session, the families decided to contact local clergies and offered to clean up their church. A couple of the church pastors were surprised, and slightly puzzled by the offer because it was something they were not used to. Two churches accepted the offer and the families split into two groups. One group focused on cleaning the inside of the church, while the other group focused on cleaning up outside the church, bundled up against the weather. While people in the community were surprised when the FLP participants offered to clean up the churches, the families felt there were many different avenues to giving back to your community and they wanted to pitch in.

Other CAPs that the families organized and implemented were a canned food drive and a Christmas meal for the community. For the food drive, families reached out to the community for food donations. Once the families collected enough donations, they organized the food into bags. Altogether the families distributed 75 bags of food to residents of Mescalero. Another group of families decided to host their CAP during the holiday. Typically, the CAP is done in the springtime, but the program families wanted to host a community meal for Christmas. The families came together and cooked the Christmas meal and served over 350 meals to the community.

Discussion

The CAPs have added unique contributions to the Family Listening/Circle Program. The children and parents learned together about their history, community values, and ways of life during the dinner-based program, and their learnings were strengthened when they had the opportunity to give back to their communities. The CAPs were important to document as they illustrate the potential range of effectiveness with their capacity to empower participants to address challenges within their communities, strengthen cultural norms and values, and improve the wellbeing of community members. Evidence of CAP effectiveness is documented through the taking of photos by the child participants during their CAPs activity. During the final session of the program, the children along with their families present what they learned in the program and they share their CAP experiences. The children create poster boards and display photos they took throughout the program and of their community action project. The photos helped the children talk about their experiences as they could describe what was happening in the photos. The photos helped trigger their memories and generated excitement as they expressed pride in what they accomplished.

The CAPs contributed to outcomes at multiple levels: individual self-confidence, skills in group decision-making and consensus-building, a sense of community empowerment, cultural pride, as well as the transformation of community environments and perceptions of the leadership. Participating in the program and learning about their cultural traditions and language empowered the children to be active participants in choosing their CAPs. The CAPs provided opportunities for the children to see their community with new eyes, to become more aware of their surroundings, and to voice solutions to the problems they were experiencing. The parents in the program were impressed by what their children noticed and voiced about the challenges in their community as well as their ideas to improve those conditions. The range of CAPs outcomes is documented here:

Personal

New skills and self-confidence have been displayed. In Ramah Navajo, the FLP high school student helpers conducted radio PSAs for the first time, one ran for the title of Ms. Ramah Navajo, and all gained skills in leading discussions with younger children. While initially less willing to use their Native language during sessions, most children in Jemez Pueblo gave their final CAP presentation in the Towa language. Participating adults have said that they have seen a change in themselves: we are "more aware of community concerns, issues with political and cultural activities. Community members want to change these."

Social support and team building

The CAPs facilitated opportunities for team building among the families. Families that decided to do group projects had to create consensus on what they were doing, identify materials/supplies needed, plan out dates/times, and show up to do the work. The community clean-ups, community food drives, and community meals strengthened the families' support of one another and their community. During the session on community concerns, both adults and children identified community issues, and ways to seek support to address them. One participating adult wrote in the journal, "There are many similarities in the concerns of community members which is eye opening, yet you feel stronger to hit these concerns head on knowing that you have the support of those around you." Another wrote, "If we all work together, we can improve our community. We can create change."

Culture and history pride

In all communities, families felt their community projects re-emphasized to them the importance of their land and culture. In Mescalero Apache, families wanted to clean up their lakes to represent cultural pride in their homelands. In Ramah Navajo, for example, children realized the elder who spoke to them about history was part of the photograph on the wall of tribal leaders who took back control of their school in the 1970's from the federal government. Participating students chose to wear traditional dress for their final presentation of their CAP. Giving back to the community has deepened cultural identity and pride in Jemez, with more children dancing at feast days, and strengthening connections to their families, a key protective factor as they grow older.

Community program collaboration

The community action projects helped facilitate new collaborations between community programs and groups. In Jemez, one of the families collaborated with the Jemez Department of Planning and Transportation to post a speed limit sign. The family had to meet with the department of planning and transportation to discuss their CAP proposal and the need for a speed limit sign in a designated area where a lot of children play. The Ramah Navajo fitness trail cleanup involved collaboration with the radio station, school, and security department. The families worked with the radio station to advertise the community trail clean-up and partnered with the school for supplies. In Mescalero, the families collaborated with the church community.

Community leaders

In Jemez, multiple leaders (fiscales, administration, governors) have joined the last session of the program and spoken about how proud they were of the children, stating what they learned in the Towa language. A couple of Tribal Council members attended the community Christmas meal that the Mescalero Apache FLP families hosted. They acknowledged the program for hosting the community meal. A former Mescalero Tribal Council member became a TRT member and as an elder fluent in the language was instrumental in teaching the language in the program. The Ramah Navajo School Board welcomed FLP families to present to them, listened to their concerns, and has been in support of the FLP program.

Community benefit and dissemination

The CAPs have had some lasting impacts in the respective communities. For example, two out of the three Mescalero Apache signs at the different lakes are still up providing messages to keep the land clean. In Ramah Navajo, families continue to upkeep and use the fitness trail years later. In Jemez, children express pride that their speed limit signs are up, that they've cleaned up areas, and that they can create bigger visions.

The purpose of the CAPs was to demonstrate to children (and adults) that they can be change agents and be empowered in their own communities to achieve successes, even if small, and build future leadership skills and confidence. In all communities, the CAPs were recognized with photos, articles in the local newsletters, and community recruitment flyers that included information on the CAPs. All three communities shared the challenge of devising CAPs that were feasible and doable within the time frame of the program. Some families and children had big visions, which resulted in families being overwhelmed or intimidated by the project. However, the TRT facilitators assisted families to narrow CAPs to smaller projects and provided support as needed.

The TRTs shared their experiences with implementing the program and the CAPs during bi-annual in-person meetings that were held as part of the research project. At these meetings, the TRTs discussed what processes worked for their community, adaptations they made to make the CAPs feasible, and how they problem-solved the challenges they faced. Through this cross-learning, the TRTs gained new ideas to strengthen how the CAPs came together in their community. TRT members from the three communities also co-presented at several conferences where they continued to learn from one another. For example; through the learnings of implementing the program and CAPs, the TRT facilitators started to introduce the CAPs earlier in the program to address the time constraints. In the Pueblo of Jemez, for example, facilitators have chosen to show pictures of previous CAPs during the first introductory session to prepare new program families to think about possible projects. Mescalero Apache focused on group projects because single-family projects can be daunting and the other communities started to provide a group option for their families.

The Family Listening/Circle Program strengthens identity through the cultural teachings and language which are protective factors and facilitators for strengthening coping, resiliency, and hope (15, 17). The literature also supports that a strong cultural identity strengthens a connection to community, a sense of place, and civic engagement, which can decrease stress and increase adaptive psychosocial (16, 25). The community action projects coupled with the teachings from each program session (communication, help-seeking, anger management, etc.) had a positive impact on the youth as indicated by preliminary effectiveness data. Promoting communication and encouraging group work, the CAPs have highlighted the benefits of families giving back to the community. Children and adults that collaborated during the planning and implementation of the CAPs have learned new skills, built self-confidence, found support among other FL/CP participants, strengthened their connection to their culture, and gained a new sense of empowerment in being able to see their accomplishments at a community level. The CAPs have expanded the program goals beyond individual family strengthening to providing service and benefit to their communities.

In sum, community action project outcomes mirror the importance of cultural connections and community benefits within the participatory community engagement literature on Indigenous youth (24). Families working together through dialogue and action deepened community capacities to promote cultural identity, connection to tribal lands, and health (14), which was a major aim of the Family Listening/Circle Program. While this article did not share program outcome data, the program has preliminary effectiveness data that shows a decrease in anxiety and depression among child participants (9). The UNM-CPR and TRTs are co-writing another manuscript to share the rigorous intervention effectiveness data.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by University of New Mexico IRB, Navajo Nation IRB, Southwest Tribal IRB. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

Author contributions

The UNM team RR, LB, MS, and NW contributed to the introduction, research, literature, results, and discussion. The tribal community partners ET, MY, BC-B, IB, PL-G, and AO contributed to the respective community background and community action projects in the results and discussion. All authors contributed to the article and approved the submitted version.

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Conflict of interest

BC-B and IB were employed by the company Ramah Navajo School Board, Inc.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Aligning clinical research ethics with community-engaged and participatory research in the United States

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The professional role in ethical review of research in which boards review proposed research involving human beings continues to evolve. The scholarly literature on institutional review boards in academic centers of the United States, at which a majority of the community engaged and participatory research emanates and is reviewed, suggests the need to implement changes in board education, the infrastructure supporting review, and the accountability of review. The recommendations for change advanced in this perspective involve enhancing reviewer knowledge of local community contexts and developing an infrastructure that supports engagement in and dialogue among individuals involved in community-academic research to inform ethical review and the assessment of review outcomes. Additionally, recommendations regarding putting an institutional infrastructure in place are advanced in order to sustain community engaged and participatory research. The infrastructure can also support the collection and review of outcome data as the foundation of accountability. The recommendations outlined intend to improve clinical research ethics reviews of community-engaged and participatory research.

KEYWORDS

clinical research, ethics, community, community engaged, participatory, community-based participatory research, institutional review board, review

Introduction

Throughout the past century, professional voices have predominated in articulating, interpreting and applying ethical principles in the review of research involving human beings (1–4). Eleven individuals with expertise in the medical and behavioral sciences, ethics, law and public policy produced the Belmont Report, articulating basic ethical principles for the prospective review of research participant protection in terms of safety and rights (5). The Report furthered reliance on the review of research by independent boards (6), which have proliferated with increases in funding and in the number of research studies (7–10). Private or for-profit Institutional Review Boards arose to meet the demand for review (11), serving researchers without institutional affiliation and institutions seeking to comply with conflict of interest policies. Associations of professionals have also shaped the management of boards and review processes (12–14).

The growth in the number of research studies and reviews has been accompanied by the emergence of new research methods and study designs. PubMed citations show “pragmatic clinical trial/trials” publications increasing from an average of three per year (1984–2012) to over 200 average citations annually for the last decade. Similarly, "comparative effectiveness trial/trials" citations begin to markedly increase around 2010. Increases in the number of community-based participatory research and community-engaged research studies and publications started to occur even earlier. These types of studies comprise subsets of research conducted within community settings and with community partners (15). The proliferation and diversification in research studies and settings present numerous and sometimes unrecognized challenges for ethical board review.

What has ethical review of clinical research looked like?

Few studies have closely examined the structure and function of the institutional review board (IRB): We know even less about private or for-profit IRBs (16). Structure has typically been interpreted as board composition, which forms a foundation for examining board function and board member interaction.

Researchers examining board composition often focus on the requirement of boards to include a non-scientist and an individual unaffiliated with an IRB's institutional sponsor. While the same individual can fulfill both roles and sometimes does, research into board composition often combines these two roles. The 28 "non-scientists" serving on the fourteen IRBs at the National Institute of Health reported actively contributing to board decisions and feeling they were listened to by others on the board. A large majority felt a primary responsibility for reviewing the informed consent documents (17). Studies of nonaffiliated and non-scientist IRB members within academic health centers reported members in these roles feeling ill prepared to actively contribute to board discussions and not respected (18, 19). All board members reported uncertainty about the roles of non-affiliated and non-scientist board members (20).

A 2011 systematic review found 43 studies of US academic IRBs reporting empirical evidence about board "structure, process, outcomes, effectiveness, or review variation (21)." Collectively IRB interpretation and application of federal guidance to protocols varied. Additionally, the review noted an absence of evidence about the quality of reviews and about IRB effectiveness in protecting human research participants. An absence of data regarding IRB quality and effectiveness of their research reviews persists.

A subsequent study explained variation in board review by summarizing research findings about risk assessment and decision-making at both the individual and group levels. Variation could result from how an individual responds to the wording used to describe risk, from the degree of familiarity with a procedure or sources of stigma as well as from trust in the people involved. Culture and political orientation can also be sources of variation in assessments of risk and its severity. Patterns in the perception and responses to risk were outlined to raise awareness about sources of bias and potentially improve review consistency. However, variation could legitimately result from a knowledge of local context (22).

A qualitative study of a single IRB characterized board members deferring to the professionals with expertise in the room (23). A second study of board structure and function, which was focused on review of social, behavioral, and economic research protocols, found IRBs largely populated by individuals possessing medical expertise and experience reviewing clinical trials. Observation, again of one IRB, suggested heightened scrutiny of social, behavioral, and economic research, including minimal risk projects. Field notes reported more board members actively participated in social behavioral reviews in comparison to biomedical protocols (24). The authors posited that board members reviewing social and behavioral protocols felt empowered to assume a sense of their own expertise. They recommended increasing the proportion of board members with social science expertise and adding members to represent research participants (25). They also recommended board education related to social and behavioral research.

Decades of growth in clinical research has fueled concern about IRB workload and mission creep. Workloads may be lessened somewhat by using reliance agreements to minimize the number of boards that review a protocol. Mission creep is more complicated. It may arise in traditional hospital-based clinical trials due to the current emphasis on increasing heterogeneity among research participants, which may lead boards to consider social/community, economic, environmental and cultural contexts to address issues of autonomy, risk and benefit and social justice (4): As suggested above, reviews might vary due to local contexts and perhaps when factoring in participants from populations that do and do not experience health disparities. Should boards scrutinize proposed samples for their representativeness and recruitment plans in considerations of social justice and equity? Mission creep is certainly a concern for academic health center IRBs where the majority of community-engaged and participatory research reviews likely occur.

The formation of IRBs focused on social and behavioral research seems one response to issues of board composition and mission creep. However, distinguishing biomedical from social and behavioral research is unlikely to ever prove adequate for the exploration of ethical issues that arise from conducting research among diverse populations in community settings, using methods and designs common among community-placed, community-engaged, comparative effectiveness, community-based participatory, participatory action, translational, implementation and dissemination, research studies.

Expanding ethical review

There are limited examples of directly engaging community perspectives in considerations of research ethics. The University of California-San Francisco (UCSF) assembled individuals from local communities who were already working with UCSF researchers and who possessed research expertise to bring together community voices within the ethical review of the institution's COVID-19 related protocols (26).

Two decades earlier, the Morehouse School of Medicine Prevention Research Center Community Coalition Board articulated principles and values for the community review of research. Their principles and values included mutual respect and justice for all people, a commitment to the principle of self-determination, and a recognition that structures and systems within which individuals live, work, and play, limit individual autonomy. Contrary to guidance instructing IRBs to avoid interpreting the creation of community jobs or clinical infrastructure as a research derived benefit (27), the Community Coalition Board required projects to demonstrate a contribution to the community capacity to benefit from research processes and outcomes (28).

The Bronx Community Research Review Board, a product of The Bronx Health Link and the Albert Einstein College of Medicine, was formed to provide consultation about "community-based research proposals." Bronx residents also demonstrated "substantial interest" in understanding how proposals responded to local needs. The Community Research Review Board goals included community education about clinical research conduct, ethics and the research occurring in the community. It expressly recognized it was not an IRB but it still sought to empower community voices through consultation with researchers and by maximizing benefits of conducting research, of implementation and advocacy based on findings. Community member training for Board service was grounded in Paulo Freire's conceptualization of participation and community empowerment by expecting trainees to reflect on and further develop the training curriculum (29).

Communities and institutions developed other approaches to research consultation (30). The Community Engagement Studio has gained prominence as a reliable way to obtain community member input on research projects, particularly recruitment and retention plans and materials (31, 32). Academic researchers have proposed sharing information about community consultations to expand their understanding of research ethics for projects collaboratively conducted with community partners (33).

A conceptual model recommending the establishment of an independent community ethical review board, positioned between IRBs and community advisory boards, has been put forward (34). A recent Patient Centered Outcomes Research Institute (PCORI) study similarly recommended sustaining engagement and partner relationships and also encouraging team science by supporting community member and stakeholder participation on research teams (35). The shift from managing research projects individually to an infrastructure for the ongoing management of community relationships and partnerships would begin to address the marginalization of community member voices on IRBs and enhance the potential for local community voices to contribute to the exploration and application of research ethics for community-engaged and participatory projects (36–41).

Recommendations: research ethics and community

Prior comments pointed to a professional hegemony in the review of research protocols and in the application of ethical guidance within academic medical center research. Examples were also provided of community initiatives seeking to understand the value of research for communities and expressing expectations of direct involvement in the research occurring within their communities. Also mentioned was literature about research review issues with a focus on challenges faced by researchers involved in community engaged and participatory research. What is lacking in the literature is empirical evidence about the quality and outcomes of IRB decisions. The failure to evaluate and critically reflect on review determinations and their outcomes creates a gap in IRB accountability. It fails to address community mistrust generated by a history of research abuses, it also fails to confirm that the ethical norms developed to guide research that involves human beings within academic clinical contexts are appropriate to or appropriately interpreted and applied to research conducted in community contexts (42).

While not absolute, the distinction between research contexts is not trivial as is evident in Woolf's contrast between two research stages within translational science (43). The two stages present a contrast in research designs and purposes. Stage one study designs are used to obtain data about the efficacy of new clinical therapies, while stage two designs attend to their effectiveness. Closed system designs ideally control for a single variable to demonstrate causality. By contrast, open system designs acknowledge variability across multiple real-world settings, producing data to address the generalizability of therapies (e.g., pragmatic and comparative effectiveness trials). These contrasting study designs and their focus on establishing internal (closed system) and external (open system) validity, complicate ethical considerations regarding informed consent (e.g., SUPPORT Trial) (44), assessments of risks and benefits (45) and social justice. We begin to address concerns about research ethics by advancing recommendations to empower community perspectives and participation within the education of IRB members, institutional infrastructure, and review board accountability.

Education or awareness raising

The Collaborative Institutional Training Initiative (CITI) which provides online training courses for both researchers and IRB members developed a course that introduces community-based participatory research and community-engaged research approaches and ethical issues. While a recognition of increased research activity, this general introduction should be augmented within the ongoing education provided board members by their institutions (46). Continuing education for IRB members might introduce the institution's approach to community within its Community Health Needs Assessment or provide board members with information about the diverse populations within the catchment area, improving board member understanding of community health issues and outcomes (47–51). Board education could explore collaborative, participatory, and qualitative research designs and methods [e.g., photovoice (52, 53)], team science (54), partnership assessment (interpersonal and research) (55), health literacy and information design (56). While such educational efforts may not in itself overcome the limited community expertise on boards, it could improve board member understanding of specific community contexts within which the community engaged and participatory research they are reviewing will occur.

Building infrastructure

An institutional infrastructure to sustain bi-directional community-academic dialogue and involvement in decision-making should be capable of supporting community partnerships and service learning and of contributing to community health needs assessments and project and program evaluation (57, 58). A standing committee betwixt and between IRBs and research project advisory boards has been proposed to enable colloquial voices to intervene in professional discourse regarding the policies, practices and norms of community engaged and participatory clinical research (59). A standing group could also be a resource of individuals from the community to participate in assessing community-based research conduct, which would involve conducting assessments as is recommended below. The individuals could also help disseminate messages to diverse communities about research (e.g., the relevance of specific projects to community health; the importance of research involving individuals from the community to inform evidence-based medicine) (56). Such a group could also help to situate research along the blurred boundary between research and clinical care within learning health systems.

Academic institutions with standing community advisory groups could add research ethics as a recurring item to their meeting agendas. Members from different community advisory boards could be brought together, providing a counterbalance to the fragmentation produced by project specific advisory groups. The group could include non-affiliated IRB members at the institution. Institutions with multiple IRBs could constitute a group from their non-affiliated and non-scientist board members. Depending on the responsibilities accorded the group, it could meet a few times a year and involve minimal cost to the institution. A cost benefit analysis could be conducted to consider whether the infrastructural cost increases the institution's negotiated indirect rate. The analysis of cost and benefit should also consider whether the increased attention to the ethics of community engaged and participatory research is associated with an increase in funded projects as well as engendering trust within the community that facilitates research participation. While the cost would depend on the form and responsibilities of the group, the purpose remains to increase the engagement of community perspectives in determining what constitutes ethical research conduct, particularly for research conducted through community partnerships and within community contexts (60).

The group could also include community-based clinicians. Why this suggestion may seem to reinforce the hegemony of professionals in determining research ethics, community-based clinicians are not typically research professionals (61); they possess different expertise, whose value has been demonstrated in determining local standards of clinical care (62, 63). The involvement of primary care clinicians would also be an asset with the expanding integration of research into community care contexts. Adding representatives from primary care could inform discussions of minimizing potential risks and maximizing potential benefits for clinical trial, implementation and dissemination research. The Hispanic Chronic Renal Insufficiency Cohort study conducted in Chicago offers one example (64, 65). Local study initiation efforts included the lead researcher (i.e., Principal Investigator) visiting primary care clinics and Federally Qualified Health Centers to explain this 5-year prospective observational study to community clinicians. The lead researcher agreed to serve community clinicians as a resource for interpreting clinical data returned to research participants and developing patient care plans. This arrangement held within it a potential for benefit to individual participants and for the community through access to a clinical specialist with expertise not readily accessible in safety-net care contexts. While the H-CRIC arrangement was informal and more than a decade ago, engaging community clinicians can strengthen community partnerships and collaborations seeking to develop ways to generate collective benefit and pursue social justice. The regular engagement of community voices and discussion of community perspectives regarding the ethical conduct of research has the potential to improve the ethical oversight of research and further demonstrate university and academic health center commitments to partnership with communities.

Accountability

IRB education and the organizational infrastructure to support research conducted in community contexts should both inform and be informed by assessments of review outcomes, particularly research team member-participant interactional outcomes and assessments of actual risks and benefits. Presently, however, there is little to no published data to assess the outcomes of board reviews. While we possess evidence of therapeutic misconception in which individuals conflate research with treatment, there is little to no published data regarding how well informed consent materials and processes contribute to an individual's understanding of a specific research study. We know little to nothing about whether the payment offered participants is potentially coercive or whether what is offered is in any way consistent across comparable studies at an institution. Data is also lacking regarding participant and community experience of research participation. While institutions support human research protection programs and the IRBs who provide ethical review of proposed research and while accreditation indicates they are doing so successfully, there is scant empirical evidence to demonstrate that the ethical training of researchers and IRB review determinations are being translated into responsible ethical conduct (66, 67). While the responsibilities for conducting research ethically are clear, the lack of available data contributes to a gap in institutional accountability.

In order to demonstrate accountability, institutions should demonstrate that their review processes are generating the expected outcomes (68, 69). Institutions might start with interactions among IRB members by inquiring whether non-affiliated and non-scientist board members actually participate in board reviews and whether they feel listened to and respected. Put simply, does the board review process actually involve contributions from all required participants. Assessments of institutional review board performance could test approved informed consent documents to determine if they are meeting announced readability standards (70, 71). Readability can be easily examined through free, online utilities (e.g., https://www.online-utility.org/english/readability_test_and_improve.jsp) and might start by examining specific sections of what are often documents of 20 pages or more; it might prove useful to begin with the templated language that institutions require their researchers use to explain research or how the language used (e.g., to describe risks and benefits) may influence decision-making (72, 73). When it comes to the review process and informed consent, researchers have demonstrated that IRBs have regularly failed to demonstrate integrity by holding themselves accountable for meeting stated readability standards.

With the heightened awareness of the scientific importance of diversity in research participation in order to obtain evidence representative of the overall population, institutions could hold themselves accountable by comparing diversity of research recruitment and participation across minimal risk and also across more than minimal risk studies; they could compare participation in hospital-based clinical trials and trials conducted in community contexts. There are numerous potential comparisons that could help institutions assess research enrollments and inclusivity over time.

In addition to the recommendation to expand education for IRB members (74), institutions should review the information that researchers are required to provide for review. Again, while the data is extremely limited, it appears that IRB members may not have the necessary information about community partnerships and about the capacity and experience of community partners to support a research protocol available to conduct a thorough review of community engaged and participatory research (75, 76). There are numerous areas for institutional self-improvement regarding the review and oversight provided community-engaged and participatory research that would indicate a commitment to IRB's primary responsibility of protecting research participants by minimizing their exposure to risk and supporting the production of benefit by every means possible.

In closing

This overly brief review of research ethics for community-engaged and participatory research has overlooked stand-alone community ethical review practices (e.g., sovereign tribal nations) (77, 78). This limitation is not meant to minimize their importance nor dismiss their practices, but rather to acknowledge differences in legal status, particularly the continuities and discontinuities of individual and group identities. We acknowledge that cultural and linguistic differences add epistemological challenges for overcoming professional perspectives on late-stage clinical research, something which has been looked at extensively by Canadian researchers. Such challenges highlight assumptions about the universality of the autonomous individual while recognizing continuities and discontinuities within sociological or psychosocial conceptualizations of the person (79, 80).

The application of ethical principles and the review of research involving human beings must continue to evolve by conducting dialogues that collaboratively explore ethics and their axiological interpretations within clinical and health research. As suggested by the Association of American Medical Colleges, institutions capable of supporting sustained community-academic partnerships and disseminating information about those partnerships within diverse community contexts are more likely to become trustworthy community partners (81).

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

The author confirms being the sole contributor of this work and has approved it for publication.

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Developing a peer-led intervention to promote COVID-19 testing in low-income housing settings

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Background: The Housing Collaborative project at Eastern Virginia Medical School has developed a method of adapting public health guidance from public housing communities, which face tremendous health challenges in cardiometabolic health, cancer, and other major health conditions. In this paper, we describe how academic and community partners in the Housing Collaborative came together to do this work with a focus on COVID-19 testing in the context of the emerging pandemic.

Methods: The academic team used virtual community engagement methods to interact with the Housing Collaborative Community Advisory Board (HCCAB) and a separate cohort of research participants (N=102) recruited into a study of distrust in COVID-19 guidance. We conducted a series of 44 focus group interviews with participants on related topics. Results from these interviews were discussed with the HCCAB. We used the collaborative intervention planning framework to inform adaptation of public health guidance on COVID-19 testing delivered in low-income housing settings by including all relevant perspectives.

Results: Participants reported several important barriers to COVID-19 testing related to distrust in the tests and those administering them. Distrust in housing authorities and how they might misuse positive test results seemed to further undermine decision making about COVID-19 testing. Pain associated with testing was also a concern. To address these concerns, a peer-led testing intervention was proposed by the Housing Collaborative. A second round of focus group interviews was then conducted, in which participants reported their approval of the proposed intervention.

Conclusion: Although the COVID-19 pandemic was not our initial focus, we were able to identify a number of barriers to COVID-19 testing in low-income housing settings that can be addressed with adapted public health guidance. We struck a balance between community input and scientific rigor and obtained high quality, honest feedback to inform evidence-based recommendations to guide decisions about health.

KEYWORDS

COVID-19, community-based participatory research, public housing, distrust, testing

1. Introduction

Although the importance of including community voices in research has been acknowledged since the mid-1990s (1) and reinforced over time through the development and ongoing operations of the NIH-funded Clinical and Translational Science Centers, how exactly to ensure that these voices break through the dominance of traditional biomedical research in science remains elusive. Institutional barriers to effective community-based participatory research (CBPR) are well-documented and have been noted for decades (2, 3). Improvement occurs in two main ways: through the ability of community engagement to facilitate the translation of biomedical and clinical research into communities and through its ability to inform research about community values and priorities and ameliorate distrust.

Effective CBPR relies on bidirectional communication that is balanced on its ends. Through trial and error, the Housing Collaborative project at Eastern Virginia Medical School (EVMS) has developed a method of establishing public health guidance from a community with tremendous health challenges in cardiometabolic health, cancer, and other major health conditions. In this case, the goal of the Housing Collaborative COVID-19 study was to increase the effectiveness of COVID-19 outreach and guidance in low-income housing communities through a peer-led intervention by Housing Collaborative members. The following article outlines one example of the use of this method to achieve the study goal by outlining the development of a peer-led intervention to support increased at-home COVID-19 testing.

Rather than viewing biomedical and clinical research as scientific, and community engaged research as ascientific, we have applied established principles of intervention research to further our goal of balanced bidirectional communication. Our approach builds on an existing body of peer-led interventions to consider the value of sustainable ties with community members in addressing jointly identified obstacles to health. We believe that our approach to working with communities in which balanced bidirectional communication extends over time can add to the knowledge base on what promotes positive change. We argue that extended communication on a variety of salient topics is essential to closing the gaps between biomedical research and clinical medicine and population health.

1.1. Brief overview of peer-led interventions in health

Peer-led interventions extend community-based participatory research to highlight the expertise of community members by including them in conducting interventions to improve community health (4). They can range from those in which peers primarily are involved in delivering interventions to those in which academic and community members work in partnership throughout the research process and across specific projects (5–7). Ross et al. noted in 2010 the need for trust to develop over time so that an environment is created in which each partner is willing to make temporary concessions to produce a long-term collaborative relationship [(4), pp. 2–3].

To date, peer-led interventions have been applied in a variety of arenas and settings, from increasing empathy and self-efficacy among medical students to training peers to provide one-on-one services to persons with serious mental illness (5, 6). Results of these interventions, often measured pre- and post-intervention, largely have been favorable. In the medical student intervention, for example, empathy scores increased despite no change in mental health stigma. In a review of 153 peer-led interventions to promote health and well-being in retirement living, the authors concluded from the seven articles meeting inclusionary criteria that “future studies are needed to better understand how to sustain promising interventions” [(8), p. 11557]. While the low-cost, feasibility, and general favorable outcomes of peer-led interventions have been noted, there is concern about the long-term sustainability of interventions that produce favorable outcomes in testing.

Emerging research involving peer-led support interventions in response to the COVID-19 pandemic has highlighted the importance of recognizing how different definitions of health can have a dramatic influence (9). These include biomedical, relational, and socio-political framings. Biomedical models emphasize disease progression or symptom control, typically outside of social context, which can be a major limitation, as has been highlighted by the experiences of marginalized groups with COVID-19 (10). While relational models recognize social context (11), framing peer interventions solely through a relational lens could fail to appreciate how within-group variation in social norms and a lack of community cohesion could lead to reduced benefit for individuals who might be disempowered relative to the rest of their community (9). Socio-political framings recognize the role that inequalities, disadvantage, and discrimination play in access to services and health outcomes and stress the importance of community-led responses. However, these efforts can be limited when individuals from marginalized groups bear the brunt of the burden for their support. Combining the three perspectives, however, shows promise for creating traction and longevity for peer-led intervention work; in fact, this type of framework appears to be a preferred structure for support by such funders as the Robert Wood Johnson Foundation, given a growing recognition that initiatives will have limited success unless they feature capacity-building and are culturally tailored (12).

1.2. COVID-19 testing

Rapid, at-home testing is an important non-pharmaceutical intervention for COVID-19 (13). Research shows that disparities in rapid, at-home COVID-19 testing exist. In a non-probability sample of adults conducted from August 23, 2021 through March 12, 2022 ($N = 359{,}399$), respondents who used home COVID-19 tests were more likely to report higher incomes, higher educational attainment, and White race. For example, only 2.8% of respondents identifying as Black had used an at-home rapid test in the prior 30 days, compared to 5.9% of White respondents. The authors noted disparities in COVID-19 testing and suggested that additional studies are needed to better understand barriers to testing so that interventions can be developed (14).

While there have been multiple outreach interventions promoting clinic-based testing [e.g., (15)], few published studies have been aimed at overcoming barriers to at-home testing, and existing work might not be well-suited to addressing individual concerns and barriers. For example, the Say Yes! COVID Test campaign employed social marketing techniques in an effort to distribute 66,035 tests in Tennessee and North Carolina communities (14, 16). While this effort is laudable, their primary focus was on promoting increased distribution of tests, rather than overcoming individual-level barriers to testing that might exist after individuals receive their tests. This is an important gap, as our current study highlights.

1.3. Housing collaborative at Eastern Virginia Medical School

The Housing Collaborative Community Advisory Board (HCCAB), in partnership with researchers at Eastern Virginia Medical School, was created in 2013 to address the challenges of residents living in public housing in Norfolk, Virginia. The 28 current active members live in some form of low-income housing (e.g., public housing or receive a housing-choice voucher) in one of these Virginia cities: Chesapeake, Hampton, Portsmouth, Newport News, Richmond, Roanoke, Suffolk, and Virginia Beach, in addition to Norfolk (Almost 73,000 low-income housing residents combined live in these cities.) All but two HCCAB members are women and all but one self-identify as Black. The mean age of HCCAB members at the time of this report was 51 years (SD = 15.61). While led by EVMS researchers, faculty members associated with the Housing Collaborative now include co-investigators from several other academic institutions, including Hampton University, Harvard School of Public Health, Norfolk State University, Virginia Commonwealth University and Washington University in St. Louis. The longstanding research partnership spans several grant-funded projects with topics ranging from respiratory health and childhood asthma to studies examining HUD-mandated smoke-free public housing (17–20). Members of the HCCAB contribute to all stages of research, including the development of long-term research agendas and choosing topics covered in individual grant submissions. Monthly in-person meetings were held on the EVMS campus prior to the pandemic, with approximately 15 CAB members in attendance before March 2020. The group shifted to virtual engagement when restrictions on face-to-face interaction were put into place. The HCCAB grew rapidly and transitioned to weekly meetings and a regional presence, with consistently high attendance; this expansion was likely facilitated by the ease of virtual participation and the fact that members were confined to their homes.

The COVID-19 pandemic became the focus of HCCAB discussions in 2020. The group's weekly reflection focused increasingly on life changes required by the pandemic, including members' reactions to pandemic-related public health guidance from national and local sources. The academic research team was struck by the candor of the HCCAB as a debate arose nationally about the wisdom and necessity of mandates like vaccination and masking. It became clear that dialogs on community attitudes about COVID-19 precautions were being driven by the broader issue of trust in science. The academic team was able to observe, based on ongoing discussions with the HCCAB, how the group's trust in science and faith in recommendations changed by virtue of their ongoing relationships with one another and with the research staff members.

1.4. Housing collaborative COVID-19 study design

This article describes the process of community-informed adaptation that was part of a study funded by the National Institutes of Health through the Rapid Acceleration of Diagnostics in Underserved Populations (RADx-UP) initiative. Engagement with the HCCAB early in the pandemic suggested that widespread distrust of information about COVID-19, especially when received from public housing authorities, was contributing to low adherence with public health guidance. In particular, the HCCAB had described how recommendations for COVID-19 testing were met with skepticism and suspicion in their communities, a situation that directly contributed to the design of the Housing Collaborative COVID-19 study and demonstrated the importance of increasing the effectiveness of COVID-19 outreach and guidance in low-income communities. This article describes our work with the HCCAB to overcome distrust in COVID-19 testing after the study was funded. We began by recruiting an additional cohort of low-income housing resident research participants with whom we would engage in focus group interviews to examine systematically the phenomena described by the HCCAB. These focus group interviews were analyzed and findings were taken back to the HCCAB to generate discussion on how best to respond to community-identified concerns. We viewed this process, the work of making COVID-19 testing guidance more responsive to community needs, to be intervention adaptation. This was informed by the collaborative intervention planning framework, which applies community-based participatory research principles by fostering joint, balanced conversations between researchers and community members. This process yielded several recommendations, including the articulation of a peer-led COVID-19 testing intervention, on which we sought additional community feedback in another series of focus group discussions.

2. Methods

2.1. Participant recruitment and support

The Housing Collaborative COVID-19 study was conducted virtually, using digital access capacity provided by the team. Required as part of COVID precautions, digital access actually fostered consistent attendance. Members of the HCCAB and research participants were provided with tablets with high definition webcam, unlimited data connectivity, and, most importantly, ongoing technical support should they experience any problems while participating in study activities. A detailed description of our digital access capacity-building method, which was developed to ensure that engagement with the HCCAB would not be interrupted by the pandemic, is available elsewhere (17).

Before the pandemic, our process for recruiting for the HCCAB began by relationship-building and with sharing project goals and intentions with community members. Restrictions on face-to-face contact required that we begin by asking for referrals from housing authority staff and existing HCCAB members. As we expanded, we also recruited residents using mailers and flyers posted in apartment buildings. Interested individuals were contacted by a research staff member, who provided information about project goals, topics of discussion, HCCAB member responsibilities, and incentives for participating. All HCCAB members received the tablet computer with internet and $10 per hour for every meeting attended.

We used our digital access capacity-building method to recruit a cohort of participants for the Housing Collaborative COVID-19 study beginning in May 2021. Eligibility criteria were being an adult resident of low-income housing in one of the cities listed above. Recruitment was conducted using flyers, re-contact based on participation in previous studies, and referral from other participants and HCCAB members. The cohort has participated in a range of study activities using the provided digital access capacity, including quantitative and qualitative assessment. Participants were offered up to four study activities per month, one of which was a focus group discussion; however, participants were under no obligation to complete any particular activity or to attend specific focus group discussions if they preferred not to participate. As compensation, participants received unlimited data connectivity via provided tablets and $5 per completed research activity, equaling an upper range of $380. Approval was obtained from the EVMS IRB (20-04-NH-0099, 21-03-EX-0069, and 21-03-FB-0046). In total, 84 online focus groups were conducted with 102 participants from June 2021 through September 2022, with the cohort being sampled separately for each topic.

2.2. Data collection

This article involves a subset of our data collected during 44 focus group discussions, including 22 discussions on trust in COVID-19 guidance ($n = 102$ participants, with an average of 4.8 attendees per group), 19 discussions on comfort with technology ($n = 81$ participants, with an average of 4.3 participants per group); there were three additional focus group discussions specifically on the proposed peer-led testing intervention ($n = 13$ participants, with an average of 4.33 participants per group), which occurred after conferring with the HCCAB about feedback from the earlier focus groups. Focus groups were convened online using the teleconferencing platform Zoom. Our attendance target for each of the planned discussions was four to six; in practice, attendance ranged from 2 to 10 participants, with nine having fewer than 4 participants. Each discussion was facilitated by three members of the research staff—one moderator who led the discussion and two others who coordinated with participants, obtained consent, and took observational notes on issues such as hesitation or speed in responding. In addition, they were on hand should a participant need technical support. Video and a redundant audio recording of each session, with consent, were obtained so that those involved could reflect on aspects of the discussions. The discussions followed a semi-structured format based on a discussion guide developed in concert with the HCCAB; this format is open-ended, allowing for the discussion to evolve in response to the conversation. Immediately following each focus group discussion, research staff would debrief and discuss any arising or similar themes, interesting topics that could lead to future discussions, and general remarks about the preparation and facilitation process of the discussions for later planning and evaluation. Staff completed field notes and uploaded the notes, along with the video and audio recordings, to a secure server for storage until needed for data analysis. Recordings of the discussions were professionally transcribed. In total, 1,188 pages of single-spaced transcripts were produced during the 44 discussions analyzed for this article. Research staff produced 237 pages of field notes.

2.3. Data analysis

The qualitative analyses presented here are part of a larger effort to develop an understanding of low-income housing residents' distrust in COVID-related public health guidance using focus group principles (21). Discussions were professionally transcribed and then analyzed using a process in which codes and categories were iteratively created to reconcile emerging concepts (22). The first author (an ethicist and social epidemiologist trained in applying qualitative research methods and experienced conducting community-engaged research in low-income settings) and second author (a master's-level research staff member experienced in facilitating focus group discussions and coding qualitative data) read each transcript to identify emergent concepts, after which they began an iterative process of identifying and reevaluating codes. Inter-coder agreement was reached by consensus. A third member of the team (the senior author; a social scientist with experience in focus group research and qualitative analysis) was available should consensus not occur. The HyperRESEARCH software was used for data organization. Analytic memo writing was utilized to reflect on and process participant responses. Memo writing was also utilized as a tool to connect participant responses across focus group discussions to track any changes in individual- and social-level processes. This first phase of analysis resulted in a list of concepts that was brought to the HCCAB for review.

2.4. Adaptation method

We used the collaborative intervention planning framework to achieve the desired balance between hearing community voices and maintaining scientific rigor [(23); see Table 1]. Our ultimate goal was to inform adaptation of public health guidance on COVID-19 testing delivered in low-income housing settings by including all relevant perspectives. The framework applies community-based participatory research principles to an adaptation process that brings together researchers and community members in a structured and systematic way. We aimed to ground our recommendations for practice and policy guidance about COVID-19 in low-income housing residents' lived experiences as they emerged in our focus group discussions. HCCAB involvement assisting the academic team members with interpretation was crucial to ensure that recommendations reflected community-identified needs.

One hundred forty-one online CAB meetings occurred between March 2020 through October 2022. Of those, 12 meetings were devoted to this adaptation process. On average, 85% of the HCCAB was in attendance at these meetings.

3. Results

3.1. Focus group feedback regarding barriers to testing

Our research participant cohort consisted primarily of Black members (93%), followed by white members (5%), and a bi- or multi-racial/ethnic identity (2%). Members of the cohort primarily identified as woman/female (74%), followed by "none of these describe me" (14%), man/male (11%), and "prefer not to say" (2%). Age ranged from 18–75 years with a mean age of 53 years (SD = 15.23). Three primary themes and two subthemes emerged from our analysis of focus group feedback.

TABLE 1 Summary of the collaborative intervention planning framework.

Step	Objectives	Activities	Products
1. Setting the stage	• Foster partnership and collaboration • Clarify CAB members' roles and responsibilities • Introduce project aims, intervention adaptation process, and intervention	Icebreaker activities, mission statement exercises, and group discussions	Mission statement
2. Problem analysis and needs assessment	• Identify community needs • Discuss how the intervention may or may not address these needs • Identify areas for intervention adaptations	Brainstorming exercises, group discussions, development of a logic model, needs assessment	Logic model and needs assessment findings
3. Review of intervention objectives and theoretical foundations	• Review the objectives, methods, materials, and theoretical foundations of the intervention • Identify specific adaptation to intervention content or delivery	Group discussions and review of intervention components, change objective tables, and intervention's logic model	Revised logic model and change objective tables of adapted intervention
4. Development of intervention adaptations	• Incorporate adaptations into the intervention manual and materials • Finalize adapted intervention	Review of intervention manual and materials and group discussions	Intervention manual and materials and training curriculum

Adapted from Cabassa et al. (23).

3.1.1. Theme 1: distrust in COVID-19 testing

Participants reported low trust in COVID-19 testing, which likely affected the decision to seek out a test. This theme was shaped by feedback reflecting low trust in COVID-19 test results coupled with misinformation about the tests themselves.

3.1.1.1. Subtheme 1: distrust of test results compounded by misunderstanding processes

Participants described concern for the motives of the institutions administering and reporting test results [e.g., "I think that test is rigged" (57-year-old Black man)] and the accuracy of the tests. Many of these concerns about test results seemed to be driven by participant confusion about the process of COVID-19 testing, which no one had addressed with them. For example:

> *But if you're just testing people and finding it in their blood, why you gotta stick the longest Q-tip up my nose? That's a flu test that you giving. You understand? Like, don't, you giving me a flu test for something that you said that could kill me. You should draw my blood and check and make sure that it ain't already infecting me and it ain't full-blown or I just think the process that they took alone lets you know that it was a bunch of trash behind it in the beginning* [31-year-old Black man].

"That's a flu test" was a common refrain, mentioned in nine focus group discussions. Relatedly, participants cited confusion about how COVID-19 occurs, when tests are able to detect infection, and how test results might change over time as contributing to their distrust. For example, a participant described how he felt when hearing that someone could get a positive result after testing negative the prior week:

> *For me, I didn't see that they were very accurate because in some instances, you would go one place and get the test and they will say, you know, you have to wait a week or 10 days before you get the results. And then you get the results and they say you're negative, but then if you go somewhere else and get the test, then they say you're positive. It was just too much confusion for me* [55-year-old Black man].

While the administration of a COVID-19 test is relatively straightforward, the progression of the disease and what that means for the process of testing and the accuracy of test results can be complicated.

3.1.1.2. Subtheme 2: distrust in institutions leading to COVID-19 testing misinformation

Feedback from roughly one-third of participants (30%) suggested that distrust in institutions providing or promoting testing primed them to be receptive to misinformation. Oftentimes the source of this distrust was the federal government. For example:

> *I've seen that the left hand never knows what the right hand is doing. So, on one hand, you may have Dr. Fauci telling you one thing, but then you had Trump saying something totally different, and then you had somebody else saying something totally different from what both of them were saying. So when it comes down to a test that's issued by the government, I'm always going to be skeptic, I'm always going to have my doubts. I'm going to do my own research and I'm going to figure it out for myself* [55-year-old Black man].

It was also common for participants to assume that healthcare institutions had a monetary incentive to report positive cases and treat more COVID-19 patients. This concern was raised in half of the focus group discussions and is described in the following quote:

> *I think the results are all misled. I've heard the doctors are saying that they are being told to say the test results are valid where they have it and it's not true. And I heard that a lot of the hospitals are getting money for having a certain amount of people with the COVID. So I think that the testing are all flawed. I think they're gonna say you got it regardless, if they need a certain percentage of people to have it* [39-year-old Black woman].

Notably, several participants reported not wanting to take tests due to their impression that testing would lead to infection. In justifying this impression, they said those individuals getting tests often ended up having COVID-19. For example, a 59-year-old Black woman participant stated, "I do not know if I would a took that test for the simple fact that a lot that's getting the test is ending up with the COVID. You see what I'm saying?" This feedback highlights how information is processed in the absence of trust. If one starts with a firm belief that testing is not being done to help those being tested, then it is reasonable to assume that a causal association exists between testing and contracting COVID-19.

3.1.2. Theme 2: fear of pain or discomfort associated with COVID-19 testing

Participants often reported anxiety about testing due to anticipated pain or discomfort. Some participants reported that they had overcome their fears, as in the case of this 58-year-old Black woman who stated, "I was scared for a while. That's what took me so long. Because people told me it was painful." Of those who do choose to overcome testing-related anxiety, the need for a test before an upcoming medical procedure was a commonly cited motivation. For example:

> *I've not had it. I'm getting ready to have a procedure next month and a day or two before that procedure, I have to have that test. And that is the only thing that's stressing me right now, is that I really don't want them sticking that long Q-tip up my nose* [71-year-old Black woman].

Others opted never to get tested because of what they had been told by others, which seems to have contributed to testing-related misinformation. A 63-year-old Black woman relayed that "I heard different stories, when people took the test, that they stuck it too far up the nose. One lady had to go to the emergency room because he went too far up. So, I never had that done to me." A 28-year-old Black woman participant reported similar concerns, saying that she had read an article that described how "some people went so far up people nose that like they would hit their brain line, like it would start leaking."

Several participants also described how educational campaigns promoting testing had contributed to their fear. A 39-year-old White woman stated, "When I first heard about it, I had a flyer and it showed a picture of that whole procedure and I was skeptical. They had their head tilted back and it showed the thing going in the nose and it tells you how deep it goes in. It was just too much."

3.1.3. Theme 3: concerns about housing undermined the importance of testing

Participants in all focus groups expressed the fear that testing might jeopardize their housing status if housing authority administrators learned of a positive test result. As described by a 70-year-old Black man, "they'd probably put you in quarantine, and try to find a way to get you out of the building." Many participants seemed to assume that a positive test result would be used against residents who were disliked by staff. For example:

> *I don't think it would be a good thing. A lot of times, you can already tell, just from the other questions that you ask them, you can already tell how they feel as far as their bias and their favoritism. So, I don't see that being a good thing, um, or anything that would go in your favor* [55-year-old Black man].

Other feedback seemed to characterize the relationship with the housing authority as fundamentally adversarial. A 70-yer-old Black woman reported the following:

> I don't trust them and they may use the information to terminate your lease. They wouldn't say that that was the reason, but they would find a way. I believe they would find a way to terminate your lease. It's ways that you can terminate a lease other than what they have in our contract. But if you don't know that and they come up with these other reasons, then, you know, you, if you don't know, they can take advantage of your lack of knowledge. But I read everything, and anything that looks like a loophole to me, I use it against them.

A perceived lack of confidentiality appeared to compound concerns about privacy. For example, a 70-year-old Black man was concerned that residents in his building would know if he became sick, saying "So if I did have it and went to the hospital, and when I come back, I'm pretty sure everybody in the building would know I had it, and do not go near them. Do not go near them, they have got it."

3.2. Adaptation of COVID-19 testing outreach with the housing collaborative community advisory board

We set aside one meeting for the first step of the process outlined in Table 1. This step was abbreviated given that our partnership with the HCCAB was in place and we had already developed a mission statement guiding our overall work ("To apply our *community awareness* and shared knowledge through networking to *build trust* in COVID-19 guidance, reduce the severity and spread, and *save lives* in our communities"). Our product from the first meeting was an agreement for us to adapt COVID-19 testing guidance in low-income housing settings with an outline of next steps. Five meetings were devoted to problem analysis and needs assessment, primarily using focus group feedback as a guide. While the objectives and theoretical foundations of COVID-19 guidance were ongoing topics of discussion with the HCCAB, we devoted three meetings specifically to exploring these concepts as they related to increasing the effectiveness of COVID-19 testing outreach. An additional three meetings were devoted to the development of intervention adaptation.

The HCCAB recommended three targeted areas of adaptation to increase the perceived usefulness and efficacy of COVID-19 testing:

- Public housing residents would benefit from convenient testing that would not be perceived as linked to the housing authority or another distrusted institution.

HCCAB feedback stressed the importance of convenience while also acknowledging that community-placed testing could easily be perceived as being linked to the housing authority. The HCCAB recommended a community-driven effort to overcome concerns about information being misused by housing authority staff and administration.

- Other residents could benefit from being engaged in a way that mirrored the experience of the Housing Collaborative Community Advisory Board.

Roughly half of HCCAB members exhibited a great deal of distrust in the U.S. pandemic response in 2020. Yet, several HCCAB members described how being authentically engaged with the project about COVID-19 testing and vaccination gradually led them to change their minds. Importantly, this was the case despite a lack of any direct effort by the academic team. They stressed that relationship-building and being treated respectfully were more important than receiving specific content promoting vaccination or testing. When asked what they appreciated about the meetings, HCCAB members variously stated that we "were not pushy," "were calm," and "did not act like you are selling something." HCCAB Members also agreed that getting information from the academic partners on the team and then being able to hear other members' reactions and reflections helped them develop their own opinions.

- Community members need help addressing their anxiety about the discomfort of COVID-19 testing.

HCCAB members reiterated that unrealistic perceptions about discomfort associated with COVID-19 testing was a real barrier to dealing with the pandemic. They suggested that community members who had undergone COVID-19 testing would likely be best-equipped to help others in their community overcome their anxiety.

Based on these recommendations, the academic team proposed an intervention that would be delivered to community members by HCCAB members serving as peer mentors. Features of the proposed intervention included (1) online delivery using the Zoom platform; (2) a relationship-focused approach, with a majority of the interaction devoted to developing rapport, rather than simply targeting COVID-19 testing; and (3) a peer-mentor demonstration of how to correctly self-administer an at-home COVID-19 test. The HCCAB approved the proposal. Materials outlining the intervention and a training curriculum were created as final products of the adaptation process. The intervention was then taken back to the research participant cohort for their input through an additional round of focus group interviews.

3.3. Focus group feedback on proposed peer-mentor COVID-19 testing intervention

Participants indicated that although attitudes about self-administered rapid COVID-19 tests were mixed, receiving direct help with them likely would increase comfort with their use. Several participants noted feeling comfortable with the convenience of rapid tests, yet feeling overwhelmed with self-administering one. For example, two participants described how assistance either had helped them with a prior rapid test or had the potential to do so in the future. Their reports follow:

> *That was a good thing. I was able to get tested, and not have to wait in long lines. But I'm a little scared, so I had my friend do it for me. I don't know, sticking the thing up your nose is, I think it's a mind-over-matter thing* [35-year-old Black woman].
>
> *Maybe I'm really feeling bad and I said, oh, you know, I could have COVID; then if I have the test, then I would do it. I would try my best to follow the instructions. And then if, of course, somebody shows me how to do it, yeah, I would do it, yeah* [50-year-old Black man].

Participant feedback also suggested that the proposed peer mentor testing model had the potential to help overcome barriers associated with prior negative experiences. A 63-year-old Black woman participant described this in her feedback about rapid tests (with interviewer content included):

> Participant: *I'm afraid to use it. I guess because when I first had the test done, I had to go to a drive-through and the lady that did my test, oh my God, it was the worst experience I ever could have had. She took the Q-tip and she stuck it all the way up in my nose until she pulled blood and tears was just rolling down my eyes.*
>
> Interviewer: *So, have you ever done an at-home test?*
>
> Participant: *No, I'm afraid. I have a test here, but I'm afraid.*
>
> Interviewer: *Okay. So, if someone showed you how to properly do it and how to swab yourself, would you feel comfortable doing it then?*
>
> Participant: *I probably would.*
>
> Interviewer: *Okay, and would you prefer if someone did it, like, over Zoom like how I'm doing it now or would it be better if someone showed you in person?*
>
> Participant: *Ah, the Zoom like we're doing would be good. The Zoom would be good, yes.*

Overall, feedback was positive about potential help with administering an at-home COVID-19 test delivered by a member of the same community. Notably, no participants were critical of the proposed intervention.

4. Discussion

Our goal was to strike a balance between community input and scientific rigor, ultimately to secure community buy-in and obtain high-quality, honest feedback to inform evidence-based recommendations to guide decisions about health. Taken from a broader perspective, we wanted to ensure that communication from communities to investigators was as robust as that from investigators to communities. The process was not intended to be for one project only but rather to establish an ongoing relationship to identify and address community-identified needs in partnership. The onset of the unfolding pandemic required that we communicate virtually with community members about COVID-19. Although not originally planned, this activity resulted in even stronger ongoing participation among group members that will continue as new issues arise.

We were able to identify a number of barriers to COVID-19 testing in public housing settings that can be addressed easily with adapted public health guidance to make outreach more effective and increase testing uptake. The perceived usefulness of testing has likely been undermined by distrust and misunderstanding of the testing process, which seems to be exacerbated by perceptions that COVID-19 testing is painful by design. Misinformation about COVID-19 testing seemed to increase as trust in the test and those administering it declined. We also observed how active distrust in testing could promote conspiratorial thinking (e.g., if testing is assumed not to work but people who get tested develop COVID-19 at higher rates, then those administering tests could be assumed to be somehow causing COVID-19). Given the paucity of research on rapid, at-home COVID-19 testing outreach tailored to address specific community needs, the intervention and the process through which we developed it represent significant steps forward.

With respect to the content of COVID-19 guidance, the trustworthiness of the messenger is likely far more important than the message itself (24). Our interaction with the HCCAB strongly suggests that developing trustworthiness through relationship-building is the primary way to overcome existing distrust. Our proposed peer-led intervention leverages the strength of this approach to address the core barriers raised by residents living in public housing settings.

Our work has several implications for future research. First, the intervention should be piloted to assess whether it increases COVID-19 testing uptake. The relationship building approach can also likely be applied to interventions targeting other health behaviors. Whereas the importance of trust-building is a central theme in the CBPR literature, further research explicitly focusing on relationship building is needed. For example, Jagosh et al. (25) describe "unanticipated benefits" associated with CBPR that primarily work through trust-related mechanisms, including a commitment to power-sharing. Our study suggests that relationship building through CBPR should be considered an intervention in and of itself, particularly in the presence of strong distrust. Researchers should be anticipating these kind of benefits and actively investigating how to promote them.

While a strength of CBPR is that it can be very responsive to community-identified needs, it is important to note that results are often context-specific, which can limit their applicability to other settings. However, we expect findings to remain relevant for low-income housing settings across the U.S., which house a significant number of residents, over 9M, based on 2021 U.S. Department of Housing and Urban Development data (26). Further, our findings could also be generalizable to other marginalized settings characterized by distrust in important institutions.

Although the COVID-19 pandemic was neither the initial nor the sole focus of our efforts, the adaptations and changes that it invoked led to important insights. We used a systematic method to ensure community participation and, in so doing, generated trust. This method is the major contribution of our work that addresses previously identified concerns with the sustainability of peer-led interventions. We also embrace the notion of balancing biomedical, relational, and socio-political aspects of peer support's impact on health, as described by Mullard et al. (9). In particular, our work offers important practical insights for capturing diverse voices that represent subgroups within marginalized communities. Perhaps the greatest insight is that genuine and ongoing communication will help communities proffer their beliefs and attitudes about important public health issues as it becomes clear that interest in their views is real and valued. The discussion space that is formed becomes an incubator in which genuine interest and sustainable good will can be built and future community health concerns identified and addressed in partnership. We anticipate that strength of the partnerships and openness to participating actively will continue to grow over time.

Data availability statement

The datasets presented in this article are not readily available because the qualitative data contain many identifiers and complete anonymization is impractical. Requests to access the datasets should be directed to plunkad@evms.edu.

Ethics statement

The studies involving human participants were reviewed and approved by Eastern Virginia Medical School IRB. The patients/participants provided their written informed consent to participate in this study.

Author contributions

AP, DG, SuG, and EM designed the research. AP, KH, and AC acquired the data. AP, KH, and SaG analyzed focus group transcript data. AP, KH, AC, DG, and EM took part in the adaptation meetings with the community advisory board. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Community engagement: health research through informing, consultation, involving and empowerment in Ingwavuma community

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Introduction: The goal of community involvement in health research is to improve a community's ability to address its own health needs while ensuring that researchers understand and consider the community's priorities. Recent data show that socio-economic and environmental challenges continue to be a barrier to informing, consulting, involving and empowering communities in community-based health research beneficial to them. The aim of this study was to assess the extent to which the Ingwavuma community in KwaZulu-Natal Province, in rural South Africa, was informed, consulted, involved and empowered about two research projects conducted between 2014 and 2021.

Methods: The study used the modified random-route procedure to administer a standardized questionnaire to 339 household heads selected randomly. The questionnaires were administered face-to-face. The sample size was estimated using the Yamane sample size generating formula. Chi-square tests were performed to assess associations between demographic variables (age, gender, education, village) and respondents' knowledge and information of the projects, Malaria and Bilharzia in Southern Africa and Tackling Infections to Benefit Africa as well as their participation.

Results: The communities were generally well-informed about the health projects that were being carried out. Fewer than half of those who had heard about the projects had directly participated in them. The majority had been tested for one or more diseases and conditions, mostly high blood pressure, diabetes, and schistosomiasis, and had participated in a community feedback group; many had given their children's permission to be tested for schistosomiasis or to participate in project research activities. Others participated in public awareness campaigns and surveys. There was some evidence of a consultation process in the form of public consultation discussed in the projects, and not much discussion on empowerment.

Discussion: The findings demonstrate that researchers' CE approach was adaptable as communities were largely educated, involved, and subsequently empowered though without much consultation and that researchers had provided a space for sharing responsibilities in all engagement process decision-making. For the empowerment of the community, projects should take into account the intrapersonal and personal aspects affecting the community's capacity to effectively benefit from the information, consultation, involvement, and empowerment procedures.

KEYWORDS

ecohealth, involvement, communities, community engagement, health research

1. Introduction

Community engagement (CE) in health research aims to strengthen a community's ability to tackle its own health problems while drawing the attention of researchers to known health challenges in the community. Communities in which community health research is conducted must perceive the research process as authentic and credible (1). However, power imbalances between researchers and the participants (communities) that result in community members not always having a voice in the decision-making process (2) sometimes lead to the withdrawal of communities from studies due to mistrust and suspicion (3). Community trust is significantly associated with community engagement and if a community lacks trust, it may decide to disengage (4). Strong evidence found poverty and unemployment in remote rural communities influence how research participants misinterpret outside researchers as potential sources of various material benefits. Many studies have reported that there is little guidance on how to assess the CE processes, the outcomes and the impact on communities, which should lead to community empowerment (5–7). CE in community health research refers to efforts that promote the exchange of information, ideas and resources between community members and researchers. It is a collaborative co-governance of research including researchers and people affected by issues under investigation or in positions to act on research findings, such as end-users including intervention participants, health managers, and policymakers (8). Researchers can acquire knowledge and trust, but they may not fully appreciate the true community health status to adequately address pertinent research questions. On the other hand, some communities may not always trust the intentions of researchers, or the methods used in the research (9, 10). Similarly, ordinary community members may have limited research skills, knowledge and training, and may not fully appreciate the complexities of research methodology and theories (11). Therefore, while health researchers share their health expertise, services, and other resources with the community as part of community engagement in the research process, the community may provide crucial local knowledge and experience that can greatly help direct the efforts of health research projects/programs. It is important to engage communities in all research processes so that they fully benefit from the research. This implies that the concept of CE is critical in community research and the inclusion of communities in the research process from inception can improve the way research is planned, carried out and used (12).

CE improves health outcomes by increasing the cultural and logistical adaptation of community-based research projects to their settings, promoting community empowerment, and facilitating the translation of research-generated health knowledge into practice (13). In addition, CE can help to uncover the social, political, and economic contexts that underpin both facilitators and barriers to knowledge and resources needed for health (14), especially when the research process is co-governed with end users. Although community engagement is considered important in health research, its implementation is still understudied (15). CE can be challenging as it requires effort, capacity, investment of time as well as money (16) and the researched community may be indispensable regarding the methods and execution of the project (17). Therefore, dialogues between community members and researchers with different levels of involvement, decision-making and control between community and health researchers can overcome these challenges (18). Consequently, researchers must approach communities as research partners, with community members and leaders' participation viewed as critical for acceptability and success of a research project/program. The challenges are amplified when a particular health issue or research question is not prominent in the consciousness of the targeted community.

In community health research settings, investigators and their teams must inform, consult, involve and empower the community about the objectives, rationale and benefits of research projects for the community. However, little is often known about the extent to which they are informed and/or educated about health research projects in their localities/communities. Without a clear assessment and understanding of the extent of information and communication communities received from research project teams, researchers are likely to fail in their attempts to involve community members in research collaborations. Establishing a research partnership without effective communication and information can lead to decisions and actions that further violate the trust of the community. Distrust not only affects the immediate research relationship, and, in turn, the validity of the data collected, but also has a profound impact on the future willingness of the affected populations to engage in the research enterprise. In this article, we present findings on the extent to which a local community was informed, consulted, involved and empowered about research projects and related activities in their locality. It is based on two community based projects; Malaria and Bilharzia in Southern Africa (MABISA) and Tackling Infections to Benefit Africa-South Africa (TIBA-SA) (19), carried out between 2014 and 2021 in the Ingwavuma area of KwaZulu-Natal Province in rural South Africa.

2. Materials and methods

2.1. Study setting and MABISA/TIBA-SA project overview

This study was conducted in Ingwavuma, an underdeveloped area in the uMkhanyakude district, KwaZulu-Natal province, South Africa (20). The area lies on the north-east border with Mozambique and Swaziland and is adjacent to the Ndumo game reserve (Figure 1). A permanent river, the Pongola River, flows through it. The Pongola has distributaries that start from within the mountains that border Swaziland, one of which is the Ingwavuma River. There is very little infrastructure in this area; the road network is still being developed and much of the area is accessible through gravel roads. Schools are sparsely distributed throughout the villages and offer minimum utilities with most of them having no tap water. Due to the dry weather conditions in the region, agricultural activities and other related economic activities are limited. Apart from an irrigation system that draws water from the Pongola Dam, which is more than 35 km away, there is no other irrigation system. The town of Ingwavuma is located in a low-lying area, characterised by hot temperatures, stagnant and slowly moving water bodies. These geographical conditions make the region a hotspot for schistosomiasis and malaria. Individuals in these areas experience extreme poverty and low levels of education. These factors indicate the need to involve the community in health education in a robust and inclusive way.

The MABISA (Malaria and Bilharzia in southern Africa) and TIBA-SA (Tackling Infections to Benefit Africa-South Africa) research projects were initiated in 2013 and 2017 respectively, upon realization

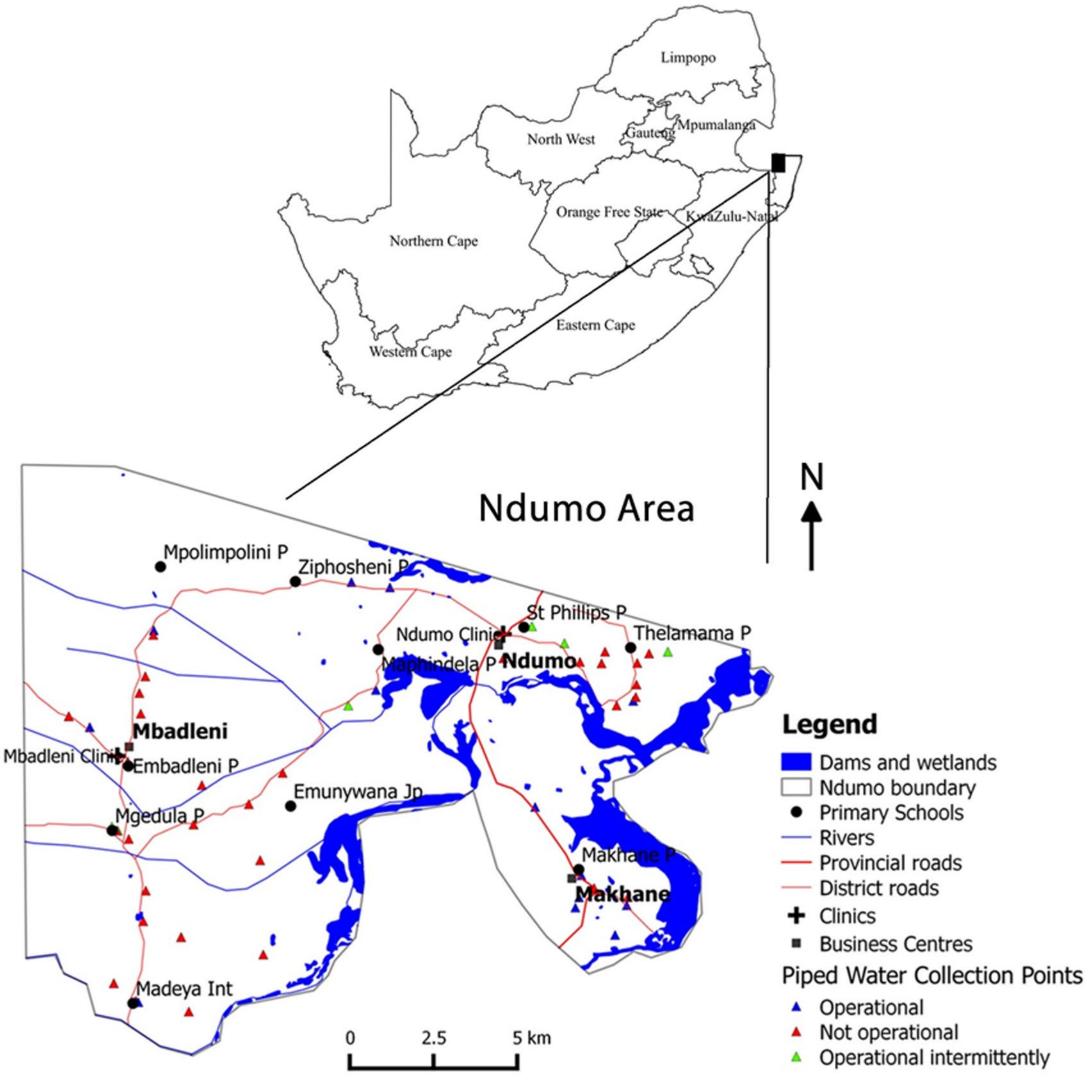

FIGURE 1
Map of Ingwavuma areas, uMkhanyakude district, Jozini Municipality, KwaZulu-Natal, South Africa.

that social and environmental determinants of health have a major influence on the epidemiology of vector-borne diseases (VBDs) and that the influence is exacerbated by climate change (19). The Ingwavuma area faces different socio-economic and environmental challenges, which offer opportunities to investigate the impact of these factors on VBDs. These community-based health research projects were designed to address the impact of social-environmental determinants and climate change on two VBDs, malaria and schistosomiasis. The projects focused on the ecologies and water systems of dry land (rivers, lakes, rain-fed systems, irrigation systems) within dry land in order to develop adaptation strategies to reduce vulnerability to these diseases in population health. TIBA-SA had components of BP and Diabetes project. Throughout the projects, the study team relied on the input of members of the community to guide the nature and structure of interventions.

The paper is based on work in a larger project, the KwaZulu-Natal Ecohealth Program (KEP) which uses a participatory action research methodology. A governance structure and an operational strategy that involves the community to ensure that the community fully participated in MABISA/TIBA-SA projects was established during the first phase (Informing) of CE. A 12-member Community Advisory Board (CAB) comprising of one headman (induna), two community leaders, three school board members, three community care givers and three ordinary community members was established at the inception of the MABISA project and is functional to date. The headmen (izinduna) are the elected gatekeepers with authority over villages and are accountable to the chiefs, the tribal council and their community (21). The informing of the community in the MABISA project was through the community liaison officer (CLO), who was referred to the MABISA project by the Provincial Health District, as he had previously worked for other NGO projects in the area. The CLO then linked the principal investigators with the leaders of the community to introduce the ideas of the project. The project principal investigators visited the community with a prepared detailed study document to engage with the community. In this methodology, it is important to note that the researchers were the ones who came up with the idea for the project, found a way to get the community involved by informing them about the project, and engaged community members to have input on the design, methodology, and execution of the project. The community meeting was organised by the induna and activities for participatory rural appraisal (PRA) (origins of PRA) were conducted to identify issues that were to be researched. This method of engagement gives a community access to accurate and objective information that will assist them in better understanding the project proposed as well as the potential solutions.

The project field operations were carried out by researchers and CRAs as they were trained to attain the required skills for the fieldwork. The presence of the CAB and CRAs has been instrumental in promoting the concept of community change makers for prevention and control of vector borne diseases including zoonosis. Decisions concerning survey design and implementation, as well as techniques to collecting anthropometric and biochemical data, were influenced by community leaders and community members employed as staff (CRAs). The initiatives in the TIBA-SA projects are designed to have an influence on the society that is affected by health issues; they take an Ecohealth approach with a focus on community participation. The projects were founded on the idea that academics working with the Ingwavuma community would be able to change health behaviour, collect information, and increase understanding of infectious illnesses including schistosomiasis and malaria. The project produced good results which were largely disseminated through various means, workshops, local radio station and journal publications (much less for communities and government agencies). As part of the uptake activities, we had school children drama competitions focusing on malaria and schistosomiasis. We have realized that edutainment is an effective way of disseminating information to communities and that uptake is likely when the information is naturally assimilated through music, dance, poetry and drama. We used a group called Ubuciko, the Art to provide edutainment. During MABISA project they performed during PRA meetings and the response from the community was overwhelming in terms of information dissemination. This method of information dissemination resonance well with the culture of communities we worked in. In addition, a community feedback meeting was used as a platform to disseminate findings of the project to all stakeholders. Because of the capacitation of CRAs we made and involvement of Department of Health personnel we believe that the project ideas will be sustained in the community and relevant government departments.

2.1.1. The community engagement Vancouver coastal health framework

The study applied the Community Engagement Vancouver Coastal Health framework[1] which involves five CE components. The stages include (1) informing the community, (2) consulting the community, (3) involving the community, (4) collaborating with the community, and (5) empowering the community and are summarized in Table 1. This paper focuses on the Informing, Consultation, Involving and Empowerment phases. Although there are different methods and frameworks for community engagement, this framework, often quoted in many studies (22–26) was suitable for this study. We wanted to engage the community across the full spectrum of participation levels ranging from informing, consulting and involving to collaborating and empowering. The Vancouver framework outlines community engagement as public participation and is based on the principle that people have the right to participate in the decision-making processes that affect them and that everyone has a say when it comes to their health care (27). This framework was adapted from Sherry Arnsteins's theory of Ladder of Citizen Participation which is one of the most widely referenced and influential models in the field of democratic public participation (28). Arnstein's theory discusses about eight levels of participation arranged in a ladder pattern with each rung corresponding to the extent of citizens' power in determining the end product. The bottom rungs of the ladder are, first (*Manipulation*), and second (*Therapy*), which describes "non-participation" real purpose here is not to give individuals a voice in planning or executing initiatives, but rather to provide those in positions of authority the opportunity to "educate" or "cure" the people who are involved (28). In the third (*Informing*) and fourth (*Consultation*) rungs, "tokenism" increases to the point that the have-nots can finally be heard and their voices heard. Rung fifth (*Placation*) is simply a higher-level tokenism because the ground rules allow have-nots to advise, but retain for the powerholders the continued right to decide. Rung six (*Partnership*) enables them to negotiate and engage in trade-offs with traditional powerholders. At the top most rungs, seven (*Delegated Power*) and eight (*Citizen Control*) have-not citizens obtain the majority of decision-making seats, or full managerial power (28). For local leaders, organizers, and facilitators who want to understand foundational theories of public engagement and participation, and the ways in which empowered public institutions and officials deny power to citizens, Arnstein's theory was also essential for this particular study aimed to assess the extent to which the community, in rural South Africa, was informed, consulted, involved and empowered about two research projects (MABISA and TIBA-SA).

2.2. Study participants and data collection

The study was carried out between November 2019 and November 2021. The study used the modified random-route procedure (29) to administer a standardized questionnaire to 339 household heads selected randomly. The sample size was estimated using the Yamane sample size generating formula (30). The modified random route procedure involved dropping interviewers at different locations within the designated geographical area and allowing them to choose a starting point and direction for the selection of households. Since this method is employed when there is not a complete list of households, it aims to produce equal selection probabilities so that each household has an equal chance of being included in the sample (31). Questions were arranged in a logical sequence and uploaded to KoboCollect (32), an online open source platform for data collection and analysis. Questionnaires were administered face-to-face.

The questionnaire was designed in English and translated into the study area local language, isiZulu. Community Research Assistants (CRAs) who administered the questionnaire received intensive training over 2 days. In order to ensure uniform understanding and evaluation of data collection, the instrument was pre-tested in one of the villages in the area, with similar socio-demographic and cultural characteristics to the study area. The village where pre-testing was done was excluded from the main study. Additional modifications to

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[1] www.vch.ca/ce

TABLE 1 Five components of community engagement.

Inform	Consult	Involve	Collaborate	Empower
Objective	**Objective**	**Objective**	**Objective**	**Objective**
To provide community with balanced and objective information to assist them in understanding the problem, alternatives, or solutions.	To obtain community feedback on analysis, alternatives, or decisions.	To work directly with the community throughout the entire process to ensure that community and organizational concerns are consistently understood and considered.	To partner with the community in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the community
Promise to the community	**Promise to the community**	**Promise to the community**	**Promise to the community**	**Promise to the community**
We will keep you informed.	We will keep you informed, listen to and acknowledge your concerns, and provide feedback on how community input influenced the decision.	We will work with you to ensure your concerns and issues are directly reflected in alternatives developed and provide feedback on how community input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	To place final decision making in the hands of the community.

the tool were done based on the results from the pre-testing. The questionnaire included questions on demographics, such as age, gender, and the level of education of the household heads. In order to determine how informed the community was about research projects in their locality, respondents were asked to name any health research project they remembered to have been conducted in their community in the past 7 years during which the two projects were undertaken in the community. Those who had lived in the research area for over 10 years may have had rich information. They were also asked whether they had ever heard of MABISA/TIBA-SA research projects, among other questions. Items were designed to be closed ended, but an option for additional open-ended responses was included for most of the questions.

2.3. Data analysis

Data were analysed using descriptive statistics specifically frequencies and percentages. Chi-square tests of associations were done to assess associations between demographic variables (age, gender, education, village) and respondents' knowledge and information of the MABISA/TIBA-SA projects, their involvement as well as empowerment. Further Chi-square tests were done to assess the association between participating in the study and knowledge about its aims, activities, researchers, sites as well as whether respondents believed they had benefitted from the projects. Cramer's V tests were applied to all statistically significant Chi-square tests to measure the strengths of associations while descriptive contingency tables were used to identify relationships within the associations with a V of 0 indicating no relationship and a V of 1 showing the strongest possible association between tested variables (33). A probability value of 0.05 was used in both the Chi-square and Cramer's V tests. The general view behind the tests was that an informed, consulted, involved and empowered audience would exhibit statistically significant results that showed strong associations between project participation and knowledge of the projects' aims, activities, researchers and research sites. Also, they would show a strong association between project participation and benefits.

2.4. Ethical considerations

Ethical approval was obtained from the University of KwaZulu-Natal (UKZN) Institutional Ethics Board, Humanities and Social Sciences Research Ethics Committee (HSSREC), Protocol reference number: (HSSREC/0001650/2020). All participants gave informed consent to participate in the study.

3. Results

3.1. Participants demographics

Table 2 below shows that respondents' demographic information. The study used a sample of 339 respondents from five villages in the Ingwavuma Community.

Of the five villages, 107 (31%) respondents came from Ndumo followed by 85 (25%) from Makhane (see Table 2). The majority of respondents (88%) had stayed in the study area for more than 10 years which could mean that they had rich information about the community projects and what happens in their community. More than 26.9% of respondents were aged 35 years and below, while those above 66 to 75 of age were 3.3%. Further, the results show that more than two-thirds (72%) of the households surveyed are female-headed and that most (over 90%) have secondary education and less as their highest level of education.

As indicated in Table 3, out of 338 respondents, 177 (52.4%) had heard about the MABISA/TIBA projects while 161 (47.6%) had not. Of the 177, 41.8% participated in the projects. Less than half of the respondents who had heard about the projects were involved as participants. Of the 177 respondents who said they had heard about the MABISA/TIBA projects, 64.4% stated that they were familiar with the projects on Schistosomiasis, 20.3% with the Malaria project while 18.6% said they had forgotten about the project they had heard about. Respectively, 10.7, 7.3 and 4.5% of the respondents who knew about and who had heard about the MABISA/TIBA projects knew about the BP, Diabetes and infectious diseases/diseases projects. The participants were therefore exposed to information about different projects with

TABLE 2 Study participant demographics.

Description	Participants	Frequency	Percent
Gender	Males	92	27.3
	Females	245	72.7
Age (Years)	<25	89	26.3
	26–35	91	26.9
	36–45	57	16.9
	46–55	45	13.3
	56–65	35	10.4
	66–75	11	3.3
	>75	10	3.0
Village	Ndumo	107	31.7
	Mbadleni	73	21.6
	Mgedula	49	14.5
	Madeya	23	6.8
	Makhane	86	25.4
Highest Education level	No formal education	60	17.8
	Primary	83	24.6
	Secondary	164	48.5
	College level	9	2.7
	Above college level	3	0.9
	Other	19	5.6

TABLE 3 Information on health research projects and involvement.

	Responses	Frequency	Percent
C2 Have you ever heard of MABISA/TIBA projects?	No	161	47.6%
	Yes	177	52.4%
	Total	338	100.0%
Did you participate in the project?	No	103	58.2%
	Yes	74	41.8%
	Total	177	100.0%
C3 Mention MABISA/TIBA projects that you know about:	Schistosomiasis	114	64.4%
	Malaria	36	20.3%
	Do not know/have forgotten	33	18.6%
	BP	19	10.7%
	Diabetes	13	7.3%
	Infectious diseases/ diseases	8	4.5%
	HIV	1	0.6%
Where did you hear about these projects?	CCG	77	43.5%
	School	50	28.2%
	Family/neighbours	27	15.3%
	Community meeting	24	13.6%
	Other	16	9.0%
	Traditional leadership	5	2.8%
	Television/radio	5	2.8%

some having no information about running projects. A considerable number reported to be uninformed or having forgotten about some projects. Among the 177 respondents who had heard about the projects, 43.5% had heard about these from CCGs, 28.2% from schools, 15.3% from family/neighbours and 13.6% from community meetings. Also, 2.8% had heard about these from their traditional leadership and another 2.8% from television/radio. CCGs and schools were therefore the commonest sources of MABISA/TIBA projects information.

3.2. Participation and benefits

The respondents were asked if they took part in any of the projects and what they had learnt from them. Table 4 summarises their responses.

Out of 76 respondents, 46.1% had been tested for one or more diseases and conditions, mostly BP, Diabetes and Schistosomiasis. Also, 25.7% had participated as part of a community feedback group and 11.8% had participated by consenting for their children to be tested or to take part in the projects' research activities. 10.5% participated in awareness campaigns and 6.6% participated as survey respondents.

The above Table 4 focuses on 76 respondents who responded "Yes" to the question *What did you learn or understand from the projects that are being done in your community?* Out of the 77, most of the respondents (68.8) learnt about Schistosomiasis, 44.2% about personal health and hygiene, 29.9% about Malaria and 20.1% about infectious diseases in general. Of these, 13% reported to have forgotten what they learnt while 6.5% said they learnt nothing from the projects. The majority had therefore benefitted through learning about Schistosomiasis. A minority had also learnt about Malaria and infectious diseases.

3.3. Associations between informing, involvement and participation

Table 5 analyses data from the 177 respondents who had participated in the projects' activities focusing on associations between participation, informing and consultation.

Out of 74 respondents who participated in the projects 52 (70.3%) of the respondents knew about the research activities conducted by MABISA/TIBA projects. The remaining 22 (29.7%), despite taking part, were not aware of the organisation's projects. Also out of the 74, only 20 (27%) were familiar with the projects' research sites. The remaining respondents had no idea about these projects. In the same group, 19 out of 74 (25.7%) participants knew about the projects' research aims while the rest did not. The majority of the respondents (69 out of 74) or 93.2% had, however, met directly with the MABISA/TIBA researchers while only 5 had not. Also, 33 out of 74 (44.6%) knew the researchers' names while the rest did not suggest that despite this contact, some respondents remained poorly informed about the

TABLE 4 Participation and benefits.

	Question/ Statement	Frequency	Percent
Did you participate in the projects? if yes how?	Tested for diseases and conditions	35	46.1%
	Survey respondent	5	6.6%
	Consented for children to participate	9	11.8%
	Community feedback group	19	25.7%
	Training and awareness recipient	8	10.5%
What did you learn or understand from the projects that are being done in your community?	Schistosomiasis	53	68.8%
	Personal health and hygiene	34	44.2%
	Malaria	23	29.9%
	Infectious diseases in general	16	20.1%
	I have forgotten	10	13.0%
	Diabetes	8	10.4%
	Importance of visiting healthcare facilities	6	7.8%
	BP	6	7.8%
	Nothing	5	6.5%
	HIV/STDs	5	6.5%
	Importance of taking medication	4	5.2%
	Cancer	4	5.2%

research projects' aims and sites. Almost all the respondents who had participated in the MABISA/TIBA projects stated that they had signed a consent form, and the same number also affirmed that these consent forms had enough background information about the project. Finally, only 26 out of 74 (35.1%) respondents said they had benefitted from the projects while 48 (64.9%) said they had not.

In the above crosstabulations, statistically significant X^2 confirms the association between participating in the projects and knowing about them specifically the activities conducted in them ($X^2(1) = 15$, $p = 0.00$); participation and knowledge of research sites ($X^2(1) = 19.68$, $p = 0.00$), aims ($X^2(1) = 23.2$, $p = 0.00$) and researchers involved ($X^2(1) = 16.8$, $p = 0.00$). In all these associations, Cramer's V ranged from 0.15 on the benefits to 0.97 on consent. Besides the low size effect (low Cramer's V) on the benefits of participation, moderately strong to very strong associations were recorded these being highest on consent (Cramer's V = 0.97, $p = 0.00$).

However, the results point to a weak association between participation and benefitting from the projects ($X^2(1) = 4.11$, $p = 0.00$) further supported by a Cramer's V of 0.15. Ironically, more respondents (50.5% or 52 out of 103) reported to have benefited from the projects without participating compared to 35.1% (26 out of 74) who benefitted from direct participation. The project, therefore, had an impact beyond those who were directly reached out to as information about projects also filtered to those who did not directly participate. The data above also highlights some inconsistencies that suggest limited information on the part of the respondents. Specifically, 71 out of 74 reported that they had received and signed consent forms that provided them with research projects' adequate background. This is despite 19 out of 74 stating that they did not know of the projects' research aims. The above data highlights the following patterns: Involvement without critical full information (aims, activities, identities, sites of the projects); Poor understanding of the research consent process among the participants and consequentially low benefits from involvement/participation.

3.4. The association between information and demographic groups

There were no statistically significant associations between the question – *Can you list the aims of the research project?* and the variables gender, age, level of education, village and the number of years one had stayed in the surveyed community. The same applied to the association between the question *Did you participate in the projects?* And the above variables.

There was also no statistically significant association between benefiting from the projects and the variables age, level of education, village and the number of years one had stayed in the surveyed community. Persons of different genders however benefitted differently from the projects as shown by statistically significant X^2 (see Table 6).

Females benefitted less (53 out of 133 or 39.8%) than males (56.8%). A Cramer's V of 0.148, however, indicates that this association was not very strong. The data in this subsection demonstrates an inclusive approach to community engagement by indicating that information and involvement in the projects were not centred towards specific demographic groups.

4. Discussion

The findings from this study show varying dynamics in the respondent's levels of information and involvement in MABISA/TIBA projects. From the sample, 52.4% of the 339 respondents indicated that they were informed of the projects, 21.9% participated in them and 6% were consulted for feedback as illustrated in Figure 2.

More respondents benefitted from the projects than those who participated. Nonetheless, the data showed an inverted pyramid pattern where fewer respondents progress to the next advanced participation phases. A 52.4% project awareness rate, however, could be justifiable considering the rural nature of the communities involved. The conversion from being an informed person to a participant highlights potential challenges in getting communities involved in the projects. Such limited interest to participate highlights engagement challenges that include, among other things, feeling marginalized, and failure to identify with research and project purposes and methods among others (34).

TABLE 5 Informing and involvement and participation.

Statement/ Question		C16 Did you participate in the project?			X^2		Cramer's V	
	Response	No	Yes	Total	Stat	Sig.	Stat	Sig.
C5 Do you know the research activities conducted by MABISA/ TIBA projects?	No	61	22	81				
	Yes	42	52	94				
	Total	**103**	**74**	177				
C7 Do you know the project's research sites?	No	99	54	153	19.68	0.00	0.33	0.00
	Yes	4	20	24				
	Total	103	74	177				
C8 Can you list the aims of the research project?	No	101	55	156	23.2	0.00	3.62	0.00
	Yes	2	19	21				
	Total	103	74	177				
C12 Have you met the MABISA/TIBA researchers?	No	74	5	79	73.8	0.00	0.65	0.00
	Yes	29	69	98				
	Total	103	74	177				
C14 Can you list the names of the research team?	No	86	41	127	16.8	0.00	0.31	0.00
	Yes	17	33	50				
	Total	103	74	177				
C18 Did you sign the consent form before you participated in the research project?	No	103	3	106	165.02	0.00	0.97	0.00
	Yes	0	71	71				
	Total	103	74	177				
C20 Did you get enough background information about the project from the consent form?	No	103	3	106	165.02	0.00	0.97	0.00
	Yes	0	71	71				
	Total	103	74	177				
Benefitted	No	51	48	99	4.11	0.04	0.15	0.04
	Yes	52	26	78				
	Total	103	74	177				

The bold values are the total of respondents who participated in the projects.

TABLE 6 Association between gender and benefits from the projects.

				X^2		Cramer's V	
				Stat	Sig.	Stat	Sig.
	Benefitted						
	No	Yes	Total				
Female	80	53	133				
Male	19	25	44				
Total	99	78	177				

4.1. Informing

The study identified two major levels of public information involved in the projects. The first was to inform whole communities of the projects' existence. The second level involved informing part of the communities that chose to participate in the research. The data shows that the five communities that took part in the research

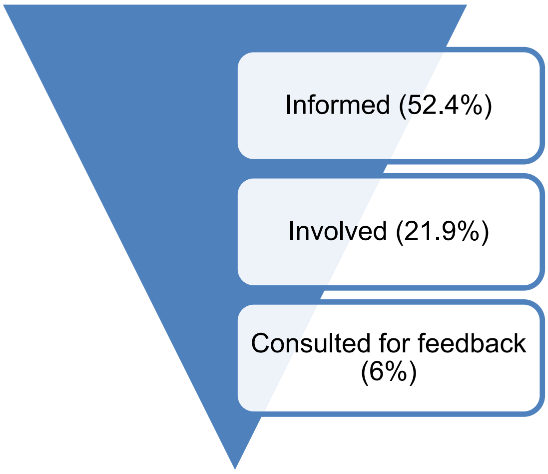

FIGURE 2
Summary (informed, involved and consulted participants) – Researchers (Source: Author, 2022).

exhibited poor levels of information about the projects on both levels. Approximately half of the respondents had never heard of the projects.

Among those who had heard about the projects and chose to participate, there were critical information asymmetries between the researchers and the participants on what the project was about, where it was based, who their researcher was and what activities it involved (35). These are considered key aspects that define research, yet they remain unknown to respondents. One of the major activities and tools used to inform communities about research is the consenting process, regularly done through the handing over and signing of a consent form. Almost all participants went through this. While that process provided all the required project background it failed to have the desired impact on the researched communities. Lack of knowledge cannot be blamed for the poor understanding of the projects' aims, as there were no statistically significant differences in this regard.

The consent issues raised above highlight possibilities of poor understanding of the consenting process among research respondents (36). The University of California, San Diego Brief Assessment of Capacity to Consent Questionnaire (UBACC) is one of the reliable and validated tool that can be used routinely to assess individuals' capacity to consent to a research protocol and improve understanding of research study through iterative learning (37). The UBACC is designed to assist researchers in identifying study participants who require a more comprehensive decisional capacity assessment and/or remedial efforts prior to enrolment (37). If individuals are assessed using the UBACC, it provides more certainty that they are informed about what they are enrolling for. This is particularly important given some risks of health research. Research respondents may agree to participate in a study without knowing or rigorously looking at its pertinent details. Procedural weaknesses particularly the handing over of a consent form together with the questionnaire for immediate filling can also deny respondents the chance to fully grasp what they are consenting to Ref. (36). Relatable findings were also made in the study on how rural community respondents fail to recall the contents of consent forms (38). In the study that was conducted in rural KwaZulu-Natal, some respondents had participated in projects under the belief that they would materially benefit from them. The process of getting meaningful consent to clinical research participation may be hampered by therapeutic misconception, which occurs when research subjects fail to appreciate the distinction between the imperatives of clinical research and ordinary treatment, and therefore inaccurately attributes therapeutic intent to research procedures (39). A study demonstrated that therapeutic misconception occurs in the South African oncology research setting and has the potential to lead to underestimating of the risks of a Phase 3 clinical trial. Therefore, it is vital to emphasise the experimental nature of a clinical trial throughout the consent process in order to overcome therapeutic misconceptions in oncology research (40). Another South African study on the ethical challenges in obtaining informed consent for genomic research in general and the implications of recruiting healthy controls for genomic research in particular discovered that diagnostic and therapeutic misconceptions were the main challenges (41). In terms of informed participation, this creates a risk of a sample that is not fully involved in a study due to information asymmetries between the researcher and the research targets (42). Such targets, reveal vulnerabilities that the researchers must consider during the research process (43).

The linkage of consent challenges to the quality of participation has previously been explored (44). Passive participation occurs when respondents consent to research they may not fully understand, either lack of knowledge or out of being poorly oriented by the researcher. Passive participation is also common when passive consent approaches are applied in research (45). In this study, the enigma is that the respondents asserted that they participated voluntarily and were fully informed of the research background, yet they were unable to identify the researchers, the research aims and sites. Therefore, before consenting to research studies, potential participants should be informed about research objectives, procedures, and benefits and risks to minimise diagnostic and therapeutic misconceptions (41). Before enrolling participants in research studies, researchers must assess their familiarity of scientific jargon and concepts. Research team recruiting potential study participants must be innovative and ethical during the process. Researchers must be able to adapt consent processes to the recruitment setting to help potential study participants make informed decisions (39–41).

4.2. Consultation

We found some evidence of consultative processes. Twenty-five-point 7 percent (25.7%) of the respondents who participated in the projects were consulted for feedback relating to the projects. Further to that, the largest percentage of respondents had heard about the projects from community caregivers. Community meetings were also another form of public consultation discussed in the projects. However, the overall data suggests that such consultative practices, despite being procedural might not have resulted in quality information output as the consulted groups mostly indicated lack of knowledge about the projects (aims, identity, activities, researchers and sites). Furthermore, the respondents did not list consultative processes as an ongoing research activity like the surveys they listed. This also suggests that the consultation processes were for post-evaluation processes (46) posit that community consultations in research projects were a basis for the creation of mutually beneficial and more productive engagements between researchers and communities. Such consultations span include methodological and content processes that can enhance the attainment of project goals (46). Consultation is a form of involvement that supports the co-creation of projects and wider participation of marginal and disadvantaged groups and communities that may otherwise be excluded from research institutions (34). This view applies to the five remote communities studied. Consultative processes help to clear up such misconceptions, thereby improving the quality of health research interventions. Poverty and unemployment in remote rural communities have been found to have a strong influence on how research participants misinterpret outside researchers as potential sources of various material benefits (38). Consultative processes iron out such misconceptions enhancing the quality of health research interventions.

4.3. Involvement

Defining involvement from the Community Engagement Vancouver Coastal Health framework there is evidence of limited public involvement from the results. This is highlighted in the majority of the respondents' failure to identify the project, specifically, its project sites and researchers. As expected, community engagement efforts generally result in the availing of such information to the research subjects. While the majority of the respondents who participated in the study acknowledged meeting the researchers, the failure to identify them suggests limited engagement. Limited engagement disempowers communities and limits their contribution, as well as benefits, from health projects (46).

4.4. Collaboration and empowerment

In the study, there is not much discussion on research collaboration between the researchers and the communities. As highlighted, community members were primarily the participants for surveys, beneficiaries of awareness programmes, and test subjects for medical examinations and screenings. A small fraction did give its feedback to the researchers as discussed earlier. Thus, according to the Community Engagement Vancouver Coastal Health framework, the research projects may be discussed as reaching the informed and involved stages. The advantages of community empowerment in research include more active and wider participation that supports desired behavioural change (47). Such benefits might have been missed by the research.

Tests of associations attempted to find relationships between information and involvement (participation) and demographic data. As indicated in Figure 3, the first dimension affecting participation consists of intrapersonal factors (48).

From the projects, the pattern of being poorly informed and less keen on participation was common among respondents of different ages, genders and levels of education. This points to the limited dominance of intrapersonal factors in the participation processes (48). This suggests that interpersonal and institutional factors may be more responsible for low information and low participation in the projects. At the same time, however, some respondents did signify that despite being engaged and informed, they had forgotten what the projects were all about, pointing to some intrapersonal limitations affecting information and involvement as well. In the conceptual model presented above in Figure 3, this could indicate knowledge retention and cognitive issues or even attitudinal issues that affect participation levels (48).

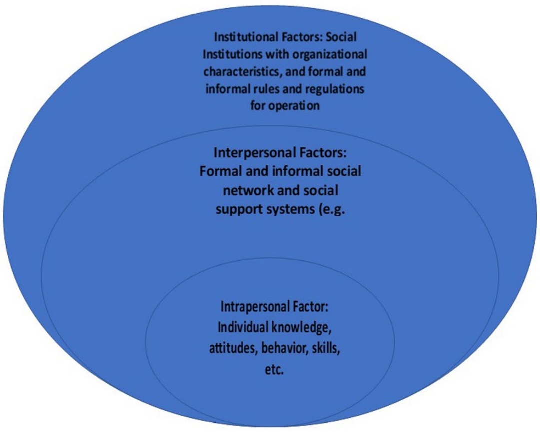

FIGURE 3
Barriers and facilitators of participation/involvement (48).

The same study by Bay et al. (48) also points to the importance of formal and informal social networks in research participation – similar to this study. Participation through social networks was mostly evident in the number of respondents who benefitted from the research projects without directly being part of them – mainly through information flows. Parents indicated benefiting from the projects through their schoolchildren whom they consented to participate. Other respondents noted that they only knew about the projects from neighbours and family. This shows a strong interpersonal component in participation.

4.5. The study's proposed framework

We propose using a hybrid framework the Community Engagement Vancouver Coastal Health framework and Bay et al.'s (48) conceptual framework on factors that affected individual and community participation in health projects (see Table 7) below.

The framework highlights a need to engage communities more meaningfully in research through effectively informing, consulting, involving and empowering processes. Our study found that the communities were mostly informed and involved but were not fully consulted and not empowered. To empower communities, projects should consider the intrapersonal and personal factors affecting community capacity to fully benefit from the information, consultation, involvement, and empowerment processes. In our study, poor understanding of the project was suggested to be a result of both intrapersonal issues – for example, respondents stated that they were involved in the project but did not understand or had forgotten what it was about. Intrapersonal factors came out as important in the dissemination of information about the project. Health research institutions had the role to develop research methods and processes that took into consideration the intrapersonal and interpersonal characteristics of the communities involved.

5. Limitations

A CE strategy that fully engages the community is limited by community research literacy levels, time, and resources, but creates an environment conducive for research. The time lapse between when participants participated in the MABISA and TIBA-SA research projects have impacted their collection of details such as researcher's names and particulars about the study. This paper currently does not address how the community was "empowered, "because measuring community empowerment may be difficult. The CE framework that forms the foundation for the study is Canadian. Apart from extensive literature in CE, there is a dearth of empirical research conducted using the Community Engagement Vancouver Coastal Health framework in a South African context. Therefore, this framework may not be generalised to apply to all studies conducted in South Africa, but it can be transferrable to communities in similar contexts seeking to strengthen the process of how researchers truly engage communities. Factors that contributed to limited dissemination of

TABLE 7 The engagement-empowerment framework (Researchers).

		Levels of engagement		
		Intrapersonal	**Interpersonal**	**Institutional**
Levels of participation and decision-making	**Inform**	Individual characteristics and understanding	Group characteristics and understanding	Institutional systems and processes to support intrapersonal and interpersonal information
	Consult	Consult individuals based on their nature and understanding of the project	Consult unique groups and niches based on their nature and understanding of the project	Institutional systems and processes to support individual and group consultation
	Involve	Involve individuals based on their nature and understanding of the project and consultation outcomes	Involve groups based on their nature and understanding of the project and consultation outcomes	Institutional systems and processes to support individual and group consultation
	Empower	Empower individuals to effectively make decisions about the project processes based on their personal capacities	Empower groups to effectively make decisions about the project processes based on identified group characteristics	Develop institutional systems and processes to support individual and group decision-making and control of projects

findings to the community are varied including but not limited to inadequate funding to produce materials in vernacular languages, incomplete data sets for developing adaptation strategies, limited engagement with other partners like NGOs and in adequate knowledge on communities' preferred channels for dissemination. It is important that the findings of the study are adequately and effectively disseminated within the community and are applied to reduce vulnerability of the communities to diseases.

6. Conclusion

Overall, the findings indicate that participants had limited knowledge of the two projects in which they had participated in, as well as an approach to the projects that was researcher-driven and community-responsive. While the researchers endeavoured to inform almost all the participants, critical information asymmetries exist in the community's understanding of research project activities, aims, sites and identities. This is despite some respondents being asked to provide feedback on the projects. The findings also show evidence of the interaction of multi-level factors affecting effective participation (information, consultation and involvement) in community research projects. Individual-level factors affected knowledge retention while interpersonal factors played a role in information dissemination creating risks that poorly connected respondents might be left out. The institutional level – consisting of the researchers, their systems and processes exhibit challenges in informing the wider communities about the projects (noting the rural nature of the communities), weaknesses in converting community members with project knowledge into active participants, enhancing consultative processes beyond feedback mechanism systems and most importantly a questionably managed consent process where respondents appeared to consent to something they did not fully understand. Nonetheless, the communities recorded benefits that included learning and being tested for Schistosomiasis and Malaria among other things. Such benefits were also appreciated by community members who had not directly participated in the projects highlighting the project's potential in disseminating information deeper into communities.

In addition to the framework discussed in Table 7, we recommend the following approaches: First, the projects needed to streamline consent processes to ensure that community members know the projects' aims, identities and activities. Second, the projects needed to widen their outreach by utilising informal communication systems and social networks as information and involvement drivers. Third, the projects' participation systems needed to consider cognitive challenges among participants through information aids that enhanced both the understanding and remembering of information disseminated to participants. Finally, the projects needed to follow more community-engaging approaches. Community empowerment through consulting participants on the methods, processes and activities to include for improving the projects has the potential to improve participant interest, knowledge and understanding of the projects.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Humanities and Social Sciences Research Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

Author contributions

ZM led all aspects of the paper's development from conceptualization and designing the study, data collection, analysis, and reporting. MC guided the process of manuscript writing and critically reviewed and edited all drafts of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Native opportunities to stop hypertension: study protocol for a randomized controlled trial among urban American Indian and Alaska Native adults with hypertension

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Introduction: American Indian and Alaska Native (AI/AN) adults experience disproportionate cardiovascular disease (CVD) morbidity and mortality compared to other races, which may be partly attributable to higher burden of hypertension (HTN). Dietary Approaches to Stop Hypertension (DASH) is a high-impact therapeutic dietary intervention for primary and secondary prevention of CVD that can contribute to significant decreases in systolic blood pressure (BP). However, DASH-based interventions have not been tested with AI/AN adults, and unique social determinants of health warrant independent trials. This study will assess the effectiveness of a DASH-based intervention, called Native Opportunities to Stop Hypertension (NOSH), on systolic BP among AI/AN adults in three urban clinics.

Methods: NOSH is a randomized controlled trial to test the effectiveness of an adapted DASH intervention compared to a control condition. Participants will be aged ≥18years old, self-identify as AI/AN, have physician-diagnosed HTN, and have elevated systolic BP (≥ 130mmHg). The intervention includes eight weekly, tailored telenutrition counseling sessions with a registered dietitian on DASH eating goals. Intervention participants will be provided $30 weekly and will be encouraged to purchase DASH-aligned foods. Participants in the control group will receive printed educational materials with general information about a low-sodium diet and eight weekly $30 grocery orders. All participants will complete assessments at baseline, after the 8-week intervention, and again 12weeks post-baseline. A sub-sample of intervention participants will complete an extended support pilot study with assessments at 6- and 9-months post-baseline. The primary outcome is systolic BP. Secondary outcomes include modifiable CVD risk factors, heart disease and stroke risk scores, and dietary intake.

Discussion: NOSH is among the first randomized controlled trials to test the impact of a diet-based intervention on HTN among urban AI/AN adults. If effective, NOSH has the potential to inform clinical strategies to reduce BP among AI/AN adults.

Clinical trials registration: https://clinicaltrials.gov/ct2/show/NCT02796313, Identifier NCT02796313.

KEYWORDS

American Indian/Alaska Native, dietary approach to stop hypertension, cardiovascular disease, blood pressure, health disparities, urban health, telenutrition, healthy diet

1. Introduction

American Indian and Alaska Native (AI/AN) people experience a disproportionate prevalence of cardiovascular disease (CVD) morbidity and mortality compared to other races (1, 2). CVD is the term for all types of diseases that affect the heart or blood vessels, including coronary heart disease (CHD), which can cause heart attack, stroke, heart failure, and peripheral artery disease (3). CHD prevalence rates among AI/AN people are greater than 12% (4) and may be underreported by 21% (5). The prevalence of CHD is particularly high among younger AI/AN people where more than one-third of deaths occur before the age of 65 years (6). Similarly, deaths due to stroke are the highest among younger AI/AN adults <45 years of age compared with other racial and ethnic groups in the United States (4).

Hypertension (HTN) is a major independent risk factor for the development of CHD and stroke (7, 8). A healthy diet can improve HTN management with or without medication (9–11) while also conferring other benefits, such as weight loss and healthier lipid profiles (12–15). Dietary Approaches to Stop Hypertension (DASH) is a high-impact therapeutic dietary intervention for primary and secondary prevention of CVD and is recognized as an effective dietary intervention to reduce blood pressure (BP) (16, 17). The DASH diet encourages low intakes of sodium and saturated fat paired with high intakes of fruits and vegetables. In a randomized trial, the DASH diet lowered systolic BP among participants with both borderline and clinical HTN (18). Despite a high prevalence of CVD-related morbidity and mortality and the effectiveness of the DASH diet to improve BP control across multiple studies, AI/AN people are noticeably absent in the research conducted to date.

AI/AN people interact with a unique healthcare system that may, in part, contribute to CVD inequities. The United States government provides healthcare to members of federally recognized Tribes through a treaty-based responsibility that has been filled by the Indian Health Service (IHS) since 1955. However, in reality, AI/AN people obtain healthcare through a fragmented process that includes IHS, Tribal, and urban Indian healthcare facilities, as well as public, private, and state-operated health initiatives. Notably, all IHS facilities are located on or near reservations, making many of them geographically inaccessible to most AI/AN people living in urban areas (19). Unsurprisingly, AI/AN adults often report more difficulties in healthcare access than White adults and have lower rates of healthcare utilization (20). Further, the IHS has been chronically underfunded, with $3,332 spent per patient per year in comparison to $9,207 per patient for federal health care nationwide (21). Despite the efforts of many Native nations to exert sovereignty and provide culturally-relevant care that incorporates both Western and traditional medicines, the complex configuration of healthcare systems, along with the policy and regulatory environments in which they operate, can adversely affect the ability of AI/AN people to obtain high-quality healthcare in Tribal and urban settings (22, 23).

Nationwide, AI/AN communities have lost access to traditional foods (24), which were historically nutrient dense and minimally processed. Furthermore, as AI/AN adults often have lower incomes than the general population, their ability to purchase healthy foods is limited (25, 26). AI/AN households are at greater risk of experiencing food insecurity, wherein a nutritionally-balanced diet is not geographically available or financially accessible, with prevalence rates ranging from 16 to 80% (27). Food insecurity is related to greater risk of HTN (27–30), and dependence on processed foods that increase sodium intake can further elevate risk (31–34). These barriers to access of healthful and affordable food options can, in part, be addressed through education and the increasingly common clinic-based food assistance programs that can involve medically-tailored groceries or food vouchers (35, 36).

Three key attributes are important for an intervention to successfully address HTN disparities experienced by AI/AN adults. First, an intervention must consider the needs of AI/AN adults in urban settings. Few studies have examined rates of HTN in urban AI/AN adults (37). Notably, most observational and intervention studies of CVD have focused on reservation-based AI/AN people, who receive care through the IHS and Tribally-run clinics, even though 71% of AI/AN adults live in urban areas (38). This urban population is an invisible minority (39), with high rates of disease and disability, low rates of healthcare usage (26, 40–42), and elevated risk of food insecurity (43–45). Second, CVD prevention through dietary practices should be a primary focus of a BP management intervention. Pharmacologic interventions can improve control of HTN and other CVD risk factors, but medications alone are sub-optimal and AI/AN adults with HTN are less likely than other racial groups to take anti-hypertensive medications (46). Further, medications do not address poor nutrition as a potential root cause of HTN. Benefits of the DASH diet have been demonstrated in primarily White and Black populations, but the DASH diet has never been tested with AI/AN participants. Given the unique historical and modern influences on the health of AI/AN communities, independent trials testing the effectiveness of interventions with AI/AN participants are warranted. Finally, an intervention needs to be relatively low cost to maximize accessibility and reach. One randomized trial of a clinic-based intervention in rural, AI/AN adults with diabetes showed that intensive BP management slowed or even reversed carotid intima-media thickening (47, 48). However, this approach is prohibitively expensive and logistically demanding for patients who lack adequate health insurance, reliable transportation, or ready access to care, all of which are common challenges for urban AI/AN adults.

The Native Opportunities to Stop Hypertension (NOSH) intervention is formulated after a recent DASH-based intervention, “Five Plus Nuts and Beans,” designed for urban Black adults, who experience many of the same barriers to healthy diet as urban AI/AN adults. In the Five Plus Nuts and Beans intervention, 120 participants were randomized to receive educational material on the DASH diet plus a weekly stipend for grocery delivery (control), or to receive DASH-oriented nutritional counseling and support from a registered dietitian (RD) plus a weekly stipend for heart-healthy grocery delivery (intervention). Participants in the intervention reported increased fruit and vegetable consumption and had improved urine potassium and sodium (49). Modeled after this intervention, the NOSH intervention includes a culturally-tailored DASH telenutrition curriculum that: emphasizes low sodium intake; emphasizes consumption of available traditional AI/AN foods; facilitates problem solving and provides strategies for maintaining healthy eating habits; and offers eight $30 weekly grocery orders. Traditional AI/AN foods, such as corn, salmon, trout, beans, and squash, are ubiquitous in contemporary grocery stores. However, recognition and acknowledgement that commonly stocked foods in grocery stores have their origins with Indigenous people is rare. By adapting various aspects of the Five Plus Nuts and Beans program and strong evidence-based dietary recommendations, the probability of effectiveness is increased.

Despite the growing number of urban AI/AN adults and longstanding disparities in CVD prevalence, no clinical trial has tested a therapeutic dietary intervention aimed to improve BP control among AI/AN with physician-diagnosed HTN. Thus, the NOSH study will evaluate an RD-delivered, adapted DASH intervention with urban AI/AN adults who receive care at one of three urban Indian clinics. In the NOSH intervention, weekly grocery orders will be complemented by nutrition counseling to promote locally-available food sources and motivate participants to adopt the DASH eating plan. This paper describes the NOSH randomized controlled trial to improve BP control among AI/AN adults. This study was approved by the Washington State University Institutional Review Board (#16118), the University of Oklahoma Institutional Review Board (#665427) and the Chickasaw Nation Institutional Review Board and has been registered with ClinicalTrials.gov (NCT02796313).

2. Materials and methods

2.1. Study aims

The NOSH study aims are to: (1) evaluate the effect of the NOSH intervention on BP and secondary outcomes in urban AI/AN adults with HTN; and (2) conduct a pilot study after the intervention concludes to evaluate extended support from an RD for an additional 6 weeks among a subset of participants. NOSH is a randomized, wait-list control trial (Figure 1). After completion of the two baseline visits, participants will be randomized into either the intervention or waitlist control group. Waitlist control condition participants will receive a brochure about the benefits of a low-sodium diet and complete weekly phone calls to collect BP readings and place grocery orders. After completion of data collection (12-months post-baseline), participants will be offered the intervention. The intervention group will receive the intervention and groceries (described in 2.6). At week 8, if participants are interested in participating in the pilot study, they will be randomized into either the pilot study control or extended support (intervention) groups. It is hypothesized that NOSH will result in improved BP management and secondary outcomes compared to the control condition. For the extended support pilot study, it is hypothesized that BP will attenuate toward baseline in both groups of the pilot study, but extended support will lead to more sustained improvement. The study design used to address these aims is shown in Figure 1.

2.2. Setting

The trial will be implemented in two urban clinics in Washington state and one urban clinic in Oklahoma. Urban AI/AN communities vary in food-related cultural norms and values, as well as in local resources for obtaining healthy food; therefore, the inclusion of three sites will support generalizability of results and feasibility of dissemination across multiple diverse sites. One Washington clinic recently recorded annual visits from 400 unique HTN patients, while the other Washington clinic recently recorded 704, and the Oklahoma site recorded 1,897 patients; all sites serve at least 100 new patients with HTN annually. The NOSH study uses a participatory research approach to ensure the intervention is feasible within clinics and relevant to participants and that research findings will benefit the study populations (50). Across all sites, this study leverages the expertise of community-based nutrition and dietetics practitioners who each have direct practice experience within these AI/AN communities.

2.3. Participants

2.3.1. Sample size

Data from previous DASH interventions (51, 52) was used to estimate a sample size of 185 participants per group required to detect at least a 5.3 mmHg difference in mean systolic BP at 8 weeks, and a 5.7 mmHg difference in the 12-week analysis excluding the 25 extended support pilot study participants. Power of 80%, alpha error rate of 0.05, and a standard deviation of 18 mmHg based on previous 8- or 9-week trials were assumed.

2.3.2. Recruitment

A total of 370 participants will be recruited (approximately 120 from each site) with equal representation of men and women. At each clinic, separate lists of men and women in the target age range with physician-diagnosed HTN and at least two systolic readings ≥130 mmHg will be created. Each list will be randomly sequenced by the study biostatistician. Starting at the top of the lists, the research team will work with clinic staff to review medical charts for additional eligibility criteria. For patients who meet eligibility criteria, study staff will contact the primary care provider to secure approval for participation. Patients will be contacted by telephone and/or in-person at their next clinic visit to ascertain interest about the study and confirm eligibility. Eligible individuals will be scheduled for an initial baseline visit, ideally within 2 weeks of the in-person contact. Final determination of eligibility will occur at the second baseline visit based on an additional BP measure and compliance with study protocols (described below).

2.3.3. Eligibility criteria

Participants must: (1) be at least 18 years old; (2) have had a clinical diagnosis of HTN for at least 1 year; (3) be on a stable regimen of antihypertensive medications for a minimum of 2 months OR not currently medicated, without anticipated changes for the duration of the study; (4) have average systolic BP ≥ 130 mmHg at the past two clinic visits and at the in-person screening visit; (5) have regular medical care and permission from their primary care provider to participate; (6) be physically and cognitively able to use the home BP monitoring device; and (7) be willing and able to follow all other study procedures. People will be ineligible if they: (1) experienced incident CVD or stroke within the previous 6 months; (2) have average diastolic BP ≥ 100 mmHg during the run-in period; (3) have a known diagnosis of secondary HTN (e.g.,

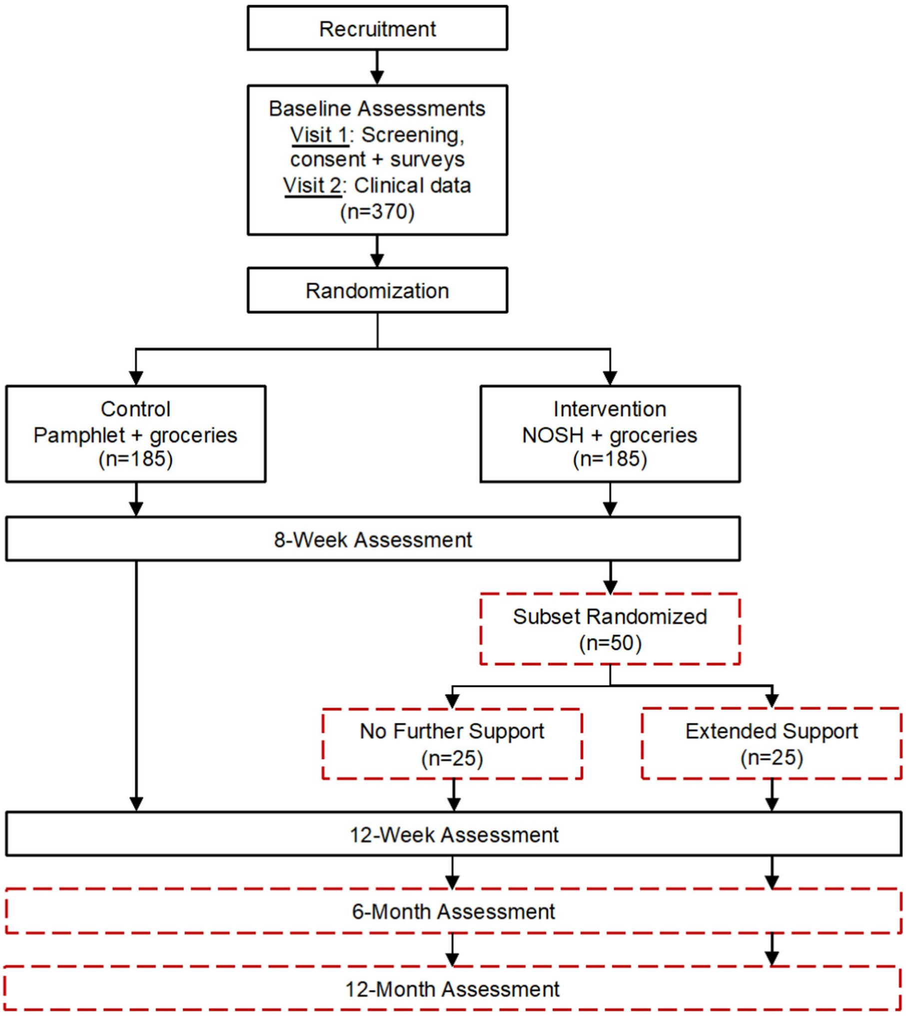

FIGURE 1
Native Opportunities to Stop Hypertension (NOSH) randomized controlled trial flow diagram and projected sample sizes.

renal artery stenosis); (4) have diagnosed Stage 4 or 5 kidney disease; (5) have a recent history or high blood potassium due to taking certain medications that can raise potassium levels; (6) are participating in another health research study; (7) are currently or planning to become pregnant during the course of the study; or (8) are receiving treatment for cancer or another serious or terminal medical condition.

2.3.4. Consent

The in-person screening will take place at the first baseline visit, which will occur within 2 weeks of initial screening for eligibility and interest. A research assistant will describe the study and risks of participation. The site study coordinator will also review the study and measure BP. For people whose average BP is within eligibility limits, the site study coordinator will administer the full informed consent protocol, explaining study goals, procedures, and potential risks, in addition to requesting Health Insurance Portability and Accountability Act (HIPAA) authorization to allow ongoing access to their medical records (HIPAA is meant to protect a patient from having their information disclosed without the individual's consent or knowledge). Clinic staff will enter information pertinent to the patient's care in the medical record notes as it is deemed appropriate and will document provider approval to participate in the study. These notes will be left to the discretion of clinic staff and will not be shared with the study team. Participants will provide written informed consent and HIPAA authorization.

For the extended support pilot study, at the 8-week appointment, while intervention group participants are completing their follow up data collection, the research assistant will access the next assignment on a randomized list created by the study biostatistician. If intervention group participants are interested in participating in the pilot study, they will undergo an additional informed consent process and be further randomized to one of the following two groups: (1) pilot study control, or (2) extended support (pilot study intervention). Potential participants will be clearly informed that their choice whether to participate in the pilot study will not affect their participation in the 12-week follow-up for the main trial.

2.4. Assessment procedures

Participants will complete four clinic visits (screening/baseline 1 visit, baseline 2 visit, week 8, and week 12) for the study. Two baseline visits are conducted to: (1) minimize the length of clinic visits by collecting surveys and clinical data on two separate dates, and (2) as a way of assessing compliance with study protocols. Participants are provided 24-h urine collection materials and the home BP monitor at the end of the first baseline visit. If they have completed the at-home urine and BP data collection when they return for the second baseline visit, they are considered compliant with study protocols. Compensation will be in the form of gift cards to local gas stations or grocery stores in the following amounts: second baseline visit ($50), 8- and 12-week visits ($50 each).

For the extended support pilot study, telephone interviews will be conducted to collect home BP data using the same study-provided devices at six and 9 months post-baseline. About 5 months post-baseline, pilot study participants will be contacted to schedule the 6-month data collection interview and provide re-training in use of the home BP cuff, if necessary. The 6- and 9-month interviews will be conducted by telephone by research staff who are masked to treatment group assignment. Staff will talk each participant through the process of accessing BP values stored in the cuff's memory. Participants will read off values, and staff will enter them into a study database. Phone conversations will be recorded as electronic data files and erased after quality control checks have been completed.

2.5. Randomization

Treatment conditions will be randomly assigned after the participant completes the clinical data collection at the second baseline visit. The study staff will generate treatment assignments using the randomization function in the study's REDCap database.

2.6. Intervention

The DASH diet is low in saturated fat, cholesterol, and total fat, focuses on fruits, vegetables, and fat-free or low-fat dairy products, and is rich in whole grains, fish, poultry, beans, seeds, and nuts. It minimizes intake of ultra-processed foods, including sweets, added sugars, and sugary beverages, as well as red meats compared to the typical American diet. Its unique composition of prescribed food groups results in a nutrition profile that is lower in sodium and rich in potassium, magnesium, and calcium. The intervention group will receive one in-person, tailored nutrition counseling visit at baseline and weekly 15-min telenutrition sessions in weeks 2–8 to provide additional DASH diet education and behavior change support.

After the final DASH session is complete, a questionnaire will be mailed to the participant in order to evaluate their satisfaction with the program. The 14-item anonymous questionnaire asks participants to rate their degree of agreement with statements such as, "The information about the DASH diet was easy to understand," "It is difficult for me to do exactly what the nutrition staff recommended," and "I will be able to follow the DASH diet and nutrition staff's advice after the program." Additional questions ask what participants liked about the program, what could have been improved or changed, what activities or information was most useful, and what diet and lifestyle changes were the most difficult to change.

During the extended support pilot study, the 25 intervention participants receiving extended support will continue to receive weekly 15-min phone consultations with the RD for an additional 6 weeks (weeks 9–14) after the end of the original 8-week study period. Consultations will provide support for continuing the DASH diet and will focus on overcoming barriers to obtaining and preparing healthy foods within the context of each person's regular food budget and resources.

2.6.1. In-person nutrition visit

Following randomization to the intervention group, participants will be scheduled for an initial appointment with an RD employed by the clinic and trained on all study procedures. This 55-min counseling visit will include: purpose of study visit (5 min.), energy needs calculation (5 min.), overview of the DASH diet based on calorie needs (15 min.), basic education on health risks of high BP and interpretation of current BP (4 min.), elicitation of patient perspective on which eating behaviors are affecting BP and ranking of readiness for behavior change (8 min.), co-creation of a customized eating plan (10 min.), and discussion of other lifestyle factors that may be affecting BP (e.g., tobacco use) (8 min.). Following the visit, the RD will assist participants with completing their first grocery order (10 min.). Participants will be provided with a daily eating goal handout for each DASH food group based on their estimated calorie needs. This handout was developed by a study co-investigator and RD (MSW), which was then reviewed and approved by RD community research staff. The handout includes references to hand images for each food group to estimate portion size (e.g., fist, palm, thumb) in addition to standard household measures (e.g., cup, Tablespoon). Participants will also receive a 56-page DASH diet booklet published by the NHLBI (53). During each weekly telephone session with the RD, specific pages of the booklet are referenced to facilitate participants' gradual review of its content.

2.6.2. Weekly telephone RD consultations

NOSH was developed to provide follow up medical nutrition therapy via telenutrition for the management of HTN. Typically delivered in person over multiple sessions, medical nutrition therapy is an evidence-based approach used by RDs to address chronic conditions, including HTN (54). However, multiple barriers, such as transportation and costs, preclude patients from accessing in-person healthcare, including medical nutrition therapy (55–57). The NOSH telenutrition curriculum will be delivered either over the phone or via password-protected secure Zoom platform, depending on participant preference, across eight weekly sessions by an RD or trained health educator under the direct supervision of an RD. Each session will begin with a check-in discussion about current BP monitoring at home with participant reporting of at-home readings (5 min.), interactive discussion about a particular eating goal within the DASH diet using a scripted, culturally-tailored telenutrition curriculum (10 min.), and placement of a $30 unrestricted grocery order (5 min.). Weekly topics will include: (1) seasoning without sodium; (2) fruits instead of processed sweets; (3) vegetables; (4) nuts, seeds, and beans; (5) whole grains; (6) healthy fats; (7) high-calcium dairy alternatives and low-fat dairy; and (8) lean meat, poultry, and fish. Telenutrition curriculum topics will relate to items that comprise the DASH diet score and include 2–3 learning objectives per session. Each session will incorporate motivational interviewing (58, 59) and provide time for the participant to reflect upon current eating behaviors, rate self-confidence in making needed eating behavior change, and develop a weekly action plan to improve dietary adherence within that session's topic. This curriculum script for weekly telephone sessions was developed by a study co-investigator and RD (MSW), which was then reviewed, culturally tailored, and approved by RD community research staff. These staff members had various levels of experience that ranged from 7 years working with AI/AN adults to more than 20 years of experience working with AI/AN adults in their specific communities. At the end of each session, the RD will assist participants in placement of an unrestricted grocery order. A weekly list of suggested DASH foods specific to that week's telenutrition topic was developed by the academic-community nutrition team for RD reference. Weekly food lists emphasized a variety of affordable perishable and non-perishable foods that could be accessed at the local grocery store.

2.6.3. Registered dietitian training

RDs will be trained in patient-centered care and communications skills in three 2-h webinars. Sessions will be conducted by a master trainer who was involved in the DASH trials. Topics will include HTN, how to work with people with limited health literacy/numeracy skills, and how to address barriers to DASH and medication adherence. Webinars also will include a detailed review of the DASH diet and strategies to assess diet, set goals, provide advice, arrange follow-up, and monitor progress. Finally, a didactic session with role-playing will be completed to ensure training comprehension. Fidelity will be maintained through booster sessions conducted every 6 months.

2.7. Control condition

NOSH is a wait-list control trial. The control condition will receive a single printed brochure about the health benefits of a low-sodium diet after the second baseline visit, complete weekly phone calls to collect BP readings, and place $30 grocery orders. After all study data collection is complete, participants will be offered the same in-person, hour-long nutritional counseling session with the study RD that was provided to the intervention group, in addition to the eight weekly telenutrition calls without additional grocery credits provided.

2.8. Primary outcome

The primary study outcome will be systolic BP assessed at home as the average of three readings spaced 30 s apart using a Microlife 3BTO Plus (60). Participants will be instructed to take their BP at least two times a day (morning and evening) for 7 days before visits at baseline, 8 weeks post-baseline, and 12 weeks post-baseline. During the initial set up of the home BP monitors, measurements will be checked against clinic BP monitor measurements or manual measurements to ensure accuracy of home BP readings. For pilot study participants, home BP monitoring will also be conducted during the 6- and 9-months post-baseline interviews.

2.9. Secondary outcomes

2.9.1. Blood pressure (clinic visits)

At the first baseline visit and at every subsequent clinic visit, systolic and diastolic BP will be measured on-site by auscultation using a mercury sphygmomanometer. A total of three BP measurements, separated by 30 s, will be obtained at each visit on the right arm of participants, using a cuff of appropriate size, after they rest quietly in the seated position for at least 5 min. If the participant indicates that there is a medical or post-surgical reason for not having the BP measured on the right arm (or if the right arm is missing), then BP will be measured with the cuff on the left arm.

2.9.2. Body composition

Height and weight will be measured at the second baseline visit to calculate BMI as a continuous variable (kg/m^2) and categorized to conventional thresholds ($<$ 25 kg/m^2 = normal; 25–29 kg/m^2 = overweight; $\geq$ 30 kg/m^2 = obese). Weight will be measured and at each following clinic visit to calculate BMI. Participants will be asked to remove shoes, heavier outerwear, and to empty heavy items from their pockets before weighing. If a participant is unable to remove shoes or heavier outerwear, two pounds will be removed from weight.

2.9.3. Lipids

Fingerstick blood samples will be acquired at the second baseline visit and at each follow-up clinic visit to assess blood lipids. Blood lipids will be measured as total cholesterol, HDL cholesterol, LDL cholesterol, and triglycerides (all mg/dL), using the Cholestech portable analyzer (61). Hyperlipidemia will be defined as LDL cholesterol >130 mg/dL.

2.9.4. Dietary intake

Two methods will be used to evaluate dietary intake at the second baseline visit and at each of the follow-up clinic visits. First, at the baseline, 8-, and 12-week assessments, the site study coordinator will assist participants with completing a food recall using the Automated Self-Administered 24-Hour (ASA24®) Dietary Assessment Tool developed by the National Cancer Institute (62). This website guides participants through a 24-h food recall and provides an animated guide and audio and visual cues that enhance use in low-literacy populations. Respondents report frequency of eating occasions and times of consumption. Detailed prompts assess food preparation, portion size, food source, and additions to food items. Dietary intake estimated through the ASA24 will be used the primary method for estimating changes in dietary intake for various components of the DASH diet across study timepoints and between intervention groups. Second, at baseline, self-reported consumption of fats, fruits, and vegetables will be assessed using the validated Block Food Frequency Questionnaire, which reflects dietary patterns during the past year (63). To reduce respondent burden at 8- and 12-week assessments, participants will complete the Fruit and Vegetable Screener, a validated, self-report measure of daily fruit and vegetable intake (64) and the Fat Screener, a questionnaire which assesses percent of energy intake from fat (65). Respondents are asked to indicate how often during the prior month they ate a variety of fruits and vegetables and a variety of food products that are high in fat, respectively. The (65) These food frequency questionnaires will be used to descriptively characterize any dietary changes indicated by the ASA24.

2.9.5. Urinary sodium and potassium

A 24-h urine collection and a spot urine collection will be used to measure electrolytes at the second baseline visit and each follow-up clinic visit by ion-selective potentiometric methods and urine creatinine by a standardized enzymatic assay on the Vitros 5.1 platform (66). Collections with total volume < 450 mL/d or creatinine <10 mg/kg/d will be considered incomplete (67). Participants will be instructed in proper technique and provided with two 3 L wide-mouthed, labelled, screw-top plastic urine jugs along with a collection device (urinal or hat). Twenty-four-hour urine collections will start following first-morning void on the day prior to the study visit and end with inclusion of first morning void on the visit day, and the spot urine will be collected in-person at the visit. Urine volume will be measured using a graduated cylinder, with aliquots frozen at -80C prior to assay.

2.9.6. Heart disease and stroke risk scores

For participants who have not experienced previous CHD or stroke events, the 10-year risk of incident CHD (68) or stroke will be estimated using prediction algorithms specific to AI/AN adults. Both risk scores were developed by the Strong Heart Study, a large prospective cohort study of CVD in AI/AN adults from three distinct geographic populations (including Oklahoma) (68). The scores are based on data collected during baseline and at each clinic visit (age, HTN medications, systolic BP, blood lipids, diabetes, smoking status, and albuminuria).

2.10. Covariate measures

2.10.1. Medications

Participants will be instructed to bring all current medications (prescription, over the counter, and herbal or vitamin supplements) to each clinic visit. The site study coordinator will review and record each participant's medications and will query the patient's medical records. Current antihypertensive medications will be documented and coded using a protocol from an ongoing study of cerebrovascular disease among American Indians (69).

2.10.2. Smoking and alcohol use

Tobacco and alcohol use at each clinic visit will be assessed with questions previously used in rural AI/AN populations (70). Smoking questions will distinguish current, past, and never smokers, including number of cigarettes smoked per day and age at initiation or cessation. Use of smokeless tobacco will not be assessed for this study. Alcohol consumption will be assessed with questions asking about frequency and type of current and past consumption of alcoholic beverages, after a standard definition and reference images for the equivalent of one alcoholic beverage is provided.

2.10.3. Comorbid conditions

We will document prevalent diabetes, stroke, or CVD (congestive heart failure, myocardial infarction, or CHD) via patient self-report at the first baseline visit and medical chart abstraction. Urine micro- and macro-albuminuria will be categorized based on lab values where a participant's albumin: creatine ratio is 30–299 mg/g or ≥ 300 mg/g, respectively (71).

2.10.4. Demographic and administrative

Sex, age in years, completed education, current employment, and marital status will be collected at the first baseline visit. Documented administrative variables will include clinic site, study arm (control, intervention), and primary care provider (anonymous ID number, used only for statistical analysis).

2.11. Monitoring

The participants' healthcare providers will be alerted that their patients are adopting an antihypertensive diet. In addition to monitoring provided by each participant's primary healthcare provider, a Data Safety Monitoring Board (DSMB) will be organized to monitor the safety of all study participants. The DSMB will be responsible for safeguarding the interests of study participants, assessing the safety and efficacy of study procedures, ensuring data quality, and for monitoring the overall conduct of the study. The DSMB will be comprised of independent, doctorate-level professionals in the fields of medicine and AI/AN health. They will provide recommendations to the lead researcher, specifically related to starting, continuing, and stopping the study. In addition, the DSMB will be asked to provide recommendations, as appropriate, about: efficacy of the study intervention; benefit/risk ratio of procedures and participant burden; selection, recruitment, and retention of participants; adherence to protocol requirements; completeness, quality, and analysis of measurements; data and statistical analysis plan; amendments to the study protocol and consent forms; performance of individual study sites and core lab; adverse and serious adverse events; and participant safety. Meetings will be held once per year, with additional meetings or conference calls scheduled as needed. The lead researcher will promptly report all protocol deviations or unexpected, serious adverse events to the Washington State University Institutional Review Board and other relevant review boards, as per their protocols.

2.12. Data analysis

All data collected on-site will be scanned and uploaded to a secure server and entered into a REDCap database (72). Data will be reviewed by the biostatistician monthly to quickly identify data quality issues. For quality control, data from 10% of randomly selected participants will be entered twice. An intention-to-treat analysis will be used. Success of randomization will be assessed by using t-tests and chi-squared tests to compare baseline variables in the intervention and control groups. All inferential results will be presented as point estimates with 95% confidence intervals. Data analysis will be performed using Stata 14 (StataCorp LP, College Station TX, 2013).

Linear regression will be used to compare primary and secondary outcomes between the intervention and control groups at 8- or 12-week post-baseline assessments, with treatment group, baseline value, and study site as the independent variables. Since there may be differences between the study sites regarding availability of healthy food at local stores, an interaction term between intervention and site will be included. If the interaction is significant, all analyzes will be repeated after stratifying by site. Sensitivity analyzes will adjust for variables that appear unbalanced between groups at baseline. All 370 participants will be included in the analysis of data from the 8-week visit, but the 25 pilot study extended support (intervention group) participants will be excluded from analyzes involving data from the 12-week visit. Next, generalized estimating equations will be used to simultaneously assess outcome values measured at 8 and 12 weeks. To assess effectiveness of the extended support pilot study, a generalized estimating equation will be used to analyze data for all four time points (8 weeks, 12 weeks, 6 months, and 12 months), with independent indicators for each time point that do not impose a linear trend on the outcome. These models adjust standard error estimates to properly account for within-person correlation in the outcome values over time.

3. Discussion

Developing an effective diet-based intervention focused on decreasing CVD risk among urban AI/AN adults is of critical public health importance. DASH-based telenutrition interventions can be enacted within or external to a healthcare system, reducing barriers to access preventive care. Adding aspects to the program, like home food delivery, might make accessing fresh produce easier for urban AI/ANs as well as promote nutritional security (73). Creating evidence-based, culturally-adapted interventions that are relevant and engaging for AI/AN individuals could be instrumental to address the disproportionate burden of CVD morbidity and mortality experienced by AI/AN populations.

This study protocol has several notable strengths. First, to the authors knowledge, no previous dietary intervention specifically developed for HTN management has ever been conducted in AI/AN adults, urban or rural. If effective, this study can be scaled up to address the disproportionate burden of CVD among AI/AN adults (5, 74, 75), in which HTN has been widely implicated (76). Second, because sites can tailor the intervention to their unique communities, while maintaining core DASH components, this is an effectiveness trial. By contrast, clinical trials of non-pharmacological therapies, while optimizing the effect of an intervention, are conducted under ideal conditions of monitoring and compliance, which are typically not desirable or feasible in diverse AI/AN community settings. Third, although a focus on traditional foods is not a typical component of DASH, the addition of this cultural tailoring was appealing and important to study partners. Lost access to traditional foods and food systems is believed to contribute to lower dietary diversity and greater CVD disparities among AI/AN communities (24). Fourth, the use of home BP monitoring is significant. Home monitoring not only provides better diagnosis and risk prediction in HTN, but may also improve treatment by engaging patients (77), thereby improving dietary adherence and study retention. Fifth, DASH trials have far-reaching implications for clinical practice and public health. Adherence to the DASH diet lowers BP to the same extent as the five antihypertensive medications used as monotherapy in the Veterans Affairs Cooperative Study (78). For patients with HTN, the DASH diet is highly recommended as a potent adjunct to pharmacologic treatment and strengthens the likelihood of the intervention's effectiveness. Sixth, this study contributes to the growing field of telenutrition, which is considered an important strategy for reducing access barriers to medical nutrition therapy. Lastly, the provision of grocery delivery may reduce barriers to access food items, encourage participants to try new foods, and direct coaching when making food purchasing decisions.

This study is not without limitations. Diet is subject to contextual effects beyond the individual and clinic, with family- and community-level influences on food choices and food access that must also be addressed (79). Therefore, lifestyle interventions in tight-knit AI/AN communities risk contamination if people in the intervention group influence the dietary choices of people in the control group. However, the study team does not expect substantial contamination, given that the study will be conducted in large urban areas, where study participants are not likely to interact directly with other participants. This limitation can be avoided only in a community-randomized trial, which is scientifically premature and beyond the scope of the current research.

If the trial is effective, NOSH will be an immediately scalable, inexpensive, and safe approach to treat HTN in urban AI/AN communities. Because most AI/AN adults live in urban settings, the widespread implementation of an effective program has the potential to dramatically improve public health of millions of AI/AN households. Further, since participants are not required to use medication for BP control, the target population includes people who have been unsuccessful at lifestyle change or are otherwise untreated for Stage I HTN. Given widespread barriers to healthcare for urban AI/AN adults, this innovation magnifies the potential population-level impact. If the program is effective, the two partner sites will start integrating the DASH diet into usual care. The more burdensome measurements taken for this effectiveness trial can be simplified to align with current clinical practice and may eventually be implemented by innovative mobile health technologies. Ongoing research probes the ability of smartphone apps to help patients adhere to the DASH diet. The NOSH intervention is inexpensive and easily tailored to community resources, such as community cooking events and neighborhood gardens that emphasize traditional foods. Because the DASH diet has been successfully used in clinical studies with other minority groups, we believe it can be readily disseminated to Native healthcare facilities across the United States.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

This study was approved by the Washington State University Institutional Review Board (#16118), the University of Oklahoma Institutional Review Board (#665427) and the Chickasaw Nation Institutional Review Board and has been registered with ClinicalTrials.gov (NCT02796313).

Author contributions

KS, VJ, and DB conceptualized the study design. MW designed the NOSH curriculum and co-led training of research staff on dietary assessment. KS, CN, MW, KN, TT, and AJ drafted the manuscript. CN supported data visualization. All authors reviewed and approved the final manuscript.

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Conflict of interest

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Transforming the field: the role of academic health centers in promoting and sustaining equity based community engaged research

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Community-based participatory research (CBPR) and community engaged research (CEnR) are key to promoting community and patient engagement in actionable evidence-based strategies to improve research for health equity. Rapid growth of CBPR/CEnR research projects have led to the broad adoption of partnering principles in community-academic partnerships and among some health and academic organizations. Yet, transformation of principles into best practices that foster trust, shared power, and equity outcomes still remain fragmented, are dependent on individuals with long term projects, or are non-existent. This paper describes how we designed our Engage for Equity PLUS intervention that leverages the leadership and membership of champion teams (including community-engaged faculty, community partners and patient advocates) to improve organizational policies and practices to support equity based CBPR/CEnR. This article describes the feasibility and preliminary findings from engaging champion teams from three very different academic health centers. We reflect on the learnings from Engage for Equity PLUS; the adaptation of the intervention design and implementation, including the development of a new institutional assessment using mixed research methods; and our organizational theory of change. In summary, our design and preliminary data from the three academic health centers provide support for new attention to the role of institutional practices and processes needed to sustain equity-based patient and community-engaged research and CBPR and transform the field.

KEYWORDS

institutional trustworthiness, community-engaged institutions, facilitative leadership, power sharing, empowerment

1. Introduction

With the dual pandemics of COVID and structural racism, which have devastated communities of color and other vulnerable communities, community based participatory research (CBPR) and community engaged research (CEnR) have never been more important for health equity goals (1, 2). These two terms have signified a range of strategies for community stakeholders engaging as partners in different stages of the research. CEnR consists of a continuum of minimum engagement through outreach, to greater shared leadership (3); with CBPR focusing on transforming power imbalances to elevate community priorities and community-driven research leadership (4). The Patient Centered Outcomes Research Institute (PCORI), as a federal funding agency launched in 2010, has added engagement of patients and patient advocates as key community partners. These efforts have led to a broad adoption of principles of engagement, as a motivating force behind grassroots community health interventions to more traditional clinical medicine interventions led by academic physicians. The clinical and translational science awards (CTSAs) since 2006 have reinforced community engagement in more than 60 academic health centers, adding to other NIH-funded translational equity centers, CDC-funded prevention research centers, and newer funding for comprehensive cancer centers, all of which have increasingly required community engagement cores (CECs). The field itself has grown beyond an emphasis on principles and practices, towards a focus on health and health equity outcomes that are promoted by community participation in all stages of research among other "best" practices (5–7). A new National Academy of Medicine engagement model has reinforced the importance of outcomes, i.e., strengthened partnerships, expanded knowledge, improved health and health care programs and policies, and thriving communities (7).

Despite this maturation of the field, significant gaps remain in the uptake and diffusion of a PCORI/CEnR/CBPR framework across institutional settings and federally-and foundation-funded grant initiatives. Even more importantly, practitioners and long-term leaders in the field increasingly recognize that research partnerships cannot singlehandedly drive health equity outcomes, nor can they support sustainable long term, health equity efforts without more cohesive and structured institutional support. A key learning in national dialogues is that partnered health mobilization efforts should exist beyond grant-funded cycles to reach successes in health equity outcomes (8).

Thus, examining the role of institutional Academic Health Center (AHC) contexts of research and research support becomes essential, including how they interact with communities and sustain (or not) efforts to ameliorate health disparities. Barriers to working with communities noted in the literature have included ongoing distrust by community members of AHCs, with demands for greater "trustworthiness" of these institutions, including the need to pair engagement strategies with anti-racism diversity, equity and inclusion efforts (9–11). Recent uncovering of realities of fiscal and administrative contextual barriers within AHCs showcase how they have not been responsive to the needs of community organizations, patient advocacy groups, tribes, and other partners (11, 12).

This paper describes the rationale for the need for institutional changes in research contexts at the institutional level; and presents our intervention, called Engage for Equity PLUS, aimed at transforming institutional policies, processes and norms. We present our logic model, theory of change, design and strategies; and offer cross-institutional preliminary results that highlight the potential for institutions to become more community-responsive and trustworthy enough to make a difference in health equity over the long-term.

With PCORI engagement funding, the University of New Mexico's Center for Participatory Research (UNM-CPR) has been implementing "Engage for Equity (E2) PLUS" with Morehouse School of Medicine, Stanford School of Medicine and Cancer Institute, and Fred Hutchinson/University of Washington Cancer Consortium since 2021. Engage for Equity PLUS emerged as a scaled-up strategy for academic health centers after 17 years of NIH funding of "Engage for Equity" (E2), by UNM-CPR with national partners, to identify engagement best practices at the project level associated with health and health equity outcomes.

Engage for Equity had earlier produced a CBPR conceptual model, with four domains (of contexts, partnering processes, intervention and research design actions, and intermediate and long-term outcomes) (13); tested and validated measures of practices and outcomes within each domain with more than 400 diverse federally-funded community-academic research partnerships (14, 15); identified and tested the E2 intervention of workshops and use of collective reflection tools to strengthen partnerships (16); and modeled pathways of how engagement practices contribute to outcomes (7) such as trust and other relationship strategies (17); and co-governance structures (18).

While producing outcomes at the project level, the Engage for Equity team realized they needed to implement the intervention at the institutional level as the next step for Academic Health Centers to become more effective at promoting and sustaining cross-sector collaborations between universities and community stakeholders. Using a mixed methods engagement approach, Engage for Equity PLUS study had three primary aims:

1. To assess institutional contextual factors (i.e., capacity, structures, process, and commitment to equity-based engagement) in three distinct Academic Health Centers to promote and sustain patient and community engaged research
2. To test the feasibility of the E2 PLUS intervention, applying E2 workshops and collective reflection tools, with a new added component of institutional champion teams as facilitative leaders to advocate for changes in academic health centers; and
3. To develop a mutual learning community of practice among champion teams from the three institutions.

The context of institutional barriers to community engaged research is described below, followed by a full description of the E2 PLUS intervention.

2. Barriers to support, increase and sustain CEnR research

Over the last several years, scholarship has revealed multiple challenges and barriers for academic health centers (AHCs) to more systematically support, increase, and sustain CEnR research. Three key challenges have emerged: the ongoing and rising public distrust of academic institutions (9–11); the reality of institutional policies, practices and norms that favor AHCs' interests in garnering funding to support internal research infrastructures rather than sharing power with community (19); and the increasing need to develop and test multi-level interventions to transform these power imbalances (20, 21).

Challenge 1: CBPR research practices may have increased trust at the partnership level, but community stakeholders continue to report ongoing distrust and lack of institutional trustworthiness in academic health centers. Despite the growth of community members engaged as research co-designers, implementers, and in project advisory committees or CTSA community boards, trust still remains a core issue with the need to articulate what trust means at the institutional level, beyond participating in research trials (22). There is ample evidence that community members participating in AHC efforts continue to demonstrate concerns of being undervalued, lacking perceived power, receiving inadequate resources, and being relegated to advisory committee roles, without decision-making authority. Studies have shown, for example, that only 10% of CTSA institutions invite community members to participate in core areas of research (23); that community members identify cultural disconnects between AHCs and community, such as lack of success metrics other than academic publications and lack of funding for community partners (10); and that contextual barriers make it difficult for community members to participate in research, including undocumented legal status, homelessness, or having little political power in their lives (24).

Institutional trustworthiness is also being regarded as the most commonly cited reason for lack of participation of minorities in research trials (25). The COVID-19 pandemic has exacerbated institutional distrust, with communities of color suffering higher mortality rates, which tragically has reproduced traumas from previous histories with research and medical institutions (26). Academic health centers continue to be charged with having hierarchies of structural racism, systems of inequitable care or inequitable distribution of resources (2). Our E2 PLUS intervention explicitly tackles these trends by incorporating strategies to improve the trustworthiness and accountability of AHCs to the communities they seek to engage in research and health equity efforts.

Challenge 2: institutional and structural forms of power limit the ability of CEnR researchers and community partners to execute transformational research. Grant funded and institutionally supported CBPR initiatives have made incremental strides in moving from purely investigator-controlled initiatives toward promoting research practices that foster collaboration with communities in project-level research. Much of this work has focused on fostering research partnerships that promote cooperative relationships (27), shared governance (18, 28), increased community capacity (21, 29), cultural revitalization (30, 31), inclusion and belonging, and community resilience (32–34). At the project level, these partnerships have led to capacity outcomes such as increases in community involvement in all phases of health research, shared power, synergistic partnerships between researchers and community stakeholders, towards longer term health and health equity goals (5).

While helpful, this inward focus has promoted a degree of instrumentalism in the field with much scholarship focusing on the ‘ingredients' needed to achieve more effective engagement within discrete research partnerships funded to impact categorical health outcomes (21, 29). While important, this approach underplays how contextual challenges impact the transparency, commitment, accountability, and efficiency of multiple stakeholders to advance strategies that achieve health equity transformation (35–37). Many of these challenges can be linked to power asymmetries that are manifested in multiple ways in PCOR/CEnR research and practice (21, 36, 38–41). Using a limiting power framework, Popay (21) and her colleagues have described multiple forms of power that inhibit community empowerment as a route to greater health equity.

Key among them is institutional power, which is exercised through organizational rules, procedures, and norms. Within academic health center bureaucracies, institutional power imbalances are often manifested in draconian management expectations that require community stakeholders to interface with fragmented and impenetrable fiscal, research, and contracting systems. For example, Carter-Edwards and her colleagues (2021) have documented multiple procedural and policy barriers inhibiting effective collaboration within CTSAs. They find that both principal investigators and community stakeholders lack familiarity with unclear fiscal and grant administration processes, community partners are burdened by challenges in navigating institutional fiscal management processes that remain un-adapted to meet the needs of community organizations, and there is a dearth of organizational practices that lead to appropriate management of budgets and timely compensation of community partners (12). Our E2 intervention starts from a deep dive into these barriers and contexts that need to be unmasked as a first step towards institutional transformation.

Challenge 3: academic health centers struggle to collaborate with community stakeholders in their long-term mobilization and organizing efforts to advance health equity through sustained multilevel interventions, policy advocacy, and transformational changes outside of academic settings. Advancing health equity has proven to be a complex and long-term endeavor that requires collaboration and power-sharing between policy makers, researchers, public and private organizations, policy makers, elected officials, administrators, place-based constituencies, patient advocates, and identity-based communities. Multi-sector partnerships striving to improve health equity do not start and end with grant funded research. They require ongoing collaborations at multiple levels to deepen and sustain innovative solutions that address the social determinants of health and structural racism. For example, patient movements and coalitions have demanded that academic health centers participate in their longer-term efforts to address health care systems issues related to chronic disease, cancer survivorship, and preventative screening. CBPR has been cited as a key strategy to promote longer-term health equity because it embraces empowering research processes that have been shown to contribute to the capabilities of patients and communities to exercise control over decisions and actions that influence their lives and health (20).

In addition, while funders acknowledge structural determinants and health care systems barriers, the requirement that health interventions demonstrate effectiveness in changing patient and individual level health outcomes has produced interventions that tend to privilege clinical and community interventions that aim to increase positive psycho-social outcomes *within* disadvantaged communities and patient populations. Common examples include intervention efforts that promote community resilience, healthy behaviors, and cultural recognition (21, 30). This individual focus on placed-based groups often neglects the social and political determinants of health, such as legacies of racism and settler colonialism, leaving systems of power and privilege intact (21).

Consequently, these approaches have succeeded in supporting marginalized communities to *adapt* to conditions of structural racism, disinvestment, and structural violence without fundamentally changing them (42–44). In addition to funding constraints, CEnR initiatives continue to struggle with transforming power into concrete practices (45). Returning to Wallerstein's (46) argument that power must be dissected to achieve collective empowerment, we argue that we must re-direct our attention towards multi-level interventions that guide us in "how to analyze and understand changing configurations of power" (39) in order to achieve longer term health equity outcomes. In short, CEnR initiatives must deconstruct how power operates in multiples contexts in order to identify viable solutions for change.

3. Methods and E2 PLUS process design

E2 PLUS aims to address these three barriers by expanding the evidence-based E2 intervention to test the feasibility of institutional engagement strategies designed to produce cultural shifts and structural changes with three participating academic health centers. Each site differed in its level of equity-based PCOR/CEnR based on their history and research priorities. Morehouse School of Medicine is a HBCU born from a need to fight racial health disparities in Atlanta, GA with a long history of collaborating with community leaders and local community based organizations to address health disparities. Fred Hutchinson/University of Washington Cancer Consortium is a designated comprehensive cancer center with a new consortium made up of three institutions (University of Washington, Fred Hutchinson Cancer Research Center, and Seattle Children's Hospital) seeking to bring together their individual histories of community engaged cancer research. Stanford is a highly prestigious private institution, which has centered its health research efforts on innovations in basic and clinical science.

Building from theories of institutional change, collaborative governance, and models of organizational engagement (36, 47) E2 PLUS as an institutional intervention, added to its workshops and collective reflection tools, a new component, the role of champion teams as facilitative leaders to advocate for reshaping institutional research infrastructures towards equity-centered PCOR and CEnR. Figure 1 describes the overall logic of the intervention including the primary outcomes, with E2 PLUS strategies described below.

Strategy 1: establish champion teams and provide coaching for them to implement facilitative leadership practices. In the first year of the project, the research team collaborated with project leads to establish champion teams consisting of 6–12 members including academic health center leaders, faculty, community partners, and patient advocates invested in PCOR/CEnR at their institution. Champion teams met monthly for coaching with the UNM-CPR team, using Zoom for the online intervention in the first intensive year of workshops and data collection; and have met less often in year two, depending on the chosen strategies. UNM coaching included training in use of the Engage for Equity tools through workshops, providing qualitative and quantitative data of institutional barriers and facilitators, and supporting the development of action strategies and working groups to advocate for specific changes. Our coaching intervention has been designed to support champion teams to identify advantage points for institutional change and to engage in rapid-cycle testing of actions as they develop into facilitative leaders. Building from our previous work, we have used an iterative reflection approach with the teams to strategize, prioritize, and plan next steps.

Strategy 2: provide workshops with E2 tools. In the first year of the project, the UNM team conducted two virtual workshops for 25–35 stakeholders that included champion team members, community engagement staff and leaders, researchers, patients/patient advocates, community advocates and leaders. Workshops offered interactive learning activities based on previously validated E2 tools that guided participants through collective reflection and strategic planning for institutional change. The first workshop started with the E2 Tool, the *Institutional River of Life,* which engaged stakeholders to collaboratively construct their engagement history, or a visual metaphor of shared historical and community experiences, grounding participants in their own contexts (48). This was followed by the E2 Tool, *Visioning with the CBPR Model*, for stakeholders to develop their first collective strategic action plan, using the CBPR model to envision desired outcomes, needed additional partners, and actions to reach outcomes. In the second workshop, a synthesis of qualitative and quantitative data was presented followed by dialogue (in breakout rooms) to re-Vision with the CBPR Model their action plans and working groups for changes in institutional processes and policies. Building from our previous workshop interventions with partnered projects, the E2 tools remain grounded in the Freirean praxis of iterative cycles of collective reflection and action and create momentum to push for change at the institutional level (49).

Strategy 3: collect and use institutional data for advocacy. After the first workshop, the research team collected quantitative and qualitative data from leader interviews and patient/community member focus groups to assess the extent to which institutional policies, procedures, and norms support PCOR/CEnR research and stakeholder engagement at the institutional level. The UNM team regularly collected, cleaned, organized, and shared data with each of the three academic health centers describing institutional facilitators and barriers from the perspective of different stakeholders. Recommendations from qualitative data, together with institutional survey baseline survey results, were presented to the wider group at the second workshop to solidify working groups for collectively leveraging actions for change over the second year of the intervention. These institutional assessments were designed to reveal differing stakeholder perspectives and tensions identified in the data to promote critical reflection on next steps, with recommendations from community members/patient advocates given high priority.

Strategy 4: support community and patient advocate power. Throughout the intervention, community/patient advocate partners were given opportunities to exercise their power, through participating on champion teams, through prioritizing their perspectives from the patient/community focus group, and from separate meetings in workshop breakout rooms to provide a safe place to interact and document their recommendations.

Strategy 5: co-create a community of practice with the three participating institutions. In the first year, we invited the academic and community/patient co-leads from each champion team to join quarterly, multi-site, Zoom calls to share their interests and concerns in strengthening research support for patient and community engagement. These quarterly meetings were designed to create a community of practice (50, 51) to establish norms of sharing across institutions their actions, goals, and desired outcomes. As part of the community of practice, teams shared their organizational Rivers of Life and CBPR Model Visioning as visualizations of their process; and have had the opportunity through a panel, at the Action Research Network of the Americas conference after the first year in June 2022, to share their data from the institutional assessments which provided a collective understanding of their institutional barriers to strengthening their engagement support infrastructures, as well as their shared and unique assets and strategies for change.

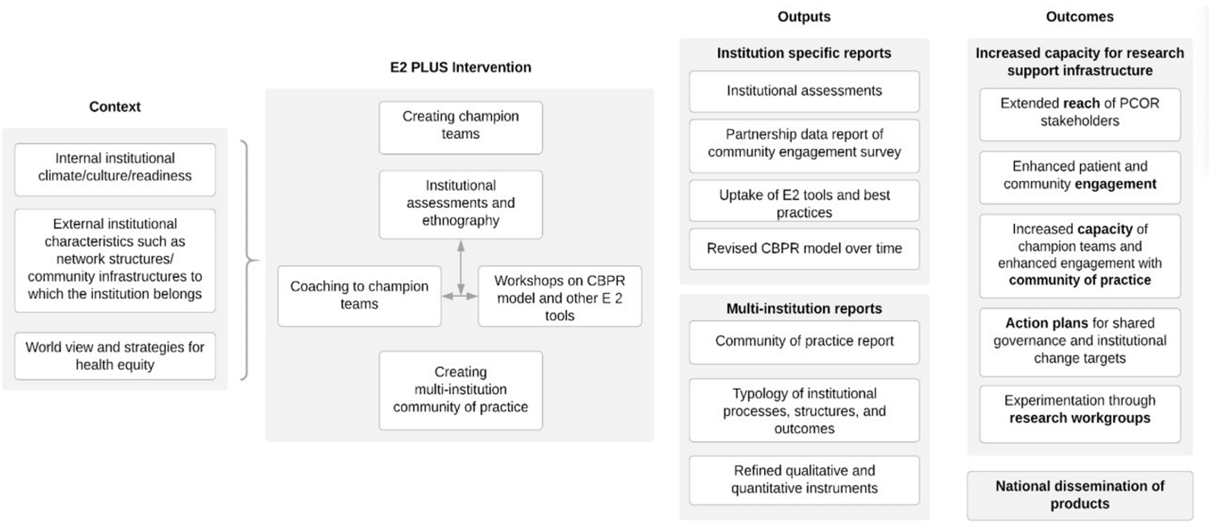

FIGURE 1
Engage for equity logic model.

3.1. Theory of change

As a conduit between funders, institutions, projects, and communities, champion teams are the core target of our engagement intervention as shown in Figure 2, which describes our core intervention strategies and processes. Through coaching, workshops, and ongoing meetings our theory of change proposes that sustained interpersonal relationships between stakeholders and systematic and contextual analyses of power can build the trust necessary to stimulate the collective organizing needed to transform inequitable structural conditions both in and outside of academic institutions.

While institutional rules, policies and norms shape the arena for collaboration, theories and evidence from public administration, public policy, and organizational development demonstrate that adopting *facilitative leadership practices* stimulates transformative action (s) and creative problem solving practices that generate successful policy outcomes and effective implementation of solutions for complex problems (52, 53).

Less pronounced than traditional, top down command and control management, facilitative leadership practices are performed collectively and are shared among groups of representatives appointed by key partners (54–56). Best practices suggest that representatives should include those with formal power to make decisions, those who can successfully block a decision, those affected by a decision, and those with relevant expertise and experience (57). In our intervention, this includes appointed leaders of community engagement centers, faculty conducting community engaged scholarship, community based organizations, patient advocates, and community and patient representatives who have participated in research. In short, this intervention galvanizes advocates of community engaged research to organize for change within academic institutions.

Successful facilitative leaders play different roles to mobilize for change (58). They convene relevant and affected stakeholders to clarify and emphasize interdependence, align goals, and build interpersonal trust in the face of diverging interests. They facilitate work groups that use adaptive strategies to enhance information sharing and mutual learning. They catalyze innovations that solicit new and sometimes disruptive knowledge to encourage groups to think out of the box. They mediate conflicts between communities, funding requirements, and institutional policies. Finally, they steward the ongoing collaboration by protecting it from external pressures (47, 58).

Facilitative leadership practices have been shown to improve multi-sector collaborative processes, accelerate the dissemination and implementation of solutions, and improve innovations and outcomes in a variety of arenas including health policy (59). Within institutions, these practices have been shown to improve the quality of collaboration between multi-sector groups, they produce more precise and nuanced understanding of complex problems, and they create a common ground for a diversity of stakeholders to communicate with each other and deal constructively with differences (56, 60). Facilitative leadership practices also demonstrate the potential to generate governance and sense-making spaces where communities as systems are able to advocate for more collective control over decisions/actions impacting their lives and health with their institutional partners (61). Finally, and at a systems level, facilitative leadership has also been theorized to enable coordinated implementation and adaptation of solutions and these practices accelerate the diffusion of successful innovations (59).

In this E2 PLUS intervention, data also serves an important role, enabling champion teams to not only characterize problems, but to generate evidence-based solutions that pay heed to institutional priorities and constraints faced by top administrators (62). Additionally, mixed methods institutional assessments also included an analysis of more subtle obstacles such as systematic biases that perpetuate social hierarchies in race, class and gender within AHCs as well as more diffuse norms and discourses that legitimate solutions for health equity rather than others. By understanding institutional barriers and leader priorities, we expect that champion teams are able to create solutions that attend to both top level and bottom up needs and concerns.

The E2 PLUS intervention is also grounded in deep engagement of patients/community members to enhance their own facilitative

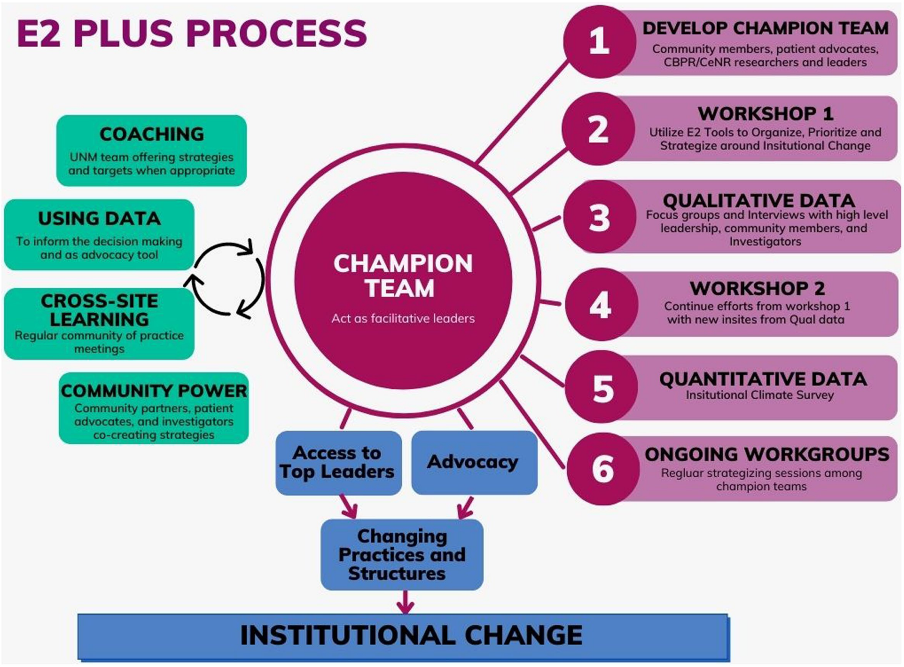

FIGURE 2
Engage for equity intervention strategies.

leadership by elevating their governance power and collective empowerment within the change process (7, 18, 57, 63). A unique aspect of our work is to craft new spaces for stakeholders in institutional academic health centers and a broader system of community stakeholders to recognize and develop shared interests to promote institutional capacity and long-term health equity changes.

Similarly, community of practice meetings between each of the institutions' champion teams allow for shared learnings from past experiences and learnings from their engagement in this project. These meetings are designed for our partners to compare institutional policies and practices that enable equity-based PCOR/CEnR planning and for champion team representatives to cross-share their successes and challenges in advocating for change within their respective institutions. In the final stages of the grant in May 2023, 6–8 members from each site's champion teams will come together for a conference to cross-analyze their efforts and plan for their engagement steps ahead.

In sum, complementing an iterative approach, the E2 PLUS design provides continuous input of institutional data, and varying stakeholder voices from workshops, coaching, and multi-institutional learning to promote change. As a result, champion teams are expected to make informed decisions that integrate community voice and build power with broader institutional stakeholders to stimulate change. The primary role of the UNM-CPR team is to act as an external consultant team to facilitate these meetings with evidence-based E2 tools and to provide experience-based coaching where teams had gaps in knowledge or experience. As an outside observer bringing awareness to PCOR/CEnR and creating additional pressure on institutional decision-makers, UNM has entered this space and conversation to stimulate forward movement within the champion teams and leadership within each institution. Using tools grounded in emphasizing collective capacity, community cohesion, and community power, E2 PLUS moves beyond promoting one-to-one relational practices focused on stimulating individual cognitive changes among decision makers, towards strategies promoting rapid cycles of collective analysis and collective action for change. E2 PLUS attends to the organizational and relational sources of social power to both coordinate and advocate for change.

3.2. Expected outcomes

As a feasibility study, we expected that coaching, workshops for collective reflection, data analyzing power imbalances and institutional capacity, and cross-site learning, would enable champion teams to adopt facilitative leadership strategies. We expected that our intervention strategies would enhance the capacities of community and academic participants to take on more leadership development, build new membership from other diverse stakeholders who can engage with others to adopt advocacy strategies that enable health equity efforts over time, distribute responsibilities across a wide collaborative network, and become stronger "boundary spanners" between community/patient advocates and academic health center leaders. We specifically supported champion teams to adopt advocacy strategies to influence decision-making by top academic leaders to reform institutional policies, norms and practices that deepen engagement to support health equity efforts (58).

An equally important long-term goal of our intervention has been to increase institutional trustworthiness in AHCs over time in order widen the scope of systemic efforts between AHCs, community stakeholders, and health systems to impact structural determinants of health. Trust in public institutions has been shown to improve other multi-sector collaborative efforts to co-develop and implement policies and programs in health, resource management, climate control, and social policy (22). As a multi-dimensional concept, institutional trustworthiness includes attributes along two major dimensions: good faith and competence (64).

Good faith refers to public beliefs that the institution will act in at the interests of relevant stakeholders because it exhibits values that emphasize promise keeping (integrity) and demonstrates that it cares about place and identity based communities through the development and sustainment of ongoing initiatives (benevolence); the public then perceives that the institution demonstrates a track record for public initiatives that follow rules and priorities co-established by institutions and their institutional partners (compatible incentives). Similarly, competent institutions demonstrate they have the ability and power to bridge multiple interests, such as conducting research that prioritizes relevant solutions for patients and communities. Competent institutions are also perceived to be consistent and predictable enough for institutional community partners to forecast potential outcomes when they join together (64).

4. Preliminary engagement findings after year 1

We collected qualitative data in the first year of the study to complete our initial institutional assessment. This included AHC leader interviews, stakeholder focus groups, patient/community dialogues at workshops and at advocacy meetings, and observational field note data. Interviews and focus groups probed into institutional contexts and how and to what extent different partners view health-equity oriented P/CEnR within their CTSA and larger AHC and the possibility for change. Using all data sources, we conducted an initial thematic analysis (65) using ATLAS.ti (66) to organize notes and transcripts into a relational database to assist in coding, searching, and retrieving textual data for each site. We followed standard process evaluation using qualitative iterative data collection and analysis feedback loops with deductive as well as inductive logic. We analyzed data throughout data collection period and research team members independently reviewed the data, following an editing approach to identify preliminary themes. This immersion-crystallization analysis stage identified any data inconsistencies. Champion teams also participated in the co-interpretation of their own data at six-month intervals as a participatory process for greater validity and for enhanced ownership of processes and findings.

Qualitative findings from leader interviews, community/patient and investigator focus groups early in the first year set the stage for analyzing the different contexts of each institution, and at the same time, uncovered shared tensions, showcasing that all could improve their accountability to communities. These tensions ranged from institutions acknowledging the outsize influence of external influences, such as the dominance of basic science and clinical NIH funding, including genomics and precision medicine, to the internal challenges of administrative and financial barriers in post-award, IRB, and other research processes. While leaders and investigators believed they were seeing changes through their equity or anti-bias training efforts, community members and patient advocates often talked about their continued experience of exclusion, with insufficient resources for community engagement. Even with successes in diversity, equity, and inclusion (DEI), respondents felt these were not connected enough to community and patient engagement. Many believed that "policies are there not to protect the community, but to protect the university."

These tensions manifested differently at each institution. Participants from Morehouse, for example, more than the other two institutions, valued that equity and community engagement were in the DNA and history of the institution, yet still identified the challenge of insufficient resources to realize equity goals, including that too few people had the CBPR expertise needed in order to grow engagement throughout the institution. Stanford participants, on the other hand, recognized the paradox of being from a prestigious national research institution in basic science and medicine, yet expressed concern for the lack of access in both clinical care and research involvement for community members. Fred Hutchinson/University of Washington Cancer Consortium, in particular, felt the tensions of movement forward on DEI yet with insufficient connection to community engagement.

As the E2 PLUS intervention progressed with the UNM team providing workshops and coaching, using the River of Life, Visioning with the CBPR Model, and a synthesis of the qualitative data at each site for their own understanding and interpretation, champion teams identified targets and advantage points for change. In the two workshops, participants identified institutional barriers including a lack of financial transparency with communities; lack of timely payments to patient advocates and community organizations; institutional review board's lack of understanding the nuances of PCOR/CEnR; insufficient collaboration among PCOR/CEnR internal efforts; and insufficient PCOR/CEnR training for investigators and community members/patient advocates. Even with variation in institutional readiness for PCOR/CEnR, by the middle of the first year, champion teams had identified working groups and expanded advocacy through their access to top leaders for change, such as, (1) pursuing a new Office of Patient Engagement at Fred Hutchinson; (2) challenging inflexible institutional review board processes at Stanford; and (3) enhancing strategies for expanded community diversity within Morehouse's premier Prevention Research Center Community Coalition Board.

In sum, even after 1 year of E2 PLUS, preliminary findings show enhanced effectiveness of champion teams to reach our goal, becoming stronger facilitative leaders and boundary spanners between top leaders and institutionally-connected community and patient partners. Champion teams also used quantitative and qualitative assessments to enhance their ongoing advocacy for changes for strengthening community and patient engagement. Patient and community voices have been given more attention at the leadership level, though the work continues. As one community member has said, "they have to make sure the community feels that they really want to hear their voices and not are just putting on a show. They need to give them appropriate compensation for the engagement of their time and their expertise which is in fact of great value."

5. Discussion

Adapting Popay's (21) limiting framework, the initial results indicate that the combination of mixed methods data analysis, workshops, and ongoing champion team coaching uncovered multiple forms of power imbalances that constrain successful systemic engagement in AHCs. Multi-method data analysis offered community and patient stakeholders a clearer picture of how authority was organized in each academic health center. Important aspects of authority were revealed in our preliminary analysis including defining what departments make decisions on how to allocate financial resources, how bureaucrats implement contracting and post-award grant processes, and which stakeholders determine IRB processes. Workshops and ongoing meetings crystalized how fragmentation of multiple engagement centers and initiatives was its own barrier in transforming institutions, with ongoing reflections uncovering how external funding and institutional leaders shape the substantive direction of research that influences the adoption of some health equity solutions as opposed to others.

Other, less visible, forms of power constrain collaborations in important, yet more subtle, ways. For example, structural power, which is invisible and embedded in broader social institutions, limits the capabilities of AHCs and their multi-sector partners to generate transformational health equity changes that address root causes of disease. Structural power generates and sustains social hierarchies of class, gender, and race/ethnicity through the distribution of resources, opportunities, and social status of groups (38). Examples of these structural constraints include when academic institutions make few investments in strengthening organizations of disadvantaged people to build their collective capabilities for long-term change and when they continue to replicate structural inequities through policies and practices that are institutionally racist and gendered. Patterns of structural racism were often cited as a key barrier at each site.

Productive power operates through diffuse social discourses and practices that legitimate some forms of knowledge, while marginalizing others (38, 67). Related to CEnR research, there is evidence from these sites that AHCs present barriers to meaningful community engagement research and action due to epistemic biases in what constitutes acceptable research, neoliberalist tendencies to generate research dollars that support the status quo, gendered norms, and colonial racist defaults (67). For example, many tenure and promotion requirements and institutional commitments are not currently organized to support effective community and patient engagement (68).

The initial results also indicate that champion teams had to be what Bryson and colleagues call "structurally ambidextrous" to manage multiple tensions in reforming policies and procedures (59). These tensions included the need to juggle institutional stability versus change, using lateral relationships to challenge hierarchical processes while still respecting the authority of university leaders, using formal versus informal networks to advocate for change, and using existing forums versus creating new ones for CeNR health equity (59).

Congruent with other findings in public administrative research (59, 69), our initial results suggested that champion teams made calculated decisions to invest their initial efforts in reforming organizational practices that have a direct impact on community engagement while acknowledging that other policies and norms are likely to continue reinforcing structural and epistemic power imbalances. Our preliminary results also demonstrate that the intervention helped champion teams generate change strategies based on lateral relations between community/patient stakeholders and formal partners, through new forums enabled through workshops, and by collectively reflecting on data that generated more power sharing to stimulate change strategies. Despite acknowledging the broader systemic issues, initial findings suggest that as teams moved to implement changes in existing processes like contracting and grants and IRB administration, champion teams also had to adapt to the hierarchies, by soliciting change from leaders and formal networks, with less power sharing, so that changes could be enacted. Future research needs to explore what kinds of ambidexterity are necessary to address these and other power imbalances.

6. Conclusion

The UNM team recognizes the dedication and forward movement of individuals, departments, CBOs, patient advocates and other stakeholders to improve equity-based PCOR/CEnR/CBPR that occurred in the past and independently occurred during this intervention. The purpose of the E2 PLUS intervention was to enhance the existing efforts and to inspire new ones with organizing and power-sharing with community members and patients.

Overall, the initial analysis demonstrates that champion teams formed quickly, they used data and workshops to plan for targets of change, and they were successful in mobilizing for policy and practice changes. Overall, the intervention shows promise in supporting champion teams through workshops, coaching, and data analysis to become agents of change in another and perhaps, deeper way. The initial results suggest that E2 PLUS provides a venue for diverse stakeholders to create greater connectivity between systems of academic community engagement and committed stakeholders: (1) to establish opportunities for collective decision making and forming wider alliances; (2) to identify and act on existing power dynamics that undermine the capabilities of diverse groups in developing collaborative solutions that promote health equity; and (3) to create new "sense making spaces" (61) in which participants collectively reflect on the stigmatizing discourses and inequalities that sabotage true health equity reform, while developing, newer, longer-term narrative strategies in the hope of prompting deeper changes.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by University of New Mexico Health Sciences Center (HRRC: # 21-320). Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

SS-Y and NW conceived the idea and theory of change and drafted the manuscript. SS-Y, PA, AG, KM, NW, and CA collected and analyzed the data. PA created the logic model. AG created the theory of change figure. PA and ED critically reviewed the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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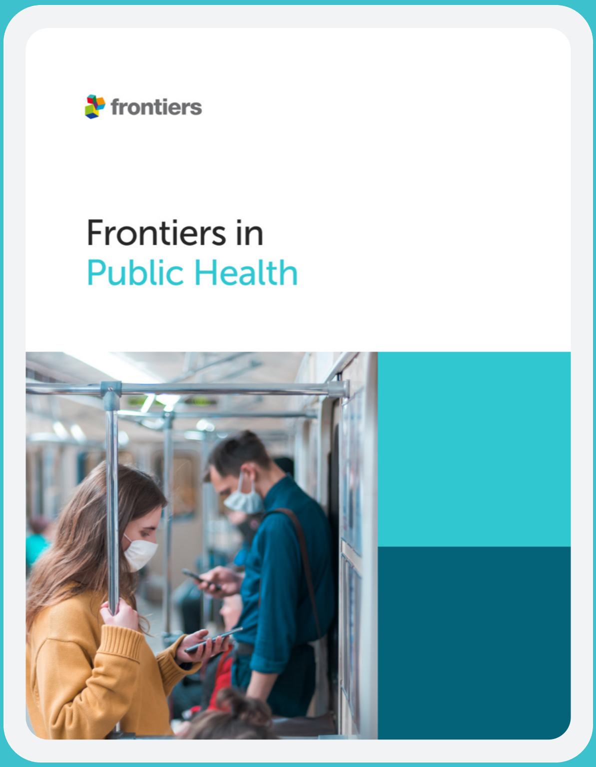
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