HOWARD BROWN HEALTH'S CENTER FOR EDUCATION, RESEARCH, & ADVOCACY SERIES

A Best Practice Guide for Community-Based Participatory Research (CBPR) in Transgender and Nonbinary (TNB) Health

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FOUR CORNERS
TNB HEALTH RESEARCH ADVISORY NETWORK

Center for Education, Research & Advocacy
A DIVISION OF HOWARD BROWN HEALTH

Howard Brown Health

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INTRODUCTION

This guide describes best practices for community-based participatory research (CBPR) with transgender and nonbinary (TNB) communities. We hope it will be a resource for people involved or interested in TNB health research and will make CBPR approachable, actionable and compelling. We anticipate readers of this guide will hold varying identities, experiences, and expertise, including their understanding of or familiarity with research and TNB communities. It is important to explicitly recognize that there are TNB people of varying cultural/language backgrounds already doing this work and to avoid reinforcing assumptions that researchers are not TNB, Black, Indigenous, people of color (BIPOC), or TNB BIPOC. While we believe the best people to initiate and practice TNB health CBPR are TNB people, we also recognize that the majority of people involved in TNB health research are not TNB themselves. This guide is designed to offer insight to all audiences. Our goal is to provide an overview of themes we believe are important and best practices to collaboratively develop and carry-out research with TNB communities.

CBPR practices in this guide are well aligned with Patient Centered Outcomes Research (PCOR) and offer methods to deepen engagement and involvement of TNB community members in PCOR. Similar to CBPR, PCOR is an approach to research that recognizes the importance of stakeholder-driven priorities and involves patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process (PCORI, 2019). Both CBPR and PCOR value mutual respect and trust, and capacity building among stakeholders to meaningfully engage in research, and strive to improve health outcomes.

This guide integrates knowledge from existing PCOR/CBPR projects, our own successes and failures in CBPR, as well as lessons learned, best practices, and challenges shared by colleagues and participants of our recent Next STEP Convening. We start with who we are, what CBPR is, and why it is a critical component of TNB health research. We also include information about how we gathered and developed these best practices. While this guide does not include every possible recommendation or approach, we hope it leaves you with new insights and a deeper understanding of the importance and effectiveness of including CBPR approaches in research. Moreover, we hope it drives discussion and development of even better CBPR approaches to integrate into TNB health research and share with others.

We deeply appreciate every person who contributed to this knowledge through their experiences, insight and emotional labor.

FOUR CORNERS: TNB HEALTH RESEARCH ADVISORY NETWORK

Four Corners envisions a world where all TNB people have access to safe, relevant, and equitable healthcare, and aims to advance health research by involving TNB community members, researchers, and clinicians as equitable partners in the research process.

Four Corners is a network of healthcare providers, researchers and community members committed to community-engaged TNB health research that is accessible, beneficial, and relevant to TNB communities. Our current partners include three federally qualified health centers (FQHCs) specializing in Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) health, representing geographically distinct regions, and serving diverse TNB patients: Howard Brown Health in Chicago, The LA LGBT Center in Los Angeles, and Whitman Walker Health in Washington D.C. We also have TNB community members representing Houston, Texas.

Four Corners has engaged in qualitative CBPR TNB health research, completing a study that identified health research priorities among TNB communities in 2020 (Four Corners: Health Research Priorities Among TNB Communities) and a study that explored the experience of TNB communities navigating COVID-19 in 2021 (Four Corners: Reflections of Trans and Nonbinary (TNB) Communities Navigating The COVID-19 Pandemic). To further develop use of CBPR in TNB health research, Four Corners sponsored a two-day Next STEP Convening in September 2021 to explore and share best practices.

THE NEXT STEP CONVENING

The Next STEP Convening was a two-day virtual conference bringing together TNB community leaders, patients, clinicians, and researchers.

The main aims of the convening were to provide an opportunity for intentional trust-building and networking, promote community-engaged, TNB-led health research, and collaboratively identify best practices for TNB community engagement across the different stages of research. Four Corners prioritized working towards language justice during the Convening, providing gender-affirming Spanish interpretation for all presentations and discussions, and offering all pre-Convening communications in English and gender-affirming Spanish.

The Convening created a unique space for 42 Convening participants to focus on CBPR TNB health research practices, centering the voices of TNB people. Eighty-eight percent (37 people) of Convening participants identified as TNB and 60% (25 people) identified as BIPOC. Convening participants included researchers (30%, 13 people), clinicians (17%, 8 people) and TNB community members (53%, 22 people) from across the United States. Participants came from different parts of the country: 19% Midwest (8 people), 19% Northeast (8 people), 15% Southeast (6 people), 19% Southwest (8 people) and 27% West (12 people). Twenty-six percent (11 people) of participants were bilingual in English and Spanish.

WHAT IS COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)?

Community-based participatory research (CBPR) is an approach to research that equitably involves all partners (e.g., community members, researchers, and other stakeholders) throughout all phases of the

research process. In CBPR, every partner's expertise and experience are valued and shared as part of the research team, with all partners sharing in decision making and ownership of the research process and results (Israel et al., 1998).

CBPR recognizes the existing strengths and resources of community members, fosters co-learning and capacity-building, and balances research with action (Israel et al., 2010). For example, CBPR supports community members learning more about research and researchers learning more about community needs, perspectives and engagement. CBPR leads to more community buy-in and support, and a greater willingness to participate in research in meaningful ways given the authentic collaboration of community members in planning and doing the research. CBPR facilitates rich, nuanced data and data interpretation as community members are actively involved in gathering and understanding the data. Ultimately, the CBPR partnership creates richer, more relevant research that directly benefits the community.

While CBPR is more often associated with qualitative research, it is just as applicable and powerful when integrated into quantitative and mixed methodology studies. While some research requires very strict standardized interaction with participants (i.e., clinical research testing new medications), CBPR can integrate community voice and lived experience into participant recruitment/engagement and research protocols while still working within required structure. The critical element is the inclusion of CBPR approaches before the research is launched.

WHY IS CBPR IMPORTANT IN TNB HEALTH RESEARCH?

There has been a surge of research related to TNB health in recent years. However, significant gaps still exist in TNB health research quality, community-engagement in TNB health research, and institutional support for TNB people and TNB organizations as leaders of TNB health research efforts.

Due to the history of TNB oppression within medical and research systems, traditional research frameworks must be reconceptualized for true engagement of TNB communities. CBPR honors community members as experts and equal partners in all stages of the research process; this reflects a conceptual shift from research "on" communities to research "with" communities. CBPR is increasingly recognized as a best practice approach to address TNB communities' distrust of academic partners and institutions (Israel, et al., 2010) and the disproportionate health disparities experienced by TNB communities. As such, the principles of CBPR should be applied when working with TNB communities to conduct and disseminate meaningful and responsible TNB health research. TNB communities must be actively engaged in defining what health means to TNB people, identifying health priorities, and creating approaches that improve health together.

CBPR aims to disrupt power differences in a typical health research team, and deeply integrates the voices and influence of patients in research that will ultimately affect how health care is offered. CBPR

makes TNB health research more democratic, ensuring TNB people have significant influence in the research process and that the voices of frequently silenced groups within TNB communities are heard, ultimately leading to more accessible, applicable, and comprehensive research.

To genuinely advance the scientific rigor of TNB health research, dedicated infrastructure, funding, capacity-building, and training for TNB people is critical. Too few TNB researchers are funded as Principal Investigators (PIs), with cisgender people in primary leadership or positions of power in much of the existing research. TNB people employed on research teams are often limited to roles in outreach or as periodic advisors. In addition, research participants are rarely engaged after data collection is completed to ensure findings are accurate and to inform the application of results. The intellectual and emotional contributions of TNB people have been historically undervalued, ignored, or exploited in these contexts. CBPR changes that.

HOW WE DEVELOPED OUR BEST PRACTICE GUIDE

A team of Four Corners researchers, clinicians and TNB community members reviewed transcripts and recordings from the 2-day Next STEP Convening. The team was led by TNB community members of various lived experiences. The team met twice a week to create a data analysis plan, review summaries of discussions and presentations from the Convening, and identify themes throughout the transcripts. In addition, the guide integrates Four Corners' own experiences and lessons learned from previous TNB health CBPR.

After developing a preliminary framework, we invited Convening participants to join a Member Check-In meeting. The Member Check-In allowed the team to share our provisional findings and receive feedback from participants. This helped the data analysis team ensure that we had accurately heard and represented participants' voices. Of the 42 people who attended the Convening, 26 attended the Member Check-In. Participants described feeling heard and that their ideas and values had been well represented in the preliminary framework. The data analysis team discussed the findings from the Member Check-In and used them to revise and inform the next stage of our data analysis and guide generation.

The guide includes key themes that should be considered and addressed in TNB health CBPR, including: "Recognizing and Valuing Emotional Labor", "Working Towards Racial Justice", "Working Towards Language Justice", and "Funding and Compensation". We encourage readers to keep these themes in mind as they move into the second part of this guide which divides the research process into four main stages: 1) Setting the Foundation, 2) Planning the Research, 3) Doing the Research, and 4) Sharing Findings and Taking Action. Each key theme and research stage include a description of the theme or stage, a quote from one of our Convening participants, key questions to consider, and a bulleted list of best practice recommendations with concrete examples. We close our guide by sharing thoughts about "What's Next for TNB Health CBPR".

KEY THEMES

RECOGNIZING AND VALUING EMOTIONAL LABOR

Being involved in TNB research as a TNB person can require intense emotional labor, whether someone is a research participant, clinician, community stakeholder, or researcher. All TNB research requires emotional labor that is often ignored, unseen and undervalued. Examples of emotional labor include, but are not limited to, hearing stories of discrimination and harm, being misgendered, being outed without consent, having to educate others about respectful communication or affirmative care, justifying yourself and experiences, potentially re-living trauma, supporting TNB participants who have experienced harm, and interacting with non-affirmative research systems. Acknowledging the role of emotional labor within research is an important first step. Implementing actionable ways to support TNB participants, clinicians, researchers, and community members is a second step that is vital to the well-being of TNB people and the overall success of a project.

Emotional labor must be considered in the role of TNB research participants, research team members and community stakeholders. Emotional labor should be proactively recognized, reduced and compensated during all stages of research. Some ways to reduce emotional labor include carefully reviewing a survey/interview instrument for possible triggering content and non-affirmative assumptions, ensuring fair compensation for participants, and having dissemination strategies that support meaningful and tangible change for TNB communities.

To reduce TNB people's emotional labor, cisgender colleages and researchers should carefully and repeatedly examine their understanding of gender, and how their own experiences of gender identity may limit their understanding of TNB people and TNB people's lived experience. Cisgender colleagues are encouraged to check their assumptions about TNB people and ask themselves, "Is this something I would ask a cisgender person?" and "Is this something I can find online?" It is critical that cisgender colleagues recognize that their words, action, and inaction

"I feel like any research that is community-led requires emotional labor, right? Especially within our community and especially when folks are being asked to divulge… narratives that are personal to them. And I think that maybe that's potentially some of the barriers to people really being involved [in research] …You give so much of yourself, and then you see nothing from it, you get nothing back. So it's like you just told your whole life story and there was nothing given back to you in return."

have power. Cisgender team members are encouraged to recognize their own privilege and power and, in true partnership with TNB people, use that for the betterment of TNB communities and TNB health research. Cisgender colleauges can talk with TNB colleagues about ways the cisgender team members could interrupt harm and reduce the emotional labor TNB team members experience. For example, a cisgender team member could meet with an institutional administrative office to raise serious concerns about dead names used in emails, HR systems and payroll.

Cisgender research team members are encouraged to receive regular continuing education about TNB identities and lived experiences, the construct of gender identity, health dispartities and gaps in care experienced by TNB people, and TNB affirmative healthcare.

QUESTIONS TO CONSIDER:

1) **What resources does my organization have internally or externally to support TNB participants and TNB organizational partners with emotional labor related to participation in research?**
2) **How can emotional labor be more equally distributed among members of a research team so that everyone feels supported and capable of engaging in the project?**
3) **What are some ways research team members can sustain themselves, set and hold boundaries, and take needed breaks when pressure to produce is high? How can my team integrate these practices through each stage of research?**

RECOMMENDATIONS:

- Offer paid time to TNB research partners to process emotional labor and rest, while also embedding recovery time into the research structure. For example, avoid overloading a work week when there may be emotionally draining research activities (e.g., interviews, trauma questionnaires) and be mindful of something politically or socially intense that influences TNB lives (e.g., the death of a TNB community leader, a bathroom ordinance, a political action restricting TNB people from serving in the military).
- Ensure that TNB team members are not tokenized and are not treated as someone who should manage any issue connected to the TNB community. Systems can easily divert TNB patients, TNB community concerns, and communication with TNB-led organizations to TNB people, regardless of their roles and responsibilities. Actively advocate that all parts of your system develop internal expertise in these areas and protect TNB team members from being repeatedly asked to be the voice of gender diversity on committees, task forces and program development teams.
- Provide research participants with a range of identity options in demographic sections, including the opportunity to self-identify or write-in responses related to identity on all research materials.
- Build intentional support into an interviewer's questioning/listening process, such as prolonged pauses, sensitive wording, and trauma-informed language.
- Consider having recovery/resting spaces for participants or having a support person available should a need arise. Recovery/resting spaces allow participants some private time to step away during a challenging focus group discussion or time to center themselves before returning to public spaces. Provide resources and opportunities for mental health and/or self-care before, during, and after any potentially emotional intervention (e.g., focus group, interview, sharing of a diagnosis). Examples include, but are not limited to: have a social worker, psychologist, and/or non-traditional practitioner available should a participant need immediate support, share recommendations for self-care, coping and boundary setting, offer a guided meditation before or after the encounter.
- Return research results to the community through accessible pathways (e.g. podcasts, social media, online forums) rather than only publishing in peer-reviewed journals or presenting at academic conferences that are inaccessible for many TNB people.
- Set aside funding to hire TNB BIPOC consultants to assist in the application of gender-affirming frameworks in the research process and in specific research tools.

WORKING TOWARDS RACIAL JUSTICE

Racial justice in research is the intentional dismantling of systemic racism, colonialism, and white superiority/supremacy that is embedded in all stages and types of health research. Racism permeates all aspects of research as it influences who has the power to allocate funding, and consequently, who receives funding, who leads research, what issues are identified as research priorities, how research is designed, who is recruited as participants, how research questions are developed and contextualized, how data is interpreted, applied, and disseminated, and who benefits from the research.

TNB communities have made repeated calls for research teams that include, and are led by, TNB people, and, most importantly, TNB BIPOC. Whoever holds power on those teams greatly influences the quality of research and a TNB person's willingness to actively participate in research. To start, research teams must utilize their privilege to create meaningful space for stakeholders whose experiences are racially, culturally, and ethnically marginalized. Beyond creating space for engagement, white research partners need to address the historical underinvestment in TNB BIPOC communities, championing pathways for TNB BIPOC to thrive in research settings and maintaining a commitment to breaking down systemic barriers that prevent access. Furthermore, to maximize the agency and leadership of TNB BIPOC, white researchers need to relinquish control, while still supporting and being accountable to TNB BIPOC partners throughout the research process.

Having white, cisgender people leading TNB health research without deep power sharing and involvement with the TNB community is problematic, disenfranchizing, and will result in incomplete, inaccurate research. Likewise, having white TNB people leading research addressing the health of TNB BIPOC, without deep power sharing and involvement with TNB BIPOC, will also yield inferior research outcomes.

Working towards racial justice in research requires TNB BIPOC to hold power in research and funding institutions, and requires resources (financial resources, training, personnel, etc.). It also requires challenging white norms and values, and interrupting how those norms systematically influence research processes. Financial resources must be dedicated to invest in and empower TNB BIPOC communities to create, implement, and lead more affirming research that meaningfully engages and addresses TNB BIPOC needs.

"..if we can see trans leaders leading research...[it's] more likely we can trust them, specifically black trans leaders and researchers. I think I'm more likely to participate and to believe their research...[with] cis[gender people], usually men doing this research, leading it, I'm less likely to participate or believe it or trust them with my…information."

QUESTIONS TO CONSIDER:

1. **Who is leading the research and how does that influence how racism and white superiority/ supremacy are (or are not) talked about and embedded in the research process?**
2. **Is there an explicit commitment to racial justice in your research team and project? What resources are devoted to this work? How are you being accountable for racial justice within your partnerships?**
3. **How are you supporting and investing in TNB BIPOC research partners and staff?**
4. **How does the research team support TNB BIPOC who often experience microaggressions, racism, and other "isms" on the job and in their lives?**
5. **What are some ways to create research so that it is racially just and gender-affirming for TNB BIPOC communities?**

RECOMMENDATIONS:

- Provide TNB BIPOC-led organizations with necessary resources (financial, structural, etc.) to lead projects that are centered on their desires, needs, and specifications for health research.
- Create TNB BIPOC-only spaces within your partnership or structure. These spaces can include discussion on the planning and implementation of each stage of research and/or provide space for TNB BIPOC to decompress that is separate from white staff or community members.

- Invest in and support TNB BIPOC (e.g., create paid internships and/or mentorship programs, offer free professional training/skill-building workshops, etc.).
- Compensate TNB BIPOC fairly, and on time, taking into consideration how economic injustices also permeate research processes and the ability for TNB BIPOC to be involved in projects.
- Avoid binary approaches to research and care. Address the dearth of information surrounding TNB people and listen to TNB BIPOC communities whose gender identities fall outside of traditionally white-centric understandings of gender (e.g. heteronormativity, gender norms, cisheteropatriarchy).
- It is important to recognize that hiring LGBQ BIPOC community team members is not a substitute for hiring TNB BIPOC people.
- White TNB and white cisgender researchers should strive to not perpetuate the hierarchy that is rooted in white supremacy. You must actively educate, reflect, and advocate for TNB BIPOC staff, participants and organizational partners.

WORKING TOWARDS LANGUAGE JUSTICE

Language justice is the intentional creation and sustainment of multilingual spaces in which all languages are equally valued and supported. Language justice celebrates the diversity of communities and cultures, and affirms the rights of individuals and communities to be present, heard/seen, and valued as equal participants (CCHE, n.d.). It includes a commitment to shared power for all stakeholders through the creation of systems that help every person understand and be understood in the language they prefer.

In the United States, English is the language used in grant applications, research, and publication. When research includes other languages, the other languages are often considered supplemental and only included in a portion of the research to access a subsection of participants. Language justice challenges and resists assumptions to create equal access for all stakeholders' voices to be heard in their language (CIR, n.d.). This includes not only the languages used (e.g., Spanish, Arabic, American Sign Language (ASL)), but also the accessibility and respectfulness of language (i.e., jargon, reading level, culturally relevant phrasing and vocabulary, gender-affirmative language).

Language justice will only be as strong as the resources and support devoted to creating it (e.g., time, priority focus, and funding) (Antena Books, n.d.). For instance, time must be proactively allocated to think through workflows (e.g., identifying all points of potential communication between the research team and participants to ensure language is accessible throughout the research process). Time and funds must also be proactively allocated to include interpretation, translation of language, and translation review/revision by community members. Quality simultaneous, gender-affirmative interpretation is a critical component of language justice. Increasing

"... it seems like working in not-for-profit organizations, certain languages get priority over other languages. And that's really doing a disservice for so many of our participants, our potential participants who can come in and contribute something beneficial to the conversation."

language access in research illuminates nuance and meanings that are vital to culturally astute and accurate data analysis and interpretation.

Efforts towards language justice must be an explicit priority that is interwoven throughout all stages of planning, engagement, communications, and budgeting. Creation of multilingual and multicultural spaces opens communication and empowers research team members, community members, and organizational stakeholders to contribute to and inform research as equal partners.

QUESTIONS TO CONSIDER:

1) **What resources (e.g,. budget, time, training, personnel) and support will be devoted to creating multilingual spaces where everyone's voice can be heard?**
2) **How will the research team systematically and repeatedly audit its research protocol, data analysis, and dissemination plans to deepen language justice, and to interrupt implicit bias and privileged assumptions?**

RECOMMENDATIONS:

- Recruit and compensate a multiracial, multilingual, gender diverse research team, including research support staff, research assistants, research managers, co-investigators, and principal investigators. Be inclusive of all languages, not limited to English and Spanish.
- Reduce the use of jargon and standard research phrases that may be inaccessible to participants. Assess the reading level of all materials to ensure written and spoken language is accessible to participants from a wide range of educational and cultural backgrounds.
- Intentionally examine every step of the research to anticipate interpretation and translation needs. For example, all communication with a person who has selected Spanish as their language of communication will need to be in Spanish. This includes participant recruitment information, consenting materials, email and phone contact (planned and spontaneous), wayfinding signs (i.e., directions to meeting rooms), information on web sites or links, and resource or referral materials.
- Locate and compensate TNB-affirming language justice organizations that provide interpretation

and translation services, and are adept at working with TNB people and using gender-affirmative language. Language justice organizations can often provide training and consultation/guidance on the best ways to make your research as accessible as possible.

- While you can use a standard translation service to produce an initial draft of a document, any translation must be reviewed/revised by TNB people who are familiar with the gender-affirmative use of that language.
- Investigate simultaneous interpretation limitations in virtual platforms before you finalize your research methods and the platform you plan to use. For example, Zoom has a simultaneous interpretation feature that can be enabled in the main room, but this feature is not available in breakout rooms.

FUNDING & COMPENSATION

Funding is a critical resource for research to exist and thrive. Funding can come from many different sources (e.g., government, public, private); however, all sources offer funding structured around their own priorities and agendas with specific rules and regulations that must be followed with any funding that is awarded. Such rules and regulations have typically been built around traditional research processes that were not built for deep integration of communities throughout the research process. It can be challenging to find funders that value (and will pay for) TNB health CBPR and support the unique ways CBPR needs to use funding.

Most governmental, public, and foundation funding for TNB health research funds research within large and well-resourced institutions, such as universities or hospitals. Although this is gradually changing, a good portion of TNB health-related research is currently conceived of and led by cisgender people. Few TNB researchers have gained access to leadership positions on large research grants. TNB-led community organizations can lack the kinds of research grant development and logistical support needed to compete for funds. Historically, funding tends to focus on the funder's interests as opposed to the interests or priorities of TNB communities and researchers. Often, the money available does not match the need because there is not enough research that proves there is a need. Collaboration between TNB community-based organizations and large research institutions is critically needed. Possible funding sources for TNB Health CBPR include, but are not limited to, the Robert Wood Johnson Foundation, Patient Centered Outcome Research Institute (PCORI), National Institute of Health (NIH), private donors, foundation grants, local public health departments, seed grants for capacity building and partnership development, and mini-grants from community organizations.

Stable funding is a community health research priority; pursuing grant funding that does not focus on TNB community research priorities can exhaust research teams and dilute research focus, diverting

"I do think it's a very fine line to walk between explaining the limitations and kind of excusing systemic injustice."

research activity and discovery. It can be very difficult to obtain funding that sustains already existing research initiatives or that provides resources for capacity building of CBPR teams. Additionally, all too often, funding is identified and a research project is built around it rather than identifying a research priority and then finding aligned funding.

CBPR requires expansive and creative thinking, exploring nontraditional uses of research funding and the use of funding to strengthen TNB community infrastructure. Some examples include: devoting funding and project time to shared learning about research methodologies and TNB community priorities, and supporting specific community needs through compensation or contribution to TNB community organizations. Building community-identified resources into a budget can be important for relationship development, and for dissemination and action. This could include buying computers for a community space that potential participants can use to complete online surveys, or budgeting a part-time "movement consultant' position to link research results to local organizing initiatives that strengthen and support the TNB community. In addition, the pandemic has highlighted the importance of equitable access to technology to connect with others, such as smartphones with WiFi capacity, computers, tablets, and laptops. Researchers should consider ways to create funding to support TNB community members who may not have access to technology. If traditional funding sources will not support such creative (and effective) initiatives, consider seeking supplemental, less controlled funding to fill in those gaps.

A common challenge in research is balancing fair compensation with protection from coercion. IRBs and research ethics exist to protect low-income research participants from potential exploitation. Financial limits are placed on compensation to avoid exploitation of participants and to ensure that researchers cannot use their economic power to get participants to do things they would not otherwise volunteer to do. However, TNB people often perceive minimal compensation to be disrespectful and predatory. Paying people small amounts to participate in research (also called token compensation) is experienced as devaluing TNB people's labor and extracting their lived experiences and ideas for others' institutional gain, profit, and advancement. This is heightened when research is initiated and developed by cisgender people and/or when participants do not see a

connection between the research and efforts to improve conditions for TNB people. CBPR approaches can help strengthen ethical safeguards. Research teams can carefully consider what research participants are being asked to do or share, and ensure that the study outcomes have value to TNB participants beyond individual compensation. At the same time, research teams can also determine what will constitute meaningful compensation by gathering information ahead of time from prospective participants and TNB partner organizations, and considering other equity factors. Research teams may need to advocate with their IRB for higher compensation levels. As part of the research study design, research teams can explore the role of compensation in participants' overall motivations to participate.

Money is power. CBPR research projects should authentically share that power with TNB communities.

QUESTIONS TO CONSIDER:

1) **How can you creatively consider non-traditional uses of funding to deepen CBPR?**
2) **What are innovative, TNB community-endorsed ways to fund relationship development and capacity building to prepare for future research collaboration?**
3) **How can researchers and funders create new funding structures and/or expand existing structures to support a CBPR research model?**
4) **What proactive advocacy can expand funding and improve resources for TNB community-led research? How can that be systematically integrated into our systems?**

RECOMMENDATIONS:

- Involve TNB community members and TNB organizational partners in the budgeting process during the application phase and all other budgeting cycles.
- Policy advocates are encouraged to include TNB community members and representatives of TNB community organizations in outreach to large funders to share TNB community research priorities and encourage a funding focus in those areas.
- When applying for grant funding, submit a proposed budget that includes fair compensation for TNB community engagement partners and stakeholder organizations at levels that were agreed upon in advance with those partners and organizations.
- Apply for funding outside of sexual/gender minority (SGM) and HIV funding streams; instead explore funding in different health-related areas (i.e., chronic illnesses, age groups). For example, research on hormone therapy and cardiovascular risk could be funded by the American Heart Association.
- FQHCs should have a designated person that searches for TNB health research funding.

- Champion smaller TNB community-based organizations and leverage funding to help those organizations do groundbreaking work.
- Develop an advocacy/policy watchdog system to identify public comment periods and mobilize all partners to make comments telling large funders that they need to prioritize TNB and CBPR funding.

RECOMMENDATIONS FOR FUNDERS:

- Allow flexible time at the beginning of a grant period for the research team to hold community capacity-building events and activities.
- Have TNB people serve as grant reviewers on applications that specifically focus on TNB participants, as well as on grant applications that may include TNB participants. Both types of research will benefit from such review feedback.
- Offer greater flexibility on food expenses for participants, permitting research teams to purchase healthier, more substantial options.
- Fund capacity-building efforts. Offer specialized grants that research teams can use to build meaningful relationships with TNB community members and TNB organizational partners so relationships are developed before the team needs to submit a proposal for funding.

RECOMMENDATIONS ON PARTICIPANT COMPENSATION

- Research participant payments methods and incentive structures need to be accessible and most convenient for participants. They should include different options such as cash, bill subsidies (i.e., funds paid directly to the gas/electric or phone service company), reloadable debit cards, Venmo, PayPal, etc. This will likely require proactive and assertive advocacy with funders and with the finance department issuing/tracking the compensation. Make a compelling case for the value of the extra administrative burden/organizational cost that may be necessary to use the most community-informed compensation processes. Electronic visa gift cards are not ideal; they expire quickly and are not easily used in many situations (i.e., rent, utilities).
- Carefully review the financial systems participants will have to interact with to access their compensation. Whenever possible, avoid payment systems that require participants to disclose social security numbers or cash a check written to a person's legal name. Understand the level and type of compensation that will require a participant to submit a W-9 form and when compensation levels will result in a 1099 tax form being issued by the finance department. Carefully consider how compensation structures will effect people who are undocumented, receiving public assistance, or are returning citizens. Include issues like this in the consent process so participants can make an informed decision about the added stress and potential impact a compensation structure might impose.
- Shared meals can increase engagement, support self-care, and signal respect and appreciation. When including food in participant gatherings or research team meetings, ask for food preferences and dietary restrictions in advance. If shared in-person meals are not possible, consider providing participants with gift cards to purchase food to share virtually.

STAGES OF RESEARCH

STAGE 1: SETTING THE FOUNDATION

Foundation setting is perhaps the most important and time-intensive stage in CBPR as it includes everything that needs to happen before designing a research study. One of the main components of foundation setting is identifying and building connections with community stakeholders to understand community priorities and mutual interests before formulating a research question. CBPR is built on equitable partnership between community members, researchers, and other potential stakeholders. Building a strong foundation for a collaborative and informed research process (including topic selection, development of research design, implementation, data collection, analysis, and dissemination) requires a significant amount of time, trust, intention, and capacity-building to generate meaningful engagement. Community members who do not have prior experience with research may need training on research and institutional procedures, while non-TNB researchers may need training to deepen their understanding of community research needs and priorities. Once a baseline of common knowledge is established, the team will still need time to collaboratively identify roles and processes that recognize and honor people's varying expertise and capacities. In addition, the team will need to consider what resources (e.g., money, time, space, and people) will be needed to successfully complete the research.

Important elements of this first stage of research include intentionality, power and privilege imbalances between researchers and community members, and systemic barriers in conducting TNB CBPR. Researchers must be mindful about forming a diverse research team and which stakeholders are represented on the team, as this will impact every step of the research process. For example, if the research team is mostly cisgender and white, engagement by TNB BIPOC communities may be limited. Having a primarily white, cisgender research team can skew research priorities, how

"Doing community-based research is not a one-time event. It is about building a relationship. And I think that what happens is folks forget that… or actually, folks don't know that. Researchers think that what it is, is we go in and I see that you're a community member, and I got this money. And of course, you're trans or maybe you're poor or maybe you have all these things, so maybe you want to participate because I'm giving you money."

the team recruits, who participates, what the results are, and how the results are disseminated.

In addition to a diverse research team, it is critically important to have community voices throughout the research. As CBPR emphasizes an equitable partnership throughout all stages and elements of research, a community advisory board of TNB community members who are merely updated on the research is not considered meaningful engagement. Researchers need to be intentional and actively create space for TNB community members to play a vital role in strategizing and implementing the research.

QUESTIONS TO CONSIDER:

1. **What should TNB people and TNB-led organizations consider before they decide to be part of a research study on TNB health?**
2. **How do power and privilege impact this stage of research and research partnerships? How can that be interrupted?**
3. **What should cisgender people and cisgender-led research teams consider before they decide to be part of a research study on TNB health or partner with a TNB-led community group?**
4. **What types of stakeholders should be represented on the research team? How is your partnership unique?**
5. **What norms will be set to center team-based consensus building between researchers and other team members with less research experience?**

RECOMMENDATIONS:

- Hire and train TNB community members with an interest in research. Provide research training to community members early and often. CIRTification (https://ccts.uic.edu/tools/cirtification/) is human research protection training developed specifically for community partners in research which can be used as a teaching tool and can be used to meet the traditional requirement of Collaborative

Institutional Training Initiative (CITI) certification with IRB approval.

- Form meaningful connections with TNB communities by showing support outside the research project, such as financially supporting TNB community mutual aid, volunteering at local TNB events, collaborating with non-profit organizations that serve TNB communities, and attending pride events and protests to support TNB communities.
- Have exploratory conversations with TNB-led organizations in your area about their research interests, needs, and desires for intentional collaboration. Show your support and willingness to partner by paying TNB-led organizations to train the research team.
- Intentionally hire, train, and place TNB BIPOC researchers, consultants, and community members in leadership positions on the research team.
- Strip away unnecessary degree requirements in job descriptions and value lived experience/TNB community involvement during the hiring process.
- Continue to invest in TNB research team members after a project closes, providing opportunities for upward mobility. This demonstrates sustained partnership and true investment in TNB team members.
- Actively engage TNB community members and TNB partner organizations before writing grant proposals; this allows community members and partner organizations to be listed as investigators on the grant application.
- After forming your research team, collaboratively develop a structure for how the team will operate. For example, consider including information about communication (e.g., how will the team communicate and how often), decision-making processes, and systems of accountability.

STAGE 2: PLANNING THE RESEARCH

The planning stage of research builds on the foundation set during stage 1 and requires continued trust-building and transparent communication between all team members. All team members must think deeply about research priorities expressed by TNB communities. These priorities are used to collaboratively develop research that is aligned with community interests and leads to data/outcomes that can be used to improve TNB lives. This includes selecting a specific research question that reflects a priority area expressed by TNB communities, identifying, reviewing, and thinking critically about existing research done in this area, selecting an appropriate design and methodology, and developing tools or interventions. This stage of research also includes creating a plan for participant engagement, developing a consenting process, deciding how data will be collected and analyzed/interpreted, and considering how research results will be disseminated in accessible ways.

"For me, something that is important is how and where the research opportunity is advertised. If you only disseminate amongst like minded people, then you only end up with like minded people, and you're not actually reaching a larger audience or a larger segment of the population to get their experiences, thoughts, opinions…"

To accomplish this, teams are encouraged to consider the existing strengths of TNB communities, as well as the make-up and unique strengths of members within the partnership. Teams should consider the types of research expertise (e.g., qualitative, quantitative) and representation (e.g., gender, race, language, ability, gender identity) present within the partnership to guide decisions about what data will be collected and from whom. Representation and equity in who plans and does the research is important for research quality. Cisgender team members and stakeholders need to recognize and constantly evaluate their own power and privilge, intentionally creating space that centers TNB voices and includes TNB communities as true partners in all aspects of the planning process.

Research teams should implement a plan for ongoing skill and knowledge sharing to support team members in developing new skills and knowledge to contribute to the research in meaningful ways. Train cisgender researchers in affirmative care practices, TNB lived experiences, and identities. Train TNB community members with limited or no research experience in methodology and data analysis. This will enrich research design, produce more affirmative research practices, nuance data interpretation, and better contextualize findings.

Proactively strategize how to identify, manage, adapt, and/or avoid potential institutional barriers that might interrupt affirmative research practices (i.e., financial compensation systems that mandate use of legal name, registration paperwork with limited gender identity options, an IRB with less experienced reviewing research that includes TNB people, department timelines that do not allow for a Member Check-In). Plan for how research can include a community building component and how the TNB community can receive greater benefit than just individual compensation for participants. Intentional planning that blends the expertise of researchers and TNB stakeholders will lay the best groundwork for a meaningful and affirmative research study. It will also maximize intervention fidelity (rigorously following the intervention as developed) and the ability to follow standardized practices.

QUESTIONS TO CONSIDER:

1. **What structure can help everyone be involved in designing the study?**
2. **How do power and privilege (e.g., race, class, language, gender, gender identity) influence how the research is designed within the team?**
3. **How will you ensure that lived experience and research experience are equally valued when designing the study?**
4. **How will the research address gaps in existing knowledge or offer a unique approach?**
5. **How will the research be used to improve the lives of the TNB community participating in the research?**
6. **How will team members work collaboratively to develop a theoretical framework that puts research questions in the context of TNB lived experience?**
7. **How are you creating a participant recruitment and consent process that best meets the needs of TNB participants?**

RECOMMENDATIONS:

- Create a planning process that actively engages all research team members and that centers TNB voices. This may include how meeting agendas are set, use of icebreakers or relationship building questions at the beginning of meetings, relationship building retreats before planning begins, or the use of some meeting time for shared work.
- Consider having a TNB majority during meetings and when making important decisions.
- Be transparent and communicate about the research process, including systemic or institutional requirements and potential obstacles. Help stakeholders and research team members understand budget and regulatory constraints. This will help everyone understand how best to make the project work within the constraints that exist.
- Allocate time to support regular, ongoing meetings with all partners for check-ins and continued relationship building. In addition, create separate space for TNB team members and/or TNB stakeholders to meet. This offers important time for discussion and support in a TNB-only space. Concerns or suggestions that arise in that group can then be brought back to the larger team and partnership meetings.
- Support the different skills and capacities of team members by providing varying ways and multiple times for team members to contribute to the research planning, including brainstorming as a team, verbal feedback and written feedback. For example, when developing survey questions, consider hosting a couple of meetings for active brainstorming for team members who feel most comfortable generating new ideas in a group while also providing the opportunity to review drafted written materials for additional comments and revisions.

STAGE 3: DOING THE RESEARCH

This stage of research rests on the critical work that has been done during the foundation setting and planning stages. It includes participant recruitment, obtaining participant consent, engaging participants in the actual research, and collecting, analyzing and interpreting data.

After working closely with the research team, community members, and organizational stakeholders, the research plan can be submitted for review to an IRB. While excellent planning lays a great foundation, it is common for the research team to identify things that need to be revised or modified for participants' benefit or to improve the research after active recruitment and engagement has begun. For example, changes would need to be considered if some TNB participants find the consent form confusing or non-affirming, if participants are concerned about the way researchers plan to contact them to offer reminders about follow-up meetings, or if an unexpected potential harm is suspected. CBPR teams should proactively plan how they will consider such changes and how TNB community members and TNB stakeholder organizations are included in these discussions. Some types of research have extremely strict, mandated procedures when a potential issue is identified. However, whether quantitative, qualitative, or mixed methodology research, all research teams can proactively plan for the most affirmative, respectful, participant-informed way to address issues that arise and build that into the research plan they submit to the IRB for approval.

Participant recruitment and engagement are significantly improved by using a CBPR approach that actively includes TNB people in the planning and design. When conducting TNB health research, building trust and connection with participants is the foundation. Without that trust and connection, TNB participants will either ignore your recruitment efforts or participate with limited trust and skepticism. Listen carefully to feedback from TNB people to sculpt engagement and recruitment processes and materials. Gather and integrate feedback on how to adjust language, images, and recruitment pathways to most affirmatively communicate with potential participants. This will help participants have a positive experience with research from the beginning and will increase the number and type of TNB people who might choose to participate.

Be keenly aware of the burden it can place on TNB people when they use their personal networks and social media to share recruitment materials. By doing so, TNB people are vouching for the quality of the research and the respectfulness/affirmation TNB people can expect if they chose to participate. This is a very serious responsibility for the research team and the team should be well prepared to meet that expectation.

Shared participation in data analysis and interpretation by TNB community members, TNB organizational members, and other stakeholders requires proactive, level-setting preparation before data analysis can begin. Level-setting preparation

"...To explain what the project is about, why this data is important, and what the data actually means or could mean, and to encourage curiosity… because science is an art, in a lot of different ways, and data can mean what the researcher wants it to mean…to get down to the nitty-gritty of what the data actually is, the raw data, that takes a lot of skill. And I do think if you find those passionate folks within your research groups in the communities, they can ask those questions, they can relate it back to their experiences. And I think having that kind of exchange and input and that energy goes a long way."

includes shared learning for team members in CBPR practices, research methodology and techniques, research ethics, intersectionality, and data analysis procedures. Ensuring all team members have foundational knowledge about research and TNB communities is important for active participation of TNB community members and other stakeholders. Some TNB community members may not have formal or traditional experience in research; however, they are experts in their community and are able to interpret and understand data in ways cisgender people cannot.

One way to implement shared participation is to create a data analysis team that includes representatives from each stakeholder group. In order for all team members to understand the data analysis approach, provide training and mentorship. If you are analyzing qualitative data (i.e., interviews, transcripts, focus groups), train everyone to understand and organize such data. This can be accomplished by involving and mentoring team members in reviewing transcripts, writing memos, and coding.

If you are analyzing quantitative data (numbers and statistics), train and mentor everyone to understand the statistics you are using, the difference between causation (caused it) and correlation (related to it), and how the type/quality of data collected affects the statistical outcomes and the strength of the data. Locate community- focused data analysis training or create your own. Host regular meetings to discuss the data together. This will take significantly longer than the traditional practice of only having expert researchers analyze the data. Intentionally plan a longer data analysis/ interpretation phase to allow time for discussion and mentoring. While this process requires extra time, it is a core tenet in CBPR practice and will ultimately yield deeper, more nuanced, and more accurate data interpretation.

Another recommended practice frequently used in qualitative research is to host a Member Check-In meeting. The objective of this meeting is to allow research participants the opportunity to review provisional findings and to ensure that the research team is correctly representing the stories and experiences the participants shared. During the Member Check-In meeting, the research team can gather feedback on the interpretation of the data, explore limitations of the study, and discuss the

application of research results to TNB peoples' health care. Such meetings can contribute to a more refined data analysis and interpretation, and can help generate applicable and community-inspired clinical recommendations. They also ensure that the voices and priorities of TNB participants are accurately heard and understood. Provide compensation to participants attending the Member Check-In for their time and feedback.

QUESTIONS TO CONSIDER:

1. **How can all members of a research team feel empowered to review and interpret the data collaboratively?**
2. **What training resources does your research partnership have (internally or externally) to support team members who may have less experience working with data?**
3. **How do we make it meaningful for TNB people to participate in health research? How do we make sure TNB people, particularly TNB BIPOC, get real benefit from research?**
4. **How do power and privilege impact research during this stage? What are some ways to challenge that?**

RECOMMENDATIONS:

- Use trauma-informed and harm-reduction principles when conducting research. For example, set and share a clear agenda in advance for participant encounters (e.g., focus group, interview, intervention appointments) and research team meetings. This allows people to prepare themselves for the encounter or the meeting discussion for best self-care and productive contribution.
- Do not make assumptions about the technology access of research team members, community stakeholders and participants. To ensure access, provide or subsidize necessary technology; this may include video conferencing licenses (i.e., Zoom, WebEx), prepaid phones, wireless internet, mobile hotspots, access to research databases, and data analysis or statistical software packages or monthly memberships (i.e., SPSS, SAS, Dedoose, NVivo).
- Before sharing participant quotes in a qualitative research study, allow TNB participants to review the quote you would like to use. Provide participants the opportunity to redact and/or clarify any parts of the quote that feel too personal or misrepresent their meaning. This fosters community trust and may help participants feel safer in sharing intimate, personal experiences.
- Build in time for unexpected delays during data collection, analysis, and writing phases of the research project. Community members, clinicians, and organizational partners may have changing capacity and experience life events that may shift the time they can contribute to the research. Authentic partnership requires that a project's timeline is built to accommodate this flexibility, especially given how hard TNB people have to work to navigate oppressive systems and unequal access to resources.

- Virtual spaces can offer important accessibility for participants who may have difficulty attending in-person meetings because of transportation, disability, chronic illness, geographic distance, social discomfort, etc. Encourage participants, who are willing and able, to use chat functions in addition to audio. Enabling chat will allow you to hear voices that might not have been included otherwise. Download the chat and include it in the data analysis with the audio transcript.

STAGE 4: SHARING FINDINGS AND TAKING ACTION

This stage of research includes collaboration with all partners to disseminate research results in ways that are accessible and easily digestible for different groups, and to leverage findings to improve TNB people's lives in tangible ways. Engaging all research partners in the dissemination process can encourage the sharing of ideas and expand team members' understanding about how to communicate effectively with different stakeholders (Horowitz et al., 2009). Most traditional research models prioritize the dissemination of research findings in peer-review publications, at academic conferences, and in information sessions at universities and hospitals. This allows researchers to secure more funding, share findings within their academic field, and advance their careers. However, traditional research dissemination excludes most TNB people who are not in the field, are low income or do not have formal associations with universities and institutions. On the other hand, community-focused dissemination opens a dialogue between community members and members of the research team, which creates space for communities to share their desires for next steps around action and advocacy. Returning research results to communities actualizes accountability, can spur community mobilization, and facilitate further collaboration and engagement with the research team (Mosavel et al., 2019).

Key audiences for dissemination of findings include all research partners, participants of the research, TNB communities, clinicians, researchers, policy makers, and other stakeholders with power to impact change. An understanding of how different audiences may access and use the research is critical to ensure findings are tailored to be the most relevant, accessible, and digestible to each group. Effective dissemination involves providing information in ways that allow people to apply it to their own lives and the systems they are living in. For example, when sharing health research findings with TNB communities, it is important to recognize that many TNB community members educate themselves and rely on other TNB people for health information. In order to advocate for care, many TNB people use the internet to research best practices for gender-affirming care to guide their

"Re-engaging folks to show them the results–I can't even imagine. I'm just trying to think of all the times I did surveys for this and that...but have no idea what happened…'hey, your participation yielded these results and now we are going to take these results to this hospital…so they fix how they treat trans folks'... those are things that feel more engaging and more worth it to participate."

own health care decisions and bring in research articles to clinicians who lack a baseline knowledge. Having this context highlights the importance of ensuring TNB people are able to easily access research that clearly outlines key considerations when making health decisions, as well as the need to disseminate research findings to healthcare providers. To tailor findings for health care providers, consider sharing focused points around implementation and applications/ implications for practice.

QUESTIONS TO CONSIDER:

1. **How is your research connected to grassroots organizations and advocacy groups? How can your dissemination strategy strengthen those organizations and systems?**
2. **What is the impact you hope your research will have? Who needs access to the information to facilitate the intended impact?**
3. **What will help teams of researchers and non-researchers make a community presentation or write an article together?**
4. **How do we give everyone visible credit for the work they put into the research study?**
5. **When presenting the research findings in an academic conference, how can you incorporate TNB team members to present and lead the discussion?**

RECOMMENDATIONS:

- Expand traditional routes of dissemination to ensure findings are getting back to the TNB community in a variety of easily digestible ways (e.g., gallery walks, podcasts, social media, known personalities/influencers, workshops, "lunch and learns," public community events, town halls).
- Ensure findings are digestible for a range of audiences, taking into account your audiences' different abilities, languages, educational backgrounds, and familiarity/comfort with research jargon.

- Use research funding to support TNB community social events and other activities that could provide a space to disseminate research findings.
- Consider including TNB community generated content in presentations to personalize the messages (e.g., quotes, poems, artwork, music, recipes, images).
- For team members and partners with little experience in academia, provide ongoing training and mentorship on how to write a peer-reviewed publication and present at academic conferences. A listed publication or presentation builds resumes/CVs.
- Collaboratively develop authorship guidelines that acknowledge the varying contributions of all stakeholders. Make it a standard practice to review the guidelines and explicitly discuss authorship/credit as a team in advance of starting any writing projects.
- Develop approaches to disseminate results in ways that effectively transition research into advocacy and activism.

WHAT'S NEXT IN TNB HEALTH CBPR?

Research approaches in TNB health are constantly evolving. It is important to consider the ways TNB community-led research can grow, strengthen, and have a sustained impact. For example, learning how to integrate and apply mutual aid values and action can alter how research is designed, implemented, and ultimately used to influence public policy and TNB people's lives. Investing in TNB communities in ways that move beyond tokenism and promote positive growth could nourish meaningful connections and shape the future of research. Building mentorship models, nurturing sustainable networks, and creating job and educational opportunities for TNB people interested in research can create a next generation of TNB research leaders and authentic community partnerships.

The next wave of TNB health CBPR should include TNB mentorship models to reduce the divide between TNB community members and researchers, and move more research outside of universities and large institutions and into TNB-led organizations. It will be critical to support continued growth of sustainable networks of TNB researchers and TNB community organizations to foster connection, collaboration, and knowledge. Deliberate efforts are needed to expand the representation of diverse TNB communities involved in research (e.g., TNB youth and elders, gay and queer TNB people, TNB BIPOC, TNB people living with disabilities). In addition, when considering research questions, research teams are encouraged to consult existing lists of TNB community identified health research priorities. Two such lists are the Four Corners Health Research Priorities Among TNB Communities (https://howardbrown.org/wp-content/uploads/2021/03/FourCorners-HealthResearchPrioritiesAmongTNBCommunities_Final_3_21.pdf) and

"...how big of a difference it feels when someone's coming to save you versus when you're given the space to move in a way that offers you agency… trans-led community models [are] really important for communities... the next step would be moving towards agency and autonomy over the projects that are taking place versus people coming into your community and telling you what you need or simply just obtaining information."

the surgical Trans-ARC Prioritized Research Questions (https://files.cargocollective.com/c821244/TRANS-ARC-Prioritized-Research-Questions.pdf).

Advocacy efforts are needed to better align institutions and funders with CBPR values, and to ensure that research includes embedded structures to protect and empower TNB communities. For example, funders should heavily weigh whether a TNB health grant includes a PI that is TNB. If the PI is cisgender, funders should look for sustained and authentic collaboration with a TNB-led organization or with other TNB research leaders.

While IRBs are charged with protecting the rights of research participants, most IRBs do not include TNB members, do not have expertise in population specific needs of TNB people, and are not aware of what constitutes affirmative care and respectful communication. IRBs should recruit TNB people to join their boards and should receive training to understand the importance of equitable community-led TNB health research. In addition, IRBs are encouraged to seek consultation and support from TNB experts in the field and/or use the services of an independent TNB-led research review board that can offer guidance on the ethical and respectful treatment of TNB research participants.

TNB-led research has the ability to critically shift existing research paradigms while simultaneously leveraging power to change the very real lived economic and health circumstances of TNB communities.

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