

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

Four Corners: Health Research Priorities Among TNB Communities

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FOUR CORNERS
TNB HEALTH RESEARCH ADVISORY NETWORK

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INTRODUCTION

Transgender and nonbinary (TNB) people experience striking inequities in health and healthcare. In the United States, these inequities are amplified among TNB Black, Indigenous people of color (BIPOC) and TNB people with disabilities, highlighting the need for all TNB health equity initiatives to recognize racism, ableism, and other intersecting forms of oppression. Despite a recent increase in TNB health research, there is a lack of peer-reviewed literature that considers priority issues and accountable research practices from the perspectives of TNB people, and particularly TNB BIPOC and people with disabilities.

In 2018, four federally qualified health centers (FQHCs) specializing in LGBTQ care across the United States: Howard Brown Health in Chicago, Whitman-Walker Institute in the District of Columbia, Los Angeles LGBT Center in Los Angeles, and Legacy Community Health in Houston, partnered to form the Four Corners: TNB Health Research Advisory Network. Four Corners is a 16-member network consisting of one researcher, one clinician, and two TNB community members from each FQHC, all of which reside in a geographically distinct region and serve a highly diverse TNB patient panel. 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 equal partners in the research process.

OUR MISSION STATEMENT

We are a diverse network of healthcare providers, trans and gender nonbinary (TNB) community members, and researchers in the U.S. committed to participant-driven health research that is relevant, beneficial, and accessible to the TNB community.

METHODS

In the summer of 2019, Four Corners conducted eight focus groups, two in each city of participating sites, in order to explore health and research priorities, participants' prior experiences with research, and preferences for research dissemination. Focus groups were facilitated by two TNB project staff and included 65 participants, all of whom were at least eighteen years of age and self-identified as transgender, nonbinary, or gender nonconforming. Participants were recruited via flyers posted at the four FQHCs and social media advertisements. Focus groups were audio recorded and transcribed.

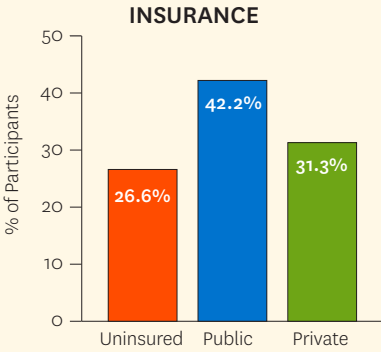
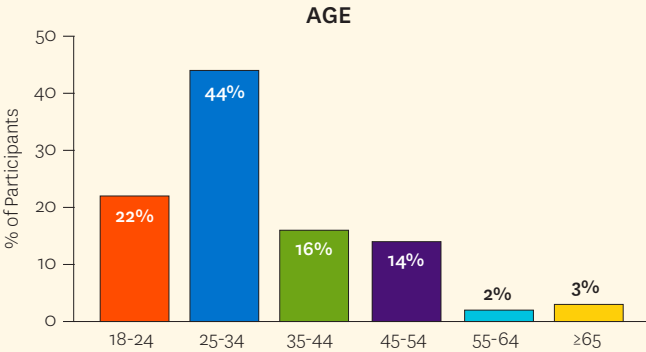
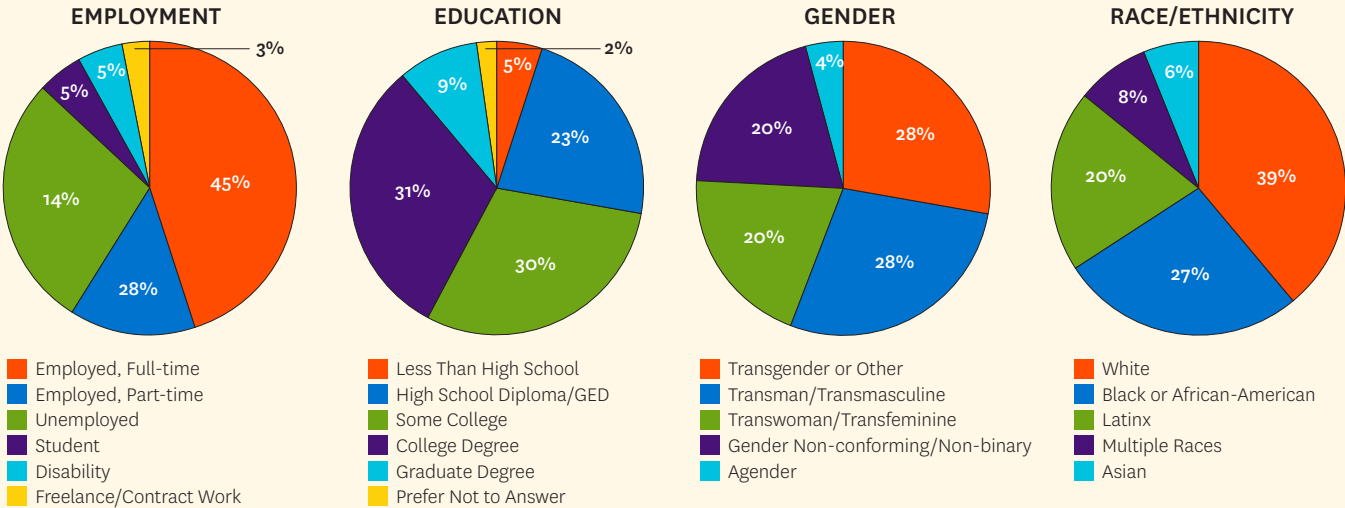
DATA ANALYSIS

Focus group data was analyzed using both inductive and deductive coding, or hybrid coding. Four Corners contracted with a qualitative analyst who developed a codebook based on themes derived from the focus group facilitation guide. The analyst coded the first four focus group transcripts using the a priori codebook and then revised the codebook based on new emerging themes. After new codes were identified and added to the codebook, all transcripts were re-reviewed for new themes. Once all coding was completed, the coded text was organized, reviewed, and analyzed to identify themes, select representative quotes, and develop a preliminary written report.

In alignment with the participatory and collaborative values of Four Corners, members of the network also reviewed the focus group transcripts. Site-based teams in Chicago, Houston, Los Angeles, and Washington, D.C. met to review and discuss the transcripts of the focus groups conducted in their respective regions. TNB Four Corners members met on a bi-weekly basis via Zoom and engaged in a participatory process of inductive analyses by identifying and discussing salient themes from the transcripts. Notes from both processes were used to revise the preliminary report and add nuance and context from the perspectives of TNB people, practitioners, and researchers. This revised draft was circulated to all network members for comments and members met to discuss and determine key findings and recommendations to include in the final report.

PARTICIPANT DEMOGRAPHICS

The focus group participants were diverse with respect to gender (20% transwomen/feminine, 28% transmen/masculine, 20% gender nonconforming/nonbinary, 5% agender, and 28% of participants identified as just trans or another gender under the trans umbrella). Participants were racially and ethnically diverse, about 27% were Black of African American, 20% were Latinx, 6% were Asian, 8% of participants reported multiple racial or ethnic identities, and 39% were White. Participants ranged in age from 18-69 with 22% of participants between the ages 18-24, 44% 25-34 years, 16% 35-44 years, 14% 45-54 years, and 5% were 55 years of age or older. In terms of formal education, 23% of participants completed high school, 30% attended some college, 31% had a college degree, and 9% had a graduate degree. More than a quarter of participants were uninsured (27%), 42% had public insurance and 31% had private insurance. More than a quarter were unemployed (28%) and less than half of participants were employed full-time (45%). Although we did not explicitly ask if participants were disabled or experienced chronic conditions (such as pain, depression, HIV), many participants talked about having a disability or described chronic conditions during the focus group discussions.



FRAMING HEALTH: CONTEXT FOR TNB HEALTH RESEARCH

“For me, somebody that lives with a disability, multiple disabilities, health means for me just having unobstructed access to what can help you live better.”

– D.C. Participant

A key goal of this study was to identify common research priorities among TNB participants. Each focus group opened with a general question about the meaning of health in the lives of the participants. As a result of this discussion, our study findings illuminate a need for broader constructs of “health” than are typically recognized within dominant approaches to TNB health research and healthcare provision. This includes more holistic definitions of positive health outcomes and greater integration of social determinants of health frameworks that incorporate multiple systems of oppression (e.g., racism, poverty, disability, etc.).

Many focus group participants discussed their desire for more health information or knowledge. They also identified areas they felt that their healthcare providers lacked knowledge or skills, and the resulting inequities in access to care. In this section, we integrate a discussion of the frameworks of health that were frequent and salient, with attention to presenting diverse perspectives.

HOLISTIC DEFINITIONS OF HEALTH & WELL-BEING

Across all four cities, participants voiced an emphatic desire for TNB health and people to be viewed holistically. Participants shared personal definitions of health that encompassed physical, psychological, spiritual, and social aspects of health and well-being, with mental and emotional well-being particularly emphasized. Participants drew links between mental and physical health, reflecting on points in their life when they were under too much emotional stress to take care of their physical health or describing how poor mental health had manifested into physical health conditions. A participant in Chicago described their own integrated understanding of health:

“For me, ‘healthy’ is mental, spiritual, and physical. I think all three of those points play a big part in how you interact with people and what happens in your day-to-day activities. When you can think clearly, you can operate easier. When you take care of your body, your body’ll move easier. And when your spirit is clear, I think you can interpret things differently.... For me, definitely the mental and emotional – if that’s off balance with me, everything else is going to go downhill.”

– Chicago Participant

Many participants with disabilities or chronic conditions critiqued dominant concepts of “healthy” as overly defined by one’s capacity for work or labor productivity. In resisting such formulations of health, some spoke of a need to reclaim a sense of self-worth in alternative terms. Other participants similarly described the process of asserting one’s own definitions of health as an act of empowerment. This included reframing the concept of “good health” in terms that are relative to each individual, and reflect the aims of living a full and meaningful life. As a participant in Houston explained:

“As a person who is disabled, who’s not able to work or not able to do school, I haven’t been able to meaningfully produce in a capitalistic society...If health is defined as the ability to work for, to be able to go to school and do things like that, then that leaves me kind of shit-out-of-luck. Because I’m at a place where I’m not able to do that...But that doesn’t mean that I’m not healthy or doing okay, because I am, relative for me, doing pretty alright. So, I think health needs to be defined more along the lines of, being healthy is being in a place where you are comfortable with how your mind and body works.”

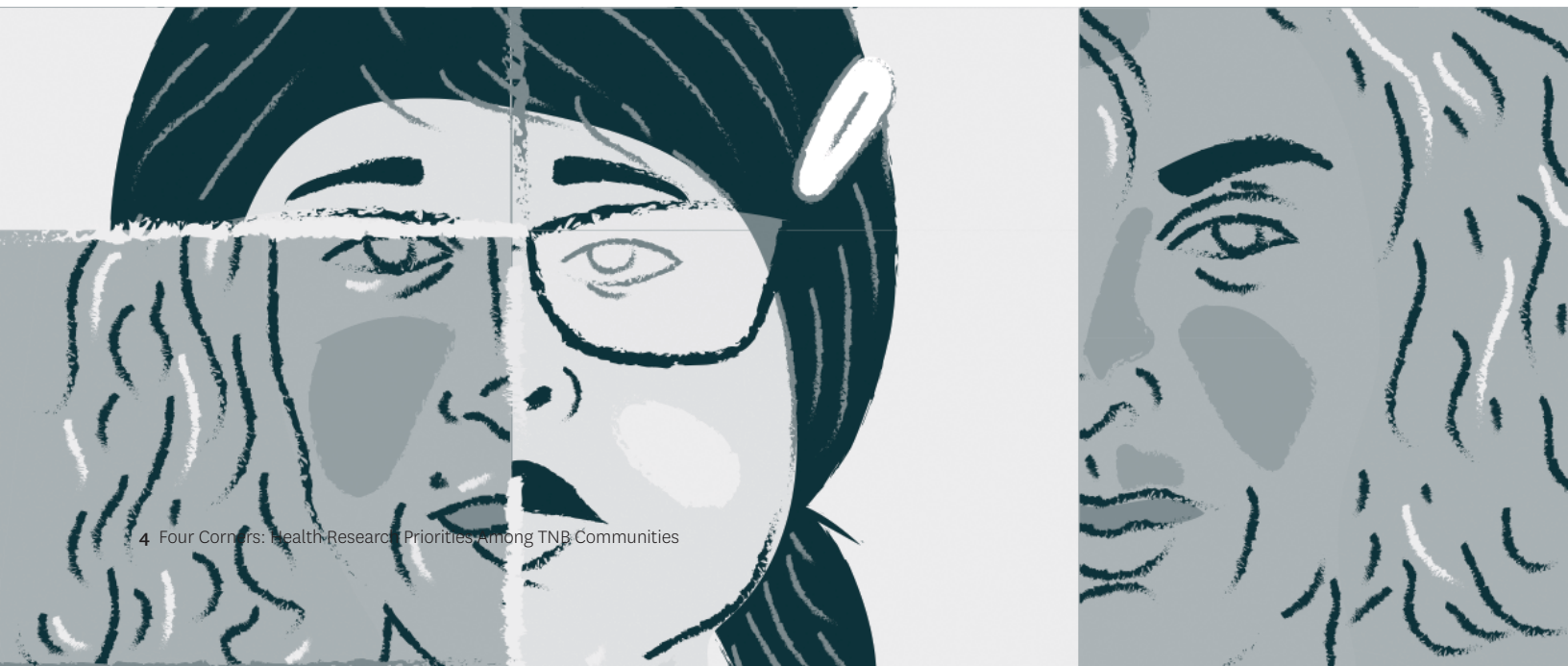
– *Houston Participant*

This holistic view of health and well-being was juxtaposed, at times, to a perception that researchers studying transgender health were all focused on the same topics. Participants criticized the overemphasis on sexual behavioral and suicidality and expressed desire for researchers to be intentional about considering the “whole person” and expanding research topics beyond HIV, sex work, and suicidality. Some participants felt that studies flattened the experiences of TNB people, and cautioned against treating TNB people as a monolithic group. As a participant in D.C. argued:

“Research doesn’t consider the intersections of health needs when it comes to trans people enough. Most research that I have been part of, or seen, or read, that has to do with transgender health, always assumes that people are trans first ... other aspects of their identity and their life might affect their health needs more, and a lot of research is like yes, that’s true, and that’s part of your experience, but let’s focus and isolate this part of your identity, and talk about your needs as that identity, as though they can’t be separated.”

– *D.C. Participant*

In illustrating a desire for more holistic approaches to health research, many participants stressed the importance of grappling with the diversity of healthcare needs among TNB people and the interaction between gender-affirming care and other forms of healthcare provision. Participants also discussed the social context in which TNB people grow up and live, including the impacts of social stigma on one’s ability to meet basic material needs while living at the intersection of multiple systems of oppression.



INTERSECTING FORMS OF OPPRESSION & SOCIAL DETERMINANTS OF HEALTH

“When I think about health I think of like environment, and how that contributes, or directly impacts my health... In a healthy environment I can practice my agency, my self-determination. I can express myself freely without any fear.”
- L.A. Participant

In generating discussion around holistic definitions of health, many participants reflected on the negative health impacts of transphobia, classism, racism, and ableism on their own health and well-being. Participants discussed direct experiences of violence and discrimination, such as being harassed in public spaces, isolated and disowned by family members, misgendered, homeless, and/or incarcerated. Participants characterized exposures to transphobia as forms of trauma that affected their ability to maintain their mental health and wellbeing. One participant made a direct link between the experiences of growing up in a transphobic culture and struggling to maintain mental health:

“Most of my mental stuff came from growing up as a trans kid. – but not because I’m trans. It’s because of the way people treat you because you’re trans.”
- Houston Participant

Participants further illustrated the ways in which transphobia shaped unequal access to resources, and consequently their health. Across all the focus groups, participants described challenges they faced with employment, financial access, stable housing, transportation, and food security. Several participants highlighted the significant role economic stability played in their overall health and well-being, as it influenced their ability to access healthcare and take care of their immediate needs. As one participant in Los Angeles shared:

“Yeah, like I just got housed, and so like my mental health is now to the point that somebody yelled at me on the bus yesterday and it was all right. It was fine. I like, went home, and then I got up, and I ate breakfast because I had a cupboard and food in it. I’m still recovering from like the – every morning the food – I’m like, I’m not going to have food ever again. So it’s the consistency – okay, Maslow’s Hierarchy, do you have your basic needs met? And the answer for our community is kind of a resounding no. Do you have stable housing, or are we constantly under the fear of, whoever we’re living off of, who can hold a normal job, deciding to kick us out.”
- L.A. Participant

Participants frequently discussed the ways in which lack of financial resources hindered or prevented their ability to access health resources or participate in community advocacy, including health research. Many participants described health as a “privilege” for the privileged, because without stable financial resources, many TNB people are forced to choose between their health and other basic needs.

“You have to make some really tough choices in what you need, what you think you’re going to need. Do I need a car, or do I need my medicine, or do I need housing, or do I need this? You have to make choices instead of – because of accessibility, money, because we’re generally poorer than everyone else is.”
-L.A. Participant

BARRIERS & ACCESS TO QUALITY HEALTHCARE

“Healthcare to me is a fight.”

– L.A. Participant

Participants articulated their needs for holistic, affirming, affordable, and accessible healthcare with knowledgeable providers. The majority of barriers to accessing healthcare services were directly linked to lack of income, stable housing, and transportation. Participants described the scarcity of gender-affirming care outside of major metropolitan areas. Still, even in the four major cities (Chicago, LA, Houston, and D.C.) where LGBT and trans-specific services exist, many cited ongoing institutional barriers, including cost and challenges with health insurers. For example, one participant described being on the phone with their insurer “three hours a day” trying to access insurance coverage for surgery.

Transphobia is another institutional barrier that often compounds existing barriers for TNB people in seeking out healthcare. Participants’ shared experiences of overt discrimination with a range of healthcare workers (e.g., medical providers, frontline staff, nurses, and pharmacists) and blatant disregard across the continuum of healthcare delivery. For example, one Los Angeles participant described:

“I came in here for a female check-up, and two doctors were throwing the ball at each other, like, ‘I don’t wanna do it’. It’s already hard enough for me to do this check-up, to come up here and do it. I wish I didn’t have to do it, period. And then I got two doctors throwing the ball. I no longer get my healthcare here.”

– L.A. Participant

Misgendering was a common experience that participants described as ranging from careless inattention to antagonistic. Misgendering contributed to participants’ decisions about whether or not to seek healthcare and raised significant safety concerns in some instances. As one participant shared:

“When I went to CVS before, I would always go up and they’re ‘Excuse me, ma’am. I have your testosterone.’ And everyone kind of looks at me [...] and that could put me in danger walking around downtown, all these people know now.”

– Houston Participant

While explicit discrimination and misgendering are overt ways TNB communities face barriers to care, provider’s lack of knowledge is another way inequities materialize for TNB people in healthcare. Even participants connected to medical providers specializing in trans healthcare, reported receiving misinformation or lacked confidence in their provider’s knowledge. As a participant in Los Angeles explained:

“I feel like doctors specializing in trans care should also be better informed than what they are now. Just to name an example, my endocrinologist, when I first started hormones he said that pills worked just as good as shots. That’s not true.”

– L.A. Participant

Across all focus groups, participants’ suggested increasing the number of TNB people working in healthcare as one step in mitigating this problem. Yet as one participant from Los Angeles described, building trust in healthcare systems requires more than representation, it requires an acknowledgement of the history of abuses and systemic failures in adequately caring for TNB people.

“It’s nice to have a transgender doctor... but it feels kind of like a sad band-aid for a system that’s failed us pretty consistently since forever, when it really wasn’t that long ago that there were these same Western doctors... were doing forced sterilization of queer people... That whole apparatus is something that’s been really harmful, and I don’t think it’s something we should trust.”

– L.A. Participant

Participants also pointed to structural racism, emphasizing the unequal distribution of resources and lack of investment in LGBT communities of color, as a barrier to quality healthcare and knowledgeable providers. For example, two participants in Chicago shared:

“From my own experience, the Southside but also the Westside doesn’t have the resources, doesn’t have the community cohesion that the Northside has [...] because the old town there, that’s where the big egg is...”
– *Chicago Participant*

“. . . I went to a hospital for a blood pressure issue. I’ve never had issues with my blood pressure before. However, when I go here, they automatically see a black man. And then when they find out that I’m transgender, they don’t ask what medications I’m already on to see if whatever they’re gonna give me is gonna interact. They just completely ignore that whole part and I’m treated as a second-class citizen, literally. And this is even here in Chicago.”
– *Chicago Participant*

As such, participants underscored the need for researchers to take account of intersecting forms of inequity when developing health equity studies and solutions. The unequal geographic distribution of LGBT-specific services and resources was also implicated in the broader connections participants made between community connectedness and health and well-being.

THE IMPORTANCE OF COMMUNITY CONNECTEDNESS

“I refuse to let society, anyone, dictate how I should feel, think, or who I am, you know? We are resilient as human beings. We’re incredibly resilient.... We constantly go through life like we need to be validated and we don’t.”
– *D.C. Participant*

Participants described the importance of feeling connected and drew direct links between community building and TNB health and well-being. Many participants spoke of isolation as both a coping strategy and a source of stress. Participants described self-isolating as a reprieve from transphobia experienced in the workplace, in public places, and by families of origin and in other important relationships. As one Houston participant explained, being “a bit of a recluse” was often preferable to risking negative attention:

“I worry about, oh, if I’m meeting all these new people, should I tell them? Are they gonna believe me?... You want to feel safe, and so voluntarily putting yourself in potentially unsafe situations, to me, just the cost-benefit of it, a lot of the times, it weighs in favor of staying in.”
– *Houston Participant*

While alienation from families of origin was a source of stress, some participants talked about ending unsupportive relationships as producing a sense of freedom and autonomy. As one Los Angeles participant shared:

“My parents disowned me like almost 10 years ago, and I transitioned this year, so I have no one to answer to, so all that’s left is the future, so I just focus on that and keep going.”

– L.A. Participant

Some participants expressed desire for more social connectedness and named their relationships with other TNB people as a powerful support system, both socially and materially. Participants in Los Angeles talked about their desire for mentorship, direct advice, and guidance. Participants in Houston described the focus group as a welcome opportunity to connect with other TNB people. Participants illuminated the creative and diverse ways they cared for themselves and others, as well as the ways in which their communities care for them. A participant in Chicago commented:

“I feel like as a community we’re not only resilient, but also we’re really – we have each other’s backs, and like the same \$10,000.00 has been passed around from person to person for the past infinite amount of money because one of us needs surgery. Or one of us has been to the hospital and we can’t pay our bills – we shouldn’t have to, but we do. We take care of each other.”

– Chicago Participant

Participants described the dynamic ways they built support systems, and the necessity of these support systems to their personal health and health of their communities. Some spoke to the value of intergenerational relationships. For example, one participant who organized within the D.C. ball scene, shared:

“I’m a big name in the community with the young’uns, and what I do is throw balls. It’s a way to connect to them, and show artistic abilities, and a lot of times you help incorporate life learning skills.”

– D.C. Participant

This participant went on to make direct connections between community building and access to healthcare in describing how ball organizers made efforts to incentivize free HIV testing at events. Others described how community relationships were important for gaining health knowledge and resources, including information and service referrals for gender-affirming medicine.



COMMUNITY-IDENTIFIED RESEARCH PRIORITIES

“You probably already know this, but we need research on the drugs that we take for years and years and years and to follow us through the years that we’re taking it. So that at least we know for the next generation what happened to us.”

– D.C. Participant

GENDER-AFFIRMING MEDICINE & HEALTH OUTCOMES

Across all cities and focus groups, participants discussed the importance of long-term research on gender-affirming hormone therapies (also referred to by participants as hormone replacement therapy or HRT). Many felt that there were too many “unknowns” about the effects of taking synthetic hormones and shared concerns about the interactive effects with other kinds of medications, chronic conditions, and/or disabilities. Some participants’ voiced their concerns and assumptions about potentially negative or life-shortening outcomes. As one participant in Houston explained:

“I’ve been taking hormones for over two decades now and I have no idea how – I know there’s some side effects and stuff but is there anything else?... Because I’m always going to have to take hormones, I don’t know that there’s much information out there as far as what the long-term effects are.”

– *Houston Participant*

As participants described the lack of information and unknowns, they touched on some collective anxieties and frustration. Participants provided examples from their own personal health histories and shared some of their outstanding unanswered questions. For example, a participant in Houston spoke about experiencing incontinence after starting hormone therapy and the lack of clear answers from healthcare providers. Another participant in Los Angeles spoke about their decision to discontinue hormone therapy and the absence of research that could inform them on what to expect:

“There’s not enough data out there to tell me, as a transman who stopped taking hormones, what are the consequences? ...What is happening inside? ...Have there been studies done? ... There’s just so much unknown.”

– *L.A. Participant*

Many participants talked about conducting their own research to find information and studies related to the effects of hormone therapy, interactive effects, and administration methods. Some reached dead-ends or were told by providers that there “is no research” when asking about specific impacts. A participant in Chicago explained their frustration in learning that many of the existing studies related to hormone therapies have not been conducted with TNB people in mind. They said:

“There’s a huge hole, and tiny bits of research that are out there get thrown in all different directions, used in ways that don’t make sense. Like the one that’s getting one of my partners is the very limited research on estrogen, and its forms that it’s delivered with topically...all of the other methods are a lot more expensive for her, and yet there’s not actually a lot of research to that point, because I understand the only research to that point was cis women doing HRT post-menopause, and that’s a very specific case.”

– *Chicago Participant*

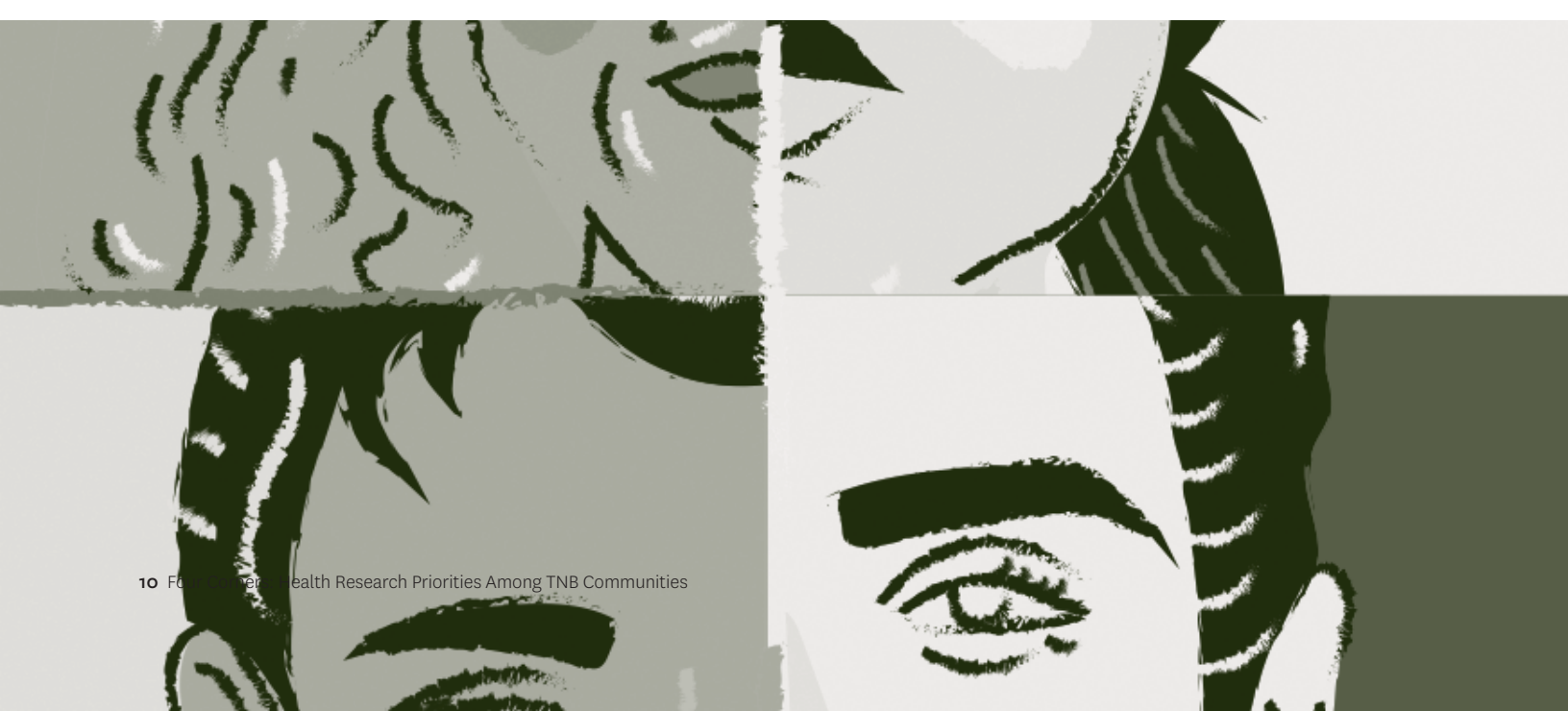
The feeling that there is a “huge hole” in research influenced participants’ health-related decision-making, including whether or not to initiate or continue gender-affirming hormone therapy. Participants raised concerns about the possibility of hormone therapy negatively interacting with other medications or worsening existing health conditions, such as high blood pressure, high cholesterol, or other pre-existing heart problems. They spoke of experiences weighing risks and potential benefits. For example, a participant in Chicago shared:

“A lot of people with epilepsy can be affected by hormonal changes so I had no idea going into HRT, whether or not it would affect my seizures at all, I just had to go well, I hope it doesn’t make me have more seizures. And no one would give me that information cause the research just wasn’t there.”

– *Chicago Participant*

There was some discussion about gender-affirming surgeries; however, this was less of a focus. A few participants expressed frustration at the lack of accessible information around surgery and surgical decision-making, such as genital reconstruction outcomes for transmen and surgical options for “people who want to end up more gender-queer, non-binary, androgynous.” Participants also highlighted the cost barriers to access gender-affirming surgical care, particularly for young people.

The Four Corner’s Network also authored a version of this report specifically developed for TNB community members. The Health Research Priorities Among TNB Communities Report, Community Report can be accessed at howardbrown.org/FourCornersCommunityReport21



REPRODUCTIVE HEALTH, FERTILITY, & FAMILY PLANNING

“And there’s no real research on like, how far into HRT, will you not be able to have children? Or, like, what kinds, there doesn’t seem to be to me any, anything about this... and that’s something to me that is important in my healthcare, is, I’d like a little bit more than that might happen and good luck.”

– *Houston Participant*

In the majority of the focus groups, participants discussed barriers to accessing reproductive health information and expressed the need for TNB inclusion in reproductive rights conversations and research. Lack of provider explanation around family planning/ pregnancy options was a concern for the TNB community, along with the financial barriers to sperm banking and adoption.

Participants commented on the lack of research on HRT and reproductive health. Topics such as hormone interactions with fertility, family planning options, polycystic ovarian syndrome, endometriosis, cervical cancer, and the lack of research on transwomen’s experiences with breast cancer were related concerns. For example, participants wanted to know how HRT dosage affects sperm production and the ability to have a child for transwomen. Participants also explained the need for more information about the impacts of testosterone, pregnancy, and conception.

“...I’m very concerned about is trans masculine access to birth control and knowledge that like that yeah, you can get pregnant while taking T, because some people don’t know that, and that really worries me, because then they may not be taking those precautions to not get pregnant.”

– *Chicago Participant*

Overall, access to reproductive health information is needed in order for the TNB community to make informed decisions about their healthcare and reproductive lives.

NONBINARY-SPECIFIC RESEARCH

“So I’m wondering, okay, what about nonbinary people? What are they compared to? I think there’s a lot of research on binary cis people and not a whole lot of research on people outside of that binary.”

– *Houston Participant*

Across all focus groups, participants mentioned the need for nonbinary-specific research. Some participants voiced concern for “being thrown under the umbrella with transmen and transwomen”, and others described frustration from feeling absent from research altogether. As one Houston participant stated, “... we, are not on the fringe, but we exist, and we have actual experiences that need to be addressed.” For example, one participant wanted to learn more about surgeries and/or procedures that would facilitate gender affirmation for gender nonconforming and nonbinary people.

OTHER PRIORITIES

Although there was a heavy emphasis on the need for research on hormone therapy, participants also discussed the following research topics, but not to a point of saturation: wrongful incarceration, domestic violence, trans people in the workplace, trans people with disabilities/chronic illness, the impact of childhood trauma, healthy relationships, long-term effects of PrEP, and substance use. In addition, some participants emphasized the need for intentional inclusion of TNB people in research that is not trans-specific.

DIRECTIONS FOR ETHICAL & MEANINGFUL RESEARCH ON TNB HEALTH

“I think all research is inherently political...there are so many research studies, and flyers that everyone has seen, like wow, that’s really terrible language, or I don’t agree with the way they’re formulating this research question, or this or that. And I think involving more trans people in the formation process of research would start to change the curve on that.”

– D.C. Participant

In addition to how participants defined health and what research community wanted to see prioritized, participants were asked about their overall impressions of TNB health research, what factors would make participating in research more accessible, and their preferences for receiving health and research information. Participant responses to these prompts revealed values and preferences for engaging in research studies. Participants drew on their lived experience, including previous research participation on issues related to TNB health and more general research studies, as well as previous encounters with the healthcare system. The section below consists of participant feedback and recommendations relevant to research ethics and practices, including proposed solutions to some of the emergent problems or barriers.

THE NEED FOR DIVERSE TNB LEADERSHIP IN RESEARCH

One of the most widely discussed values was having TNB people engaged in research. Many participants thought that research participation would be more relevant and safe if more trans people were engaged. Participants said they would like to see more TNB people in leadership roles, working as researchers, facilitators, healthcare providers, and researcher staff. Some participants emphasized the importance of working with advisory boards made up of diverse trans folks during the formation of research questions and research processes. Some felt TNB researchers would not only better understand the experiences of participants, but be more likely to translate research into improving the lives of trans people. As one participant in Los Angeles explained.

“I’d feel more comfortable... being around [TNB] researchers, because they’re more sensitive to what’s going on, and they’re going to be more likely to understand you better, and want to help you genuinely.”

– L.A. Participant

Participants recognized a need for intentional investment in TNB communities, including education and professional development to support more TNB people pursuing leadership roles in health and research-related fields.

“As a trans person who wants to go into academia and who is on that pathway now, there’s so many institutional barriers to that, it’s hard to just say, oh, trans people, do research. You can perform research, but if you need an institutional review board, you need sponsored by a university. You need this and that funding. There becomes so many barriers that only the same people that have always been doing research are able to do it or are able to do research that’s recognized as valid.”

– *D.C. Participant*

In alignment with the desire for more holistic healthcare and research that addresses multiple systems of oppression, participants expressed the value and importance of having a multitude of perspectives on research teams that involve TNB people. As one Houston participant explained:

“My certain experiences might have never even been considered. So by having a diverse research team that can think outside of other people’s boxes, it can make the questions that are asked more accessible, it can make the information that’s gathered more accessible as well.”

– *Houston Participant*

Increasing the diversity of research teams was viewed as imperative to meaningful and accessible research on TNB health. For participants, this meant being attentive to the representation of gender experiences, racial and ethnic diversity, neurodiversity, and the inclusion of those that might be perceived as “fringe voices.”

VISIBILITY & COMMUNITY BENEFIT

“We’re so eager to participate because we want something for the younger generations.”

– *Chicago Participant*

Although many participants expressed skepticism regarding the intention of some research(ers), many also expressed a real value for research that leads to meaningful knowledge or action. For instance, one participant expressed the need for research “to turn into solutions, not just statistics” while another commented on how their participation feels important due to the many unknowns in TNB health research. Another frequently discussed reason for research participation was visibility and legitimacy. Several participants saw research as an opportunity to be represented, and externally legitimized – less for themselves and more for the education of others and improvement of healthcare overall:

“Research equals visibility. Like if someone tells me non-binary’s not a thing, they/them isn’t a pronoun you can use, and I can pull up a fucking spreadsheet that’s like, “Okay, this percentage of people use it; this is where it is in the world; here are the demographics,” to someone who’s old, white, and conservative, and I pull that up, that’s visibility. That’s legitimacy to them.”

– *Chicago Participant*

On the other hand, some participants described gender assumptions and a binary view of gender as a barrier towards participation. As one participant articulated:

“I just wanted to add that I’ve seen research where we’ve had to accept data when they lump MSMs [men who have sex with men] with transwomen, oftentimes from behavioral health and sexual health data. Transmen aren’t even present in the data because the numbers are so low, or transmen are still being reported otherwise, if at all. So that’s one of the biggest things around research, around this community, is that I see that transmen and transwomen aren’t being reported or counted, or captured as themselves.”

– D.C. Participant

TRUST, TRANSPARENCY, & ACCESSIBILITY

“I think just knowing who is doing the research, and who’s funding it, and are we, as the participants, going to be able to have access to the results? How is this going to affect our community?”

– Chicago Participant

Participants expressed feelings of distrust around the purpose, quality, and results of TNB research. Some described racialized histories of medical exploitation with participants referencing the Tuskegee syphilis experiment, while others decried “Big Pharma” and referenced PrEP, with concerns about the exploitation of TNB communities. For example, one participant questioned the benefits of spending financial resources on TNB research:

“I would much rather see that money being spent on actually getting us F-ing jobs, or actually fulfilling the incredible amount of mental health need that we have, that there’s no way that we can fulfill.”

– D.C. Participant

Lack of researcher communication, from recruitment to dissemination, was identified as a barrier to research engagement by participants across all four cities. For instance, participants discussed the weight of how researchers inform the community about potential research projects as an important consideration for research engagement and provided recommended modes of communication for how researchers can better communicate about their projects that focus on TNB communities. For example, in terms of recruitment, participants’ suggested developing a research email listserv, coordinating with other community organizations, using bus, bench, and billboard ads, as well as social media, including Twitter and Instagram. Participants also emphasized the importance of hiring TNB community members to advise and assist in the research process:

“The best people to reach us are us, so getting access – I would say getting access to networks of trans people, but not in a transactional way, like they’re not just there to be your guinea pigs to find more trans people to bring to you. Like having a collaborative setting where they’re able to give feedback on research and feel like they have more than just a subject role.”

– D.C. Participant

Many participants who had previously engaged in research had not received any follow-up from researchers regarding study results or final analysis. Participants expressed frustration with this lack of follow-up from researchers after participating in studies, as it reinforces the power dynamic between researchers and participants and contributes to general feelings of distrust. Without efforts to reach out to study participants to relay relevant findings, participants question researchers' intentions and can feel exploited in a research system designed to advance the researchers' career.

“I think what would make it more appealing for me is seeing the results, but not just seeing them in a Facebook post, or a National Geographic post, or a hospital post. Being contacted as I'm contacted to participate in it, I would like to see somebody at the end of the research say to me, “Remember that research you participated? This is what came about. This is what happened afterwards.”

– *Houston Participant*

Participants were asked both how they currently received health and research information and about the ways in which they wanted to receive health and research information. Responses illuminated the need for tangible outcomes and resources in direct response to research findings. Many participants expressed the desire to be contacted directly with results of the study. Other participants wanted a single website that would include relevant TNB research, including opinion pieces, stories and different perspectives. Another suggestion included creating pamphlets with up-to-date TNB research findings to have available for patients in the clinic waiting rooms. One of the most innovative recommendations was the development of a secure app or digital platform that community members could log into to learn more about TNB-specific research participation opportunities and accessible up-to-date research findings.

Moreover, participants described the need for greater access to research. Those who had engaged more directly with research recommended peer-review publications be made accessible to a broader, non-academic audience.

“...I believe that better greater transparency with accredited research with peer review research, having that transparency and making it accessible for the common person rather than having to pay the \$30 to the publisher, rather than to the person actually conducting the research that would benefit people, because now instead of the professors who want to make their students read the research, it will be accessible to people it's actually affecting...”

– *Houston Participant*

Other participants were not necessarily interested in dissecting the research jargon in academic articles, but wanted materials that summarized findings and were easy to read and more accessible to a wider range of audiences. Participants also emphasized the importance of making participation in active research studies accessible. Participants noted that travel assistance and compensation for their time would facilitate their participation in research. One participant in L.A. said:

“It also shows that they value our voices and our time, and that we're worthy of compensation, that what we're saying is important. So having that incentivized thing – I feel like it adds value in a form of respect. They're respecting what you have to say and your time, by knowing it's a hard thing to be able to talk about this stuff sometimes. It's not always fun, even though it's really great to be in a room with trans people.”

– *L.A. Participant*

Overall, participants discussed the importance of utilizing research for purposes of empowerment, rather than embarrassment or harm. Researchers must be responsive to community recommendations in order to begin repairing relationships with TNB communities.

LIMITATIONS

This was an exploratory study primarily designed to direct the research priorities and practices of the Four Corners: TNB Health Research Advisory Network. Participants were primarily recruited by the four participating FQHCs of Four Corners, all of which cater to LGBTQ communities. As such, we recognize this as a limitation knowing many TNB people do not receive primary care services at an LGBTQ-specific FQHC or are not engaged in primary care. Furthermore, there is a need for research that addresses the intersections of racism that Black, Indigenous, transgender people of color face. Four Corners will aim to conduct research that empowers and furthers knowledge in these communities.

Additionally, focus groups were conducted in English (with American Sign Language (ASL) interpretation upon request); thus, non-English speaking TNB people were excluded. The Four Corners team is in pursuit of funding to conduct focus groups in Spanish in order to augment this study and call attention to the need for language access in research aiming to represent diverse TNB people and communities.

RESEARCHER RECOMMENDATIONS

This study was primarily conducted to provide insight and guidance for the Four Corners: TNB Health Research Advisory Network, and other interested researchers, who are pursuing health research by and for TNB people.

Recommendations from this report include utilizing approaches to research that not only engage, but build capacity and invest in TNB communities. Researchers must be intentional about building relationships with TNB communities and working with TNB people throughout all stages of the research, from development of an idea to dissemination of the results. Researchers should seek to partner with existing trans-led organizations or groups with strong TNB leadership in order to ensure research goals are aligned with existing calls for action and that TNB communities can best benefit from the research agenda. That is, research must be meaningful and of interest to TNB communities with the ultimate goal of promoting equity and social justice for TNB people.

Researchers must also work to resist pressures of “fundability” that circumscribe existing research on TNB people, including writing proposals and advocating to funders to develop resources for community-engaged research practices and to fund health issues identified by and for TNB people. Further, all research fund proposals should adequately compensate community members for their time, expertise, and emotional labor in addition to provision of stipends for transportation.

More holistic approaches to health research that consider intersections of identities are needed. Future research should seek to engage multiple aspects of health and well-being. If research is disease-specific or population-focused, it should intentionally examine multiple mental, physical, spiritual, social, and other related factors while also accounting for structures and systems of power and oppression. Moreover, intentional efforts to understand and deconstruct the inherent power dynamics and inequities between TNB people and researchers is needed, especially if the researchers are not TNB. Future research should build on existing analytic frameworks and theories that examine the root causes of health inequities.

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DISCLAIMER: All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

FOUR CORNERS NEXT STEPS

As the Four Corners Network, we plan to continue our investment in building capacity for TNB people to conduct health research and strengthen the relationships of our 16-member network. This includes soliciting resources to increase member's paid monthly time commitments, creating communities of care through hosting social events, forming smaller mentorship teams by research interest for more hands-on and relevant research training, and developing emergency funds for members who are experiencing acute crises such as loss of housing, food insecurity, or unexpected medical costs. We have applied for additional funding to invest in ongoing and meaningful opportunities for TNB people involved in community engaged health research to convene, build networks, access training, and share skills, findings, and strategies. We have also applied for funding to conduct thorough reviews of existing health literature, including scientific and academic publications, as well as community-developed resources and literature by and for TNB people, in each of the above community-identified priority areas. Through this work, we will engage TNB people in appraising the quality and limitations of existing research, as well as translate existing high-impact research findings into accessible materials for providers and TNB communities. Further, we plan to develop a TNB-led community ethical review board to work in collaboration with each of the Four Corners participating FQHCs, and other interested researchers, to review, support, and guide researchers in ethical and meaningful research on TNB health.

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FOUR CORNERS

TNB HEALTH RESEARCH ADVISORY NETWORK

