

Four Corners: Health Research Priorities Among TNB Communities

Community Report

FEBRUARY 2021



FOUR CORNERS
TNB HEALTH RESEARCH ADVISORY NETWORK



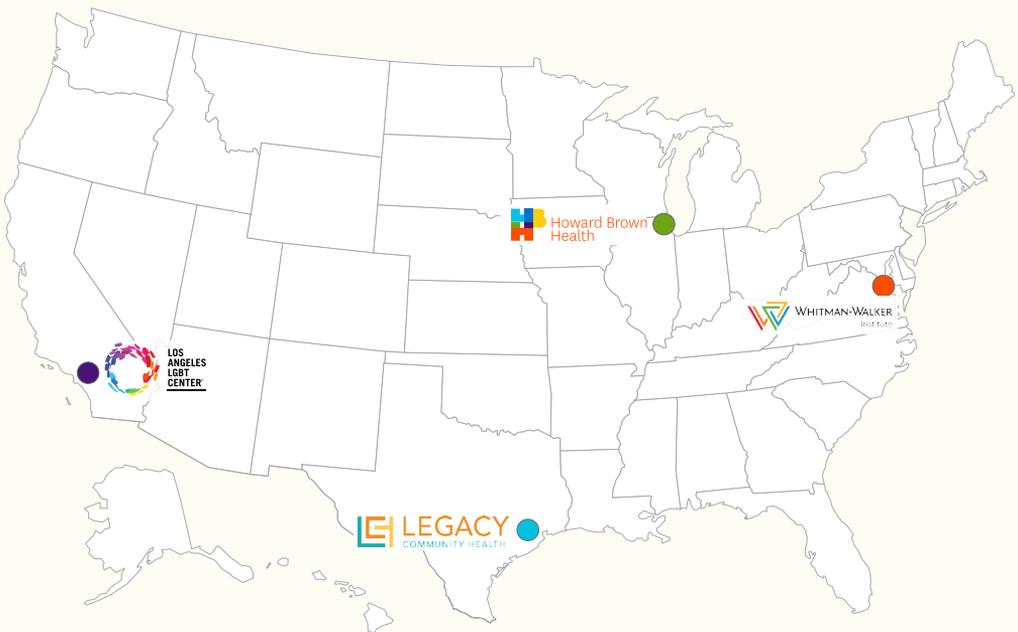
OUR STORY

We are a group of trans and nonbinary community members from the **Four Corners: Trans & Nonbinary (TNB) Health Research Advisory Network**. In 2019, we conducted our first study on TNB health research priorities. We want to share the project, research, and findings with **YOU**, our community! We also want to provide helpful guidelines for TNB people to engage in meaningful research that reflect our values and we want to challenge researchers and institutions to prioritize our needs, because we know us better than anyone else does!

FOUR CORNERS: TNB HEALTH RESEARCH ADVISORY NETWORK

In 2018, 4 federally qualified health centers (FQHCs) specializing in LGBTQ care across the U.S. partnered to form the **Four Corners: TNB Health Research Advisory Network**. Four Corners is a 16-member network with 1 researcher, 1 clinician, and 2 TNB community members from each health center (Howard Brown Health in Chicago, Los Angeles LGBT Center in Los Angeles, Whitman-Walker Institute in D.C., and Legacy Community Health Services in Houston).

“We envision a world where all TNB people have access to safe, relevant, and equitable healthcare and aim to advance health research by involving TNB community members, researchers, and clinicians as equal partners in the research process.”



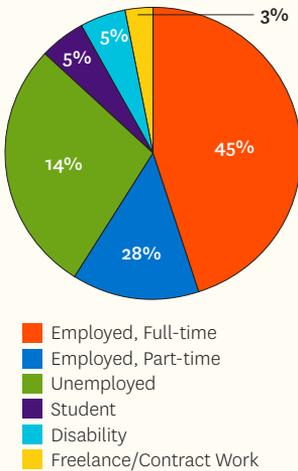
FUNDING ACKNOWLEDGEMENT: This work was supported through a Patient-Centered Outcomes Research Institute (PCORI) Project Program Award (EA-10754).

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.

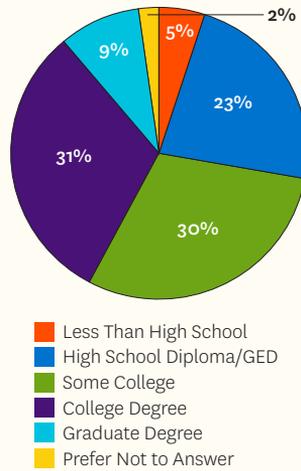
OUR STUDY

In 2019, we conducted eight focus groups, two in each city, in order to identify the research priorities of our TNB communities. We also asked about participants' prior experiences with research and their 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. **Our study findings illuminate a need for broader constructs of “health” than are typically recognized within dominant approaches to TNB health research and healthcare.**

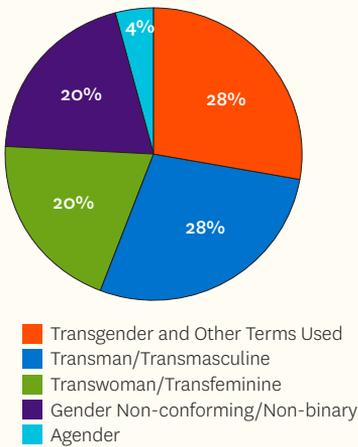
EMPLOYMENT



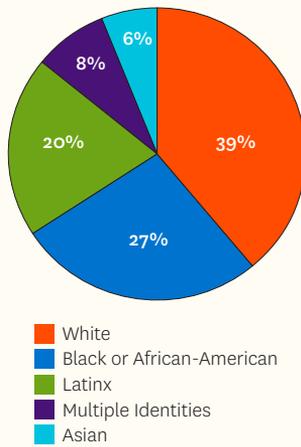
EDUCATION



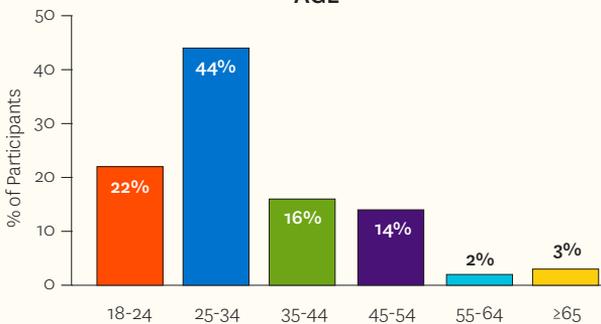
GENDER



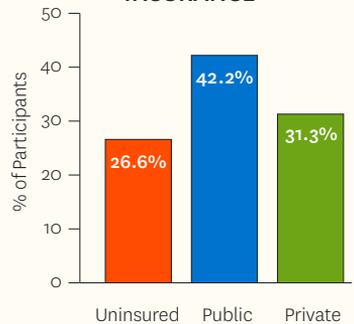
RACIAL/ETHNIC IDENTITY



AGE



INSURANCE



OUR FINDINGS

HOLISTIC HEALTH & WELL-BEING

“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

Across all cities, TNB focus group participants discussed the need for:

- more holistic views of TNB people and health, including definitions of health that encompass physical, psychological, spiritual, and social aspects of health and well-being, with mental and emotional well-being particularly emphasized
- reframing the concept of “good health”. Many participants with disabilities or chronic conditions critiqued dominant concepts of “healthy” as overly defined by one’s capacity for work or labor productivity
- expanding trans health research by moving away from over researched topics like suicidality and sexual behavior
- attention to the diversity of health care needs among TNB people, often influenced by oppression and lack of access

INTERSECTING OPPRESSIONS

“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

TNB participants discussed:

- the negative health impacts of transphobia, classism, racism, and ableism on their own health and well-being; many participants reported direct experiences of violence and discrimination and characterized exposures to transphobia as forms of trauma that affected their ability to maintain their mental health and well-being
- the significant role economic stability played in their overall health and well-being, including challenges with access to resources such as employment, stable housing, transportation, and food security
- health as a “privilege”, because without stable financial resources, many TNB people are forced to choose between their health and other basic needs

BARRIERS AND ACCESS TO QUALITY CARE

“Healthcare to me is a fight.”

– L.A. Participant

TNB participants discussed:

- direct links between accessing healthcare and lack of income, stable housing, and transportation
- the need for holistic, affirming, affordable, and accessible healthcare with knowledgeable providers
- experiences of overt discrimination from healthcare workers (e.g., medical providers, frontline staff, nurses, pharmacists, etc.), misgendering, and lack of safety in clinical infrastructures
- racism as a barrier to care for LGBTQ+ communities of color and LGBTQ+ health resources disproportionately benefitting white people
- the need for acknowledgement by health care institutions about the history of abuse and systemic failures in caring for TNB people
- the scarcity of gender-affirming care outside of major metropolitan areas and the ongoing institutional barriers (including cost and challenges with health insurers) within major cities where trans-specific services exist
- the need for more TNB people working in health care

COMMUNITY CONNECTEDNESS

“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 has been passed around from person to person for the past infinite amount of time 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

TNB participants discussed:

- the power of feeling connected. Many participants drew direct links between community building and TNB health and well-being
- Isolation as a coping mechanism for stress and transphobia experienced at home, workplace, public spaces, etc.
- Ending unsupportive relationships to produce a sense of freedom/autonomy
- Necessity of support systems for social and material support and overall health

GENDER AFFIRMING MEDICINE & HEALTH OUTCOMES

“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

Across all cities, TNB participants discussed:

- the importance of long-term research on gender-affirming hormone therapies (or HRT)
- concerns, anxieties, and frustrations with the lack of clear answers from healthcare providers and research about the many “unknowns” (e.g., the interactive effects with other kinds of medications, chronic conditions, and/or disabilities)
- conducting their own research to find information and studies related to the effects of hormone therapy. Some participants were told by providers that there “is no research” when asking about specific impacts

REPRODUCTIVE HEALTH, FERTILITY, & FAMILY PLANNING

“...I’m very concerned about 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

In the majority of the focus groups, participants discussed:

- barriers to accessing reproductive health information
- the need for TNB inclusion in reproductive health conversations and research
- the lack of provider explanation around family planning/pregnancy options
- concerns around financial barriers to sperm banking and adoption
- the need for research on: HRT & fertility, such as sperm production, Polycystic ovarian syndrome (PCOS) & HRT, Endometriosis & HRT, Trans women’s experiences with breast cancer, and cervical cancer

Read the full report, *Four Corners: Health Research Priorities Among TNB Communities*, at howardbrown.org/FourCornersReport21

GENDER DIVERSITY & NONBINARY SPECIFIC HEALTH 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 health research. Folks described frustration from feeling absent from health research. As one Houston participant stated, “...We are not on the fringe, but we exist, and we have actual experiences that need to be addressed.”

HEY RESEARCHERS!

“The best people to reach US are US.”

– D.C. Participant

We want research that is social justice oriented and includes all of our complexities, glory, and magic! We need YOU to:

- Build **INTENTIONAL** relationships with us
- **VALUE** our expertise, time, and emotional labor
- **CENTER** health research on the experiences of Black, Indigenous, and People of Color (BIPOC)
- **INVEST** in us by prioritizing our research interests
- Work with **LOCAL** trans led organizations and groups to build **TRUST**
- Work with us through **ALL** stages of research, from development to reporting back findings
- **RESIST** “fundability” & advocate for community engaged research practices
- **COMPENSATE US** in meaningful ways, including a travel stipend
- **UNDERSTAND & DECONSTRUCT** the power structures inherent between researchers and our community, especially if they are not TNB
- Create **MULTI-LINGUAL** research initiatives and spaces
- Embrace the **COMPLEXITY OF GENDER AND IDENTITY**

WHAT ARE MY VALUES?

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

– Chicago Participant

Our voices matter and we deserve to be a part of meaningful research projects that align with our values. Below is a brief guide to make sure you’re participating in research that aligns with what makes sense for you.

ASK YOURSELF:

- Is this project trans led or does it involve TNB researchers? What is the relationship of this project to my community?
- Have the researchers worked with local organizations or stakeholders in the community?
- Does the language on outreach materials resonate with me?
- Is it paid? Am I comfortable with this amount for my time, expertise, and/or emotional labor?
- Are there travel stipends available?
- Will I have access to the findings after the study ends? Are there ways to stay engaged after the project ends?
- Is there contact information listed? Who funded the project?
- What is the study focused on? Is this a priority for my communities and me? How will this research benefit my communities?

WE ARE EVOLVING

Our Four Corners Network has learned so much throughout this process and we are excited to keep evolving to center TNB needs in research. We value transparency and want to share our collective commitments for strengthening the Four Corners Network and centering TNB involvement in research. We are working to:

- **INCREASE** funding to expand the depth of community member involvement and the number of community members involved.
- Host social events to prioritize **BUILDING** connections
- Develop **EMERGENCY FUNDS** for acute crisis that our community members can access
- Internally form **MENTORSHIP** teams and provide relevant research **TRAINING**
- Invest in ongoing and meaningful **OPPORTUNITIES** for TNB people such as building networks, providing training, skill sharing, findings, and strategies
- Develop a TNB **ETHICAL REVIEW BOARD** to review, guide, and support research

We understand this takes time and is an ongoing process. The Four Corners Network aims to re-evaluate how we approach this work and continue to do the reflection needed to support our community members and inform our TNB centered research initiatives.

WHAT'S NEXT?

You can expect to hear from us again over the next year as we launch our second project, focused on the healthcare priorities of TNB people and research engagement strategies in the wake of COVID-19. We will be looking at the economic, medical, and community impacts of COVID-19 on TNB people, especially among TNB people of color, as we know COVID-19 has had a severe and disproportionate impact on communities of color. Keep an eye out for us on social media!

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