

Partnership with our community extends beyond survey language and recruitment; it includes us in interpreting the data and working together to create change.

**Nothing about us,
without us.**

2018-2019 Advisory Board Members

Collaborators

Brayden A. Misiolak¹ (he/they)

Ashton Niedzwiecki¹ (he/him)

Shanna K. Kattari, PhD, MEd, CSE, ACS² (they/them)

Edited By

Danielle Emerson¹ (she/her)

Caitlin Tupper, LCSW¹ (she/her)

Report Design By

Daniel Herrle¹ (he/him)

Jane Warunek¹ (she/they)

Sponsor

¹Transcend the Binary, Ferndale, MI

²University of Michigan School of Social Work, Ann Arbor, MI

Grantor

Community-University Partnership Seed, Pilot Grant Program

Michigan Institute for Clinical & Translational Research

University of Michigan

Find the full report at transcendthebinary.org/thrab

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<http://www.transcendthebinary.org/thrab>.

Transcend the Binary

Transcend is a community-driven organization led by trans and gender diverse folks. Our team spans multidisciplinary backgrounds, from social workers, therapists, pharmacists, and a physician, to researchers, journalists, creatives, peer advocates, multi-media and broadcasting, and more. We build programs and design and deliver services through the lens of the community to empower and promote integrative wellness and resilience of our community. Through our research and education, we actively seek to create change within healthcare systems and institutions, and to broaden awareness of the needs of gender diverse folks. We have been formally serving our community as Transcend since 2015, and as an initiative of our late co-founder, Darnell Jones RPh, since 2012.

University of Michigan School of Social Work

Advancing the social work profession's vision and values, the University of Michigan School of Social Work seeks to develop a more equitable, caring, and socially just society. Such a society meets basic human needs, eliminates social and economic inequities, and empowers individuals, their communities, and institutions to reach their aspirations and potential. Drawing on an interdisciplinary faculty within a public university seated in a region of enormous need and promise, the School is dedicated to education, research, and service that fosters progressive change at local, national, and global levels.

A Continued Partnership

The Community-University Partnership Seed award, made possible by the Michigan Institute for Clinical and Translational Research (MICHR), marks another contribution to trans health and research through the continued partnership of Transcend the Binary and the University of Michigan. Our partnership yields a combined body of work that has been supported by Dr. Shanna Kattari, as well as other researchers from the University of Michigan, and includes the Michigan Trans Health Survey, Finding Our Strength Survey, the Michigan Trans Health Research Advisory Board, and an Institute of Social Research Diversity, Equity and Inclusion focus group to investigate effective minority recruitment strategies. The goals of the MICHR Pilot Grant Program is to impact clinical outcomes and community health, drive the translation of scientific concepts to clinical investigators and the community; and stimulate research projects that address community identified health priorities.



Call to Action

A Message from Our Board

To researchers and beyond:

The trans and gender diverse (TGD) community faces widespread, systemic barriers to health equity and affirming care. Research is critically needed to understand our challenges and create change for the betterment of the community. To achieve these goals, it is our unwavering belief that our community's diverse voices are essential to conducting trans and gender diverse research.

Research creates opportunities to inform meaningful change and further action is required to make change a reality. The goal of research must be dedicated to collective action in which every provider or influencer of the trans and gender diverse journey collaboratively works with community members. Research done in partnership with the community honors the voices and contributions of trans and gender diverse individuals. Only when our voices are present can research accurately address the needs of our community, produce meaningful data, and result in impactful change.

The messages of this report should be considered by all – from grassroots advocacy groups to healthcare professionals and community allies. We urge you to read this report, share its findings with others, and stand with us in making the vision of holistic, high-quality, and accessible care a reality for our community. This report shares distinctive guidelines created by the benefactors of trans health research, healthcare systems, and community programs. It is a call to accelerate the research and solution-building needed to improve the well-being of our community, roadmaps how to do so in partnership with us.

Applications of these guidelines:

- Investigations of general population/health issues to ensure gender identity is collected to allow population comparative analysis
- Implementation of best practices within healthcare systems and professional practices to ensure the inclusion of trans/gender diverse health concerns with solutions built alongside the community
- Agencies and nonprofit programs that service the identified areas of need for the community
- Advocacy efforts promoting comprehensive, inclusive coverage under Medicaid, or other public insurance options (e.g. Medicare for All planning)
- Community leadership to gain buy-in and support for designing and implementing trans-led programs
- All policies and actions taken to create meaningful, material change for the trans/gender diverse community

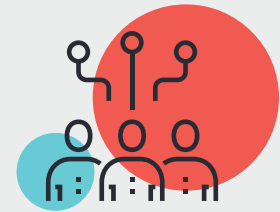
Michigan Trans Health Research Advisory Board (MI-THRAB)

Meet the Board

MI-THRAB was created via a partnership between Transcend the Binary and the University of Michigan with the distinct purpose of ensuring trans and gender diverse voices are at the forefront of health research. This groundbreaking initiative was a community-led effort. MI-THRAB provides guidelines for research that seek to combat the daily challenges impacting health and access to care for a distinct community whose needs are often overlooked, underserved, and misunderstood.

MI-THRAB consisted of 14 trans and gender diverse individuals, 11 of whom served as Board advisors. Board members represented various geographical areas of Michigan and a multitude of occupations, including healthcare providers, faith leaders, individuals in creative arts, community service and advocacy organizations, and academia. MI-THRAB member perspectives spanned multiple generations, gender identities, races, ethnicities, spiritualities, disability statuses, and military experiences (Table 1).

Board members drew upon their lived experiences and communal connections to provide a greater understanding of the barriers trans and gender diverse individuals routinely face in healthcare. Dr. Shanna Kattari, the university researcher co-facilitating this initiative, met with each board member individually in their local community to build rapport, gain insights, and share ideas. Brayden Misiolek, executive director of Transcend the Binary, facilitated online discussions about a range of health and research topics related to trans health and research. Forum discussions were compiled into a summary and referenced throughout this project. A day-long retreat of advisory board members was led by Dr. Kattari and Ashton Niedzwick (Transcend the Binary), and identified priorities and best practices for the MI-THRAB guidelines. Audio recordings of the retreat, forum summaries from online discussions, and visual assets created during the retreat guided the creation of these guidelines. Daniel Herrle, creative director of Transcend the Binary, and Brayden Misiolek collaborated to translate MI-THRAB's content into an illustrative report. From conception to dissemination, MI-THRAB was led by members of the TGD community.



These guidelines are unique in that they are based on the lived experiences of our community - the intended benefactors of trans health and research.

Table 1: Characteristics of the Advisory Board

County	Dickinson, Genesee, Houghton, Huron, Ingham, Oakland, Washtenaw, Wayne
Gender Identity	demigirlflux, transfemale, female, trans man, transmasculine, male, nonbinary
Age	ranged from 18 to 62 years old
Sexual Orientation	bisexual, heterosexual, lesbian, pansexual, queer
Religion/Spirituality	Agnostic, Atheist, Baha'i, belief in a creator that isn't involved with us, Catholic, Christian, Episcopalian, Humanist, Non-theistic Pagan, none, questioning
Race/Ethnicity	Asian, Middle Eastern, Black, Bi-racial, Mixed white/Persian, Caucasian/White Non-Hispanic
Income	ranged from <\$10,000 to \$80,000, though the majority fell between \$40k and \$59k
Education	high school, some college, associates degree, graduate/professional degree
Experiences that influenced guidelines	navigating Veterans Affairs services, post-traumatic stress disorders, Autism, physical disabilities, cognitive impairments, chronic illnesses, neurodivergence, mental illness/concerns



Research Priorities

Real change is not happening soon enough.

MI-THRAB assessed critical barriers to our health and wellness and was charged with identifying areas of research that could most significantly impact our community.

Our board emphasized the inclusion of intersecting identities, sexual and reproductive health, and access to care (e.g., comprehensive insurance coverage) as the immediate, most urgent focus areas. Board members unanimously agreed upon the prioritization of these areas.

Additional research areas include support for trans youth, standardization of medical practices, training healthcare providers.

Inclusive of Our Intersections

Members of our community face marginalization and disparity beyond gender. Research must recognize our community's diversity and unique challenges. We are:

- Racially and ethnically diverse;
- Immigrants, including undocumented statuses;
- Non-native English speakers with various proficiency;
- Varied in religion/spirituality;
- Living with HIV/chronic illness;
- Survivors of traumatic brain injury;
- Survivors of violence;
- People with addictions;
- People with disordered eating;
- Autistic and neurodivergent;
- Veterans;
- Sex workers;
- Living with mental health concerns;
- Physically, cognitively, or learning disabled;
- Currently or formerly incarcerated;
- Of various socio-economic backgrounds with ranging access to educational institutions;
- Varied in age; from youth to older adults



We call for designing, analyzing, and disseminating research that considers the depth of our diversity and effectively leads to change across healthcare systems, institutions, community-based programs, public policy, and representation.

Actionable Research Questions:

- 1 How can future research capture these experiences and ensure proper data analysis, including trans-specific, general population, and issue-specific studies?
- 2 How can targeted research in population-specific groups offer insights into the compounding, complex needs of our community's most marginalized sub-populations?
- 3 How can these findings fuel advancements in the quality of life, safety, and security of those most marginalized and vulnerable?

Sexual and Reproductive Health

We deserve accurate information about our bodies, access to essential treatments to ensure our safety and wellness, and family planning options. This is critical to equitable health.



Accordingly, we call upon researchers and influencers of healthcare to further the medical knowledge and availability of such knowledge regarding sexual health treatments, family planning options, and the interactions with gender-affirming treatments (e.g. hormones, surgeries). This includes the often-overlooked AFAB¹ individuals in sexual and reproductive health research.

Actionable Research Questions:

- 1 What is the relationship between hormone treatment and fertility, including the intentional discontinuation of hormone treatment for family planning?
- 2 What, if any, are the interactions between hormone treatment with PrEP as both post-exposure and preventative treatment?
- 3 How can this information be effectively and widely disseminated, and how can the search for new information become something tangible the community can use?
- 4 How can health equity for our trans/gender diverse community be achieved within sexual health?
- 5 How can our community be empowered through better family planning options?

Affirming Care and Coverage

Lack of accessible care² impacts our daily lives through



- Inadequate coverage in both public and private insurance;
- Challenges in navigating complex systems of diagnostic codes/exclusionary coverage;
- Emotional labor of self-advocacy in;
 - Denials/appeals, and
 - Financial costs of needed care/treatments.

We call upon researchers and influencers of healthcare/coverage policies to inform and advocate for future policy shifts toward inclusive transgender healthcare coverage.

Actionable Research Questions:

- 1 What are the barriers to accessing gender-affirming trans healthcare,³ and the challenges in navigating healthcare systems/insurance coverage?
- 2 What are the effects of lacking coverage of desired treatments on a patient's health and wellness, examining health through a holistic lens, including physical, mental, emotional, and social well-being?
- 3 What is the impact of access to gender-affirming medical treatments, procedures and mental health services?

¹Those who have been assigned female at birth.

²Care includes medical treatments, procedures, and mental health services.

³While 'Intervention Science' is an established field that relates to the study of treatments and procedures, MI-THRAB felt strongly that this language was pathologizing and fails to capture the trans experience and communicate health needs. Treatments for the trans and gender diverse population opens up affirming pathways for actualizing one's life, authentically and our board recognizes this as very different than treatment for a disease.



MI-THRAB also identified the following priorities as critical for improving the health and wellness of our community

Trans Youth and Stigma

There are many challenges faced by trans/gender diverse youth, including, but not limited to, experiencing trauma and/or violence with family rejection, navigating academic institutions, seeking peer support, coping with stigma, and building positive relationship skills. The healthcare system depends on family support, advocacy, or acceptance, as well as the availability of gender-affirming pediatric providers.

Actionable Research Topics:

- 1 Explore youth needs and the effects of stigma, cyberbullying, and various levels of peer and parental support.
- 2 Examine youth trajectories and comparisons between those who experience acceptance at a young age and those who face rejection. Measure the comprehensiveness of rejection and support. Consider the quality of support and intensity of rejection.
- 3 Examine youth trajectories for those who have access to affirming pediatric care for hormone blockers/hormone treatments.
- 4 Leverage findings to build awareness around educational programs for peer groups, academic institutions/administrations, parents, caregivers, and other youth-support roles.

Standards of Practice

MI-THRAB shared our experiences of receiving inconsistent information from the medical field, including differing recommendations over surgical techniques. Some providers tout anecdotally derived treatment methods. Evidence-based best practices and guidelines are an expanding and developing area of research and exist for hormone therapy (including for adolescents). We deserve continued research invested in advancing surgical techniques and procedures.

Actionable Research Topics:

- 1 Continue research and development of treatment best practices with large, significant sample sizes, focusing on intervention science. Disseminate information to the community on the most effective procedures.
- 2 What are the best surgical options, considering rates of complications, functionality, retention of sensation, and patient satisfaction? What are the best recovery methods?
- 3 Continue to research and develop best practices and effective treatments for body dysphoria, social dysphoria, trauma, minority stress, and resiliency skill-building within mental health.

Training of Healthcare Providers and Staff

Our board voiced that a provider's approach is just as important as the treatment itself. Building on the knowledge and skills of providers to our community requires both cultural sensitivity and knowledge of effective treatments. Through the skill-building of providers, we can significantly increase the availability of healthcare providers.

Actionable Research Topics:

- 1** Investigate current training and education for healthcare providers on transgender healthcare needs, treatments, and medical procedures.
- 2** Explore and identify engaging modes of training for healthcare professionals that effectively build on skills to provide;
 - Affirming, culturally responsive care, and
 - High-quality and effective treatment for trans-specific needs. This includes but is not limited to general care, medical treatments, surgical procedures, recovery, mental health interventions for trauma, dysphoria, and resiliency skill-building.

ACCESS is not simply obtaining medical treatment - it is receiving affirming care of **high quality.**



Best Practices

The trans/gender diverse community is vastly unique in its membership, identities, and the pervasive, complex challenges faced. Only with community guidance can research be effective in its design, community engagement, and quality of results. To center the voices of the community is imperative for respecting the dignity of the community and for the overall success of the initiative.

Trans/gender diverse people should be involved at every stage of the process.

- 1 Goals & Objectives
- 2 Methods Used
- 3 Recruitment
- 4 Analysis
- 5 Dissemination

Our board identified ways to partner with the trans/gender diverse community. It is strongly encouraged to work with the community in all steps of the process.



Partner with Us

MI-THRAB has created a framework for working with our community. Our community is diverse and evolving, thus these recommendations are a starting point.



Community Partners

- Always have trans/gender diverse community members on the research team
- Because of the diversity and need for multiple perspectives, establish a community advisory board and/or conduct multiple focus groups throughout the process
- **The expertise and contributions of community members must be compensated**
- The research/development team should complete, at minimum, a Trans 101/Ally training
- At each stage of the process, work with your community advisors, board and team to ensure culturally appropriate studies, guide the best language on gender/identity, recruitment strategies and more to be specific to the context of your work

Partners in Survey Design

Include us in your General Studies

- We exist within your population samples and are erased if the study is not inclusively designed (see Language for Gender Demographics, p.12)
- We need data allowing for comparative analysis with the general cisgender population

Make your data Accessible

- If your data-analysis plan does not include comparative analysis with the trans/gender diverse community, share with trans researchers.

Meet Our Needs

- Partnering with the community allows your team to better frame research questions and adapt to meet the needs of the community, as well as any target sub-populations (e.g. older adults)
- Use/include open-ended questions relating to identity as this practice affirms self-determination
- If the research involves patients, make sure it's clear that declining/participating does not impact their treatment or access to care

Integrative Health and Wellness

- Researchers are encouraged to take a comprehensive view towards health and well-being
- Investigate environmental and systemic issues impacting the community
- Investigate factors that impact health such as socio-economic status, race/ethnicity, nation of origin, education level, geographical location, chronic illness status, disabilities and/or impairments, neurodivergent, under-employed

Survey Language

- Work with community advisory teams to tailor research and language to meet the needs of those of intersectional experiences;
- Be clear and direct: roundabout language can be harmful; for instance, vague language such as “bottom surgery” should be avoided and instead, ask culturally appropriate and specific language if surgical history is relevant to the research

Example: Language about people with disabilities

The board discussed using person-first or identity-first language. The same principles should apply in community-driven survey design.

¹Cisgender: Someone who identifies with the sex/gender they were assigned at birth.

How to Ask About Gender

Inclusive language is important for respectfully engaging with our community. Culturally sensitive and inclusive survey language also ensures transgender visibility within population data sets. The following is intended as a starting point for discussion with your trans-advisory boards and/or focus groups.



Do

General Population Study

- Do you identify differently than the sex you were assigned at birth?
- **Skip Pattern**
If yes, then skip to trans-specific questions.

OR

Non-Skip Pattern

All respondents answer the same question regarding gender. This question must provide option(s) for nonbinary and agender individuals.

Trans-Specific Study

- What was your sex assigned at birth?
- What is your gender: _____
(fill in the blank)
- Of the following options, which feels most authentic to you?*

 - man/masculine
 - woman/feminine
 - nonbinary/genderqueer
 - agender

Don't

- **DO NOT** use terms like "biological sex," "natal sex," or "true sex"
- **DO NOT** separate men and trans men; women and trans women
- **DO NOT** use "other" as a gender option

*MI-THRAB also discussed using common responses from prior research's open-ended gender question to guide a simple list (above).

Research conducted by Transcend the Binary and the University of Michigan support the designations identified by this Advisory Board.

Methods

The Gold Standard • Longitudinal studies with robust, large sample sizes

Roadmap for Future Research

- We recognize a foundation may need to be laid to successfully obtain funding for large, longitudinal studies
- We call upon researchers to contribute to the body of work necessary to achieve this goal
- Cross-sectional studies and meta-analyses of multiple studies still have value



Medical Studies

Small sample sizes or physician's anecdotal evidence is insufficient. We need investment in evidence-based practices, justified by increased sample sizes.

²Nonbinary individuals may describe their identity as being beyond the man/masculine or woman/femine "binary," whereas agender individuals may describe themselves as having no gender.

Mixed Methods

- Mixed methods of both quantitative and qualitative is strongly recommended
- Quantitative data is greatly valued and useful for the community
- Qualitative responses offer the richness of diverse narratives

Hear Our Voices

Emphasize transgender narratives in research with open-ended questions.



Recruitment

Dynamic Recruitment Strategies

- Build recruitment strategies with the community
- Invest in outreach and social media campaigns
- Recruit at community events and through social media channels
- Recruit through service agencies, affirming healthcare clinics and providers

Invest in community-led outreach initiatives.

⚠ It must be clear that lack of participation does not impact patient care.

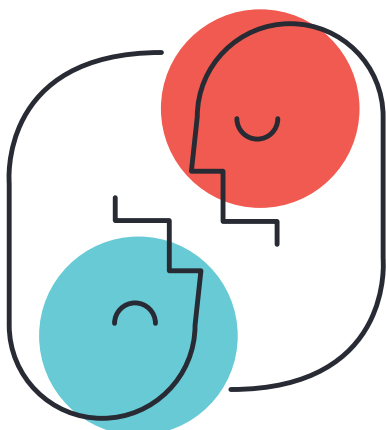
- Recruitment efforts should center on the inclusion of Black, brown, people of color, immigrants, those living with HIV/chronic illnesses, disabled people, Autistic and neurodivergent people, Veterans, youth and older adults
- Outreach should emphasize often overlooked rural areas, as well as urban and suburban areas

Partnership with the trans/gender diverse community extends beyond framing survey language and recruitment; it includes us in interpreting the data and working together to create change.

Nothing about us, without us.

Data Analysis

- Partnership with the community during data analysis is vital
- Lived experience is expertise that is paramount to identifying key research messages and implications
- Empower the community during analysis to explore findings that challenge barriers to health and equity



Symbiotic partnership working with researchers on developing plans for action for continued research, and how to best use these findings to create **lasting, meaningful change**

See guidelines specific to Dissemination for recommended best practices.

Dissemination

Translating these findings into action is critical to honoring the community through the research process. Continued partnerships between allied researchers and the community can lead to creative dissemination strategies centering on the actual needs of the community. Effective use of results to promote positive health outcomes for the community is paramount.



Throughout the Board's work together, several key themes were present:



Community Inclusive

- Our voice is effective in informing how data can be shared and the goals served;
- We are invested in creating meaningful change for our community and want to learn about findings;



Actionability

- We need meaningful change and real access to equitable health and wellness;
- Change is not happening fast enough; as we wait for our needs to be prioritized, we continue to be deeply impacted by gaps in care, access, and health equity.



Accessibility

- Multiple avenues of accessible dissemination promote broad visibility and usability of findings; and
- Accessibility is more than access to research, but so too is digestible content.

The Board emphasizes a multi-faceted dissemination strategy centered around creating change. Our discussions centered on creating effective messages with key findings to reach intended audiences and dissemination goals. Communication should be tailored for the intended audience of researchers, healthcare professionals, community organizations, change-makers, policy influencers, and the community itself.

Dissemination can include, but not be limited to, academic journals. While we recognize the value of peer-reviewed research, this is not widely available and does not reliably lead to action. Publishing through Open Access and other academic platforms was encouraged, but the Board strongly advocated disseminating digestible, impactful messages across common platforms such as press releases, op-eds, blogs, online publishers (Medium; the Conversation), podcasts, and YouTube.

Directly engaging with members of professional associations, healthcare professions, universities, and researchers was also recommended, including presenting at national conferences, TedTalks/TedX, and the creation of interactive learning exhibits and training. We also want the findings brought back to the community through community-led reports, town halls, events, and exhibits.

The Board recommended:

- Creating a centralized website offering access to trans health research and information, and
- Establishment of a bi-annual or regular Michigan Trans Research Conference.

THANK YOU.

We thank the trans/gender diverse folks across the state of Michigan that joined the state's first-ever Trans Health Research Advisory Board (2018-2019). Our work together was the first trans-led advisory group within the state of Michigan to assess the research and health needs of our community.

Thank you to the University of Michigan, by way of the MICHR Community-University Partnership Seed Grant, for making the funding for this project possible, and to Dr. Shanna Kattari for the co-facilitation of this initiative, along with Transcend the Binary.

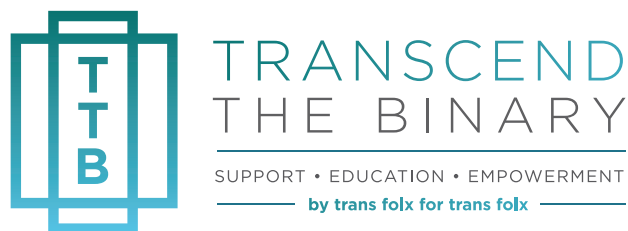
Because of this grant, all board members were compensated for their time and expertise. The report was designed and authored by community members.

Thank you for reading, sharing this work, and implementing the findings.

You are essential to our collective impact.



MICHR Pilot Grant Program | Community-University Partnership Seed



290 W. Nine Mile Rd., Ferndale, Michigan 48220
<https://transcendthebinary.org>



1080 S. University Ave Ann Arbor, Michigan 48109
<https://ssw.umich.edu/>