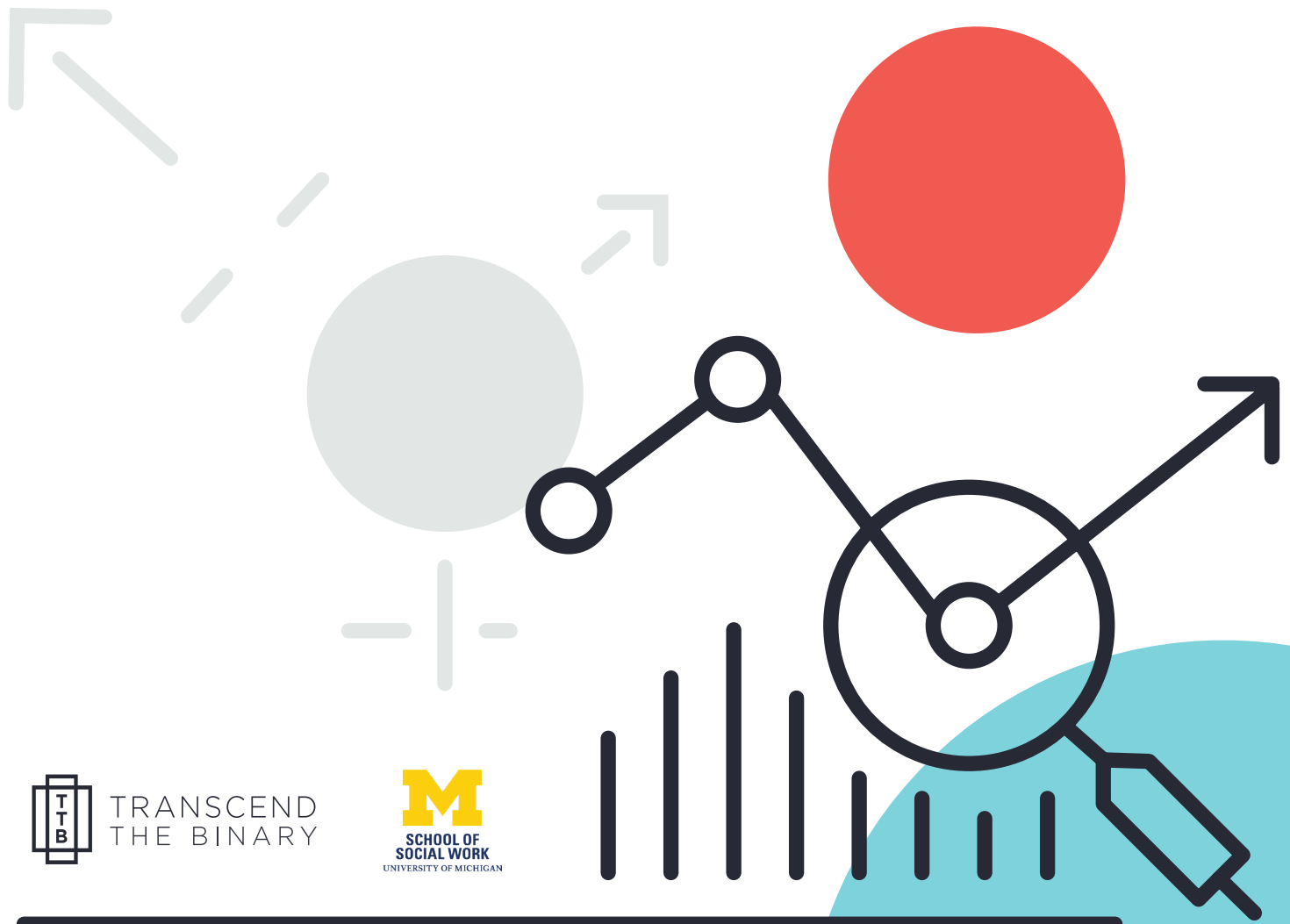


# Trans Health Research

Research Priorities | Best Practices | Dissemination

Guidelines created by the Michigan Trans Health Research  
Advisory Board of 2018-2019

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TRANSCEND  
THE BINARY



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.**

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# 2018-2019 Advisory Board Members

## Facilitators

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Transcend the Binary

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## Grantor

Community-University Partnership Seed, Pilot Grant Program  
Michigan Institute for Clinical & Translational Research  
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Find the full report at [transcendthebinary.org/thrab](http://transcendthebinary.org/thrab)

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## RECOMMENDED CITATION

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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 across multidisciplinary backgrounds, from social workers, therapists, pharmacists, physician, researchers, journalists, creatives, peer advocates, multi-media and broadcasting, and more. We build programs, design and deliver services through the lens of the community, to empower and promote holistic wellness and resilience of our clients. Through our research and education, we actively seek to create change within healthcare systems and institutions, and broaden awareness on 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.

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## School of Social Work, University of Michigan

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.

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## 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 by 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 2018 Michigan Trans Health Survey (MTHS), 2016 Finding Our Strength Survey (FOS), the 2019 Michigan Trans Health Research Advisory Board (MI-THRAB), and a 2020 Institute of Social Research Diversity, Equity and Inclusion focus group to investigate effective minority recruitment strategies (DEI-ISR). The goals of MICHR Pilot Grant Program are to impact clinical outcomes and community health; drive 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

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### Our message to researchers and beyond:

The trans and gender diverse 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, community involvement is essential in conducting trans and gender diverse research. It is our unwavering belief that our diverse, unique voices must be interwoven into research.

Research creates opportunities to inform meaningful change; further action is required to make change a reality. The goal of research must be dedicated to collective action – where 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 unique 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, providing guidelines on how to do so in partnership with our community.

### Applications of these guidelines:

- Ensure gender identity is collected in general to allow for population comparative analysis;
- Guide healthcare systems and professional practices to ensure the inclusion of trans/gender diverse health needs;
- Support agencies and nonprofit programs that service the community;
- Empower advocacy efforts promoting comprehensive, inclusive coverage under Medicaid or other public insurance options;
- Equip community leadership with tools to gain support for trans-led programs;
- Promote all policies and actions to create meaningful, material change for our trans/gender diverse community.

# Michigan Trans Health Advisory Board (MI-THRAB)

## Meet the Board

MI-THRAB was created via a partnership between Transcend the Binary and University of Michigan Assistant Professor Shanna K. Kattari with the distinct purpose of ensuring trans and gender diverse voices are at the forefront of health research. This ground-breaking initiative was a community-led effort to identify and provide guidelines for research that seeks to combat the daily challenges impacting health and access to care for a unique community whose needs are too often overlooked, underserved and misunderstood.

MI-THRAB consisted of 14 trans and gender diverse individuals, 11 of whom served as Board advisors on the Board. Board members represented various geographical areas of Michigan as well as varying occupations, including healthcare providers, a faith leader, individuals in creative arts, community service and advocacy organizations, and academia. MI-THRAB member perspectives spanned across generations, gender identities, races, ethnicities, spiritualities, disability status, 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. Kattari, the university researcher co-facilitating this initiative, met with each Board member individually in their own communities to empower them, build rapport and share ideas. Brayden Misiolek, Executive Director of Transcend the Binary, facilitated online discussions on a range of topics relating to trans health and research. These discussions were compiled into a forum summary and used as a reference throughout this project. A day-long retreat of the MI-THRAB with Transcend the Binary, led by Ashton Niedzwick and Dr. Kattari to identify priorities and best practices for the guidelines. Audio recordings of the retreat, summaries from online discussions, and visual assets created during the retreat guided the creation of these guidelines. A graphic designer from the trans community translated MI-THRAB’s content into a graphical report.



**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	<\$10,000 to \$80,000; 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, neurodivergent, mental illness/concerns



# Research Priorities

## Our clear message to researchers and beyond:

MI-THRAB identified significant vulnerabilities within our community that, in order to achieve equitable health and wellness, need to improve. MI-THRAB considered the following research areas to be of first immediacy and priority. We call for research that defines clear actions and leads to change.

## Inclusive of Our Intersections

*Research must recognize the diversity of our community and the unique challenges it faces. Members of our community face marginalization and disparity beyond gender. We are:*

- Racially and ethnically diverse;
- Of varied documentation status/nations of origin;
- 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, disordered eating;
- People with Autism and who are neurodivergent;
- Veterans;
- Sex workers;
- Living with mental health concerns;
- People with physical, cognitive, or learning-based disabilities;
- Currently and/or formerly incarcerated;
- Of varied socio-economic backgrounds with ranging access to educational institutions;
- Varied in age, from youth to older adults.



We call for dissemination of research that considers the depth of our diversity and effectively leads to change across healthcare systems, institutions, community-based programs, policy advisories and legislatures.

## Actionable Research Questions:

- 1 How can future research be designed to capture these experiences and ensure proper data analysis, including both trans-specific studies and general population/issue-specific studies?
- 2 How can targeted research in population-specific groups offer insights on the compounding, complex needs of those most marginalized within our community?
- 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, as well as access to important treatments to ensure our safety and wellness, as well as 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 all members of our community, including AFAB<sup>1</sup> individuals.

## 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 be stimulated and translated into information 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?

# Access to Affirming Care and Coverage



## Lack of accessible care<sup>2</sup> impacts our daily lives through:

- Inadequate coverage in both public and private insurance;
- Challenges in navigating complex systems of diagnostic codes and 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 towards inclusive transgender healthcare coverage.

## Actionable Research Questions:

- 1 What are the barriers of accessing gender-affirming trans healthcare, as well as 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, inclusive of physical, mental, emotional and social well-being?
- 3 What is the impact of access to gender-affirming medical treatments, procedures and mental health services?

<sup>1</sup>Those who have been assigned female at birth.

<sup>2</sup>Care includes medical treatments, procedures, and mental health services.





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. This is pervasive throughout healthcare systems in terms of accessing quality, pediatric care, as well as navigating academic institutions and peer groups. Both are also dependent on family support, advocacy or acceptance. Moreover, emotional trauma and attachment injuries due to family rejection can significantly impact the health and wellness of youth, so families face stigma and institutional roadblocks in navigating these systems.

### Actionable Research Questions:

- 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 compared to those who face 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, and other caregiver/youth-support roles.

<sup>3</sup>While '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.

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## Standards of Practice

MI-THRAB shared our experiences of receiving inconsistent information from the medical field, including contradictory recommendations over surgical techniques, best practices, and anecdotally derived methods of care. The lack of evidence-based best practices for our community is concerning. We deserve the research and development of evidence-based standard operating procedures.

### Actionable Research Questions:

- 1 Research and develop best practices and effective treatments for gender-affirming medical care with large, significant sample sizes (and a focus on intervention science).
  - This includes longitudinal studies on hormones over time, surgical procedures and recovery methods.
- 2 What are the best surgical options, considering rates of complications, functionality, retention of sensation, and patient satisfaction, and what are the best recovery method
- 3 Research and develop best practices and effective treatments for body/social dysphoria, trauma, and resiliency skill-building within mental heal

# Training of Providers

We find that culturally sensitive, affirming care is just as critical to evidence-based treatment for efficacy. Building on the knowledge and skills of providers who provide care to our community requires both cultural awareness and knowledge of effective treatments. Through the skill-building of providers, we can significantly increase the availability of healthcare providers.

## Actionable Research Questions:

- 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 – from general practitioners to specialists – that effectively builds on skills to be able 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.

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



# Best Practices

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

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



1 Goals & Objectives



2 Methods Used



3 Recruitment

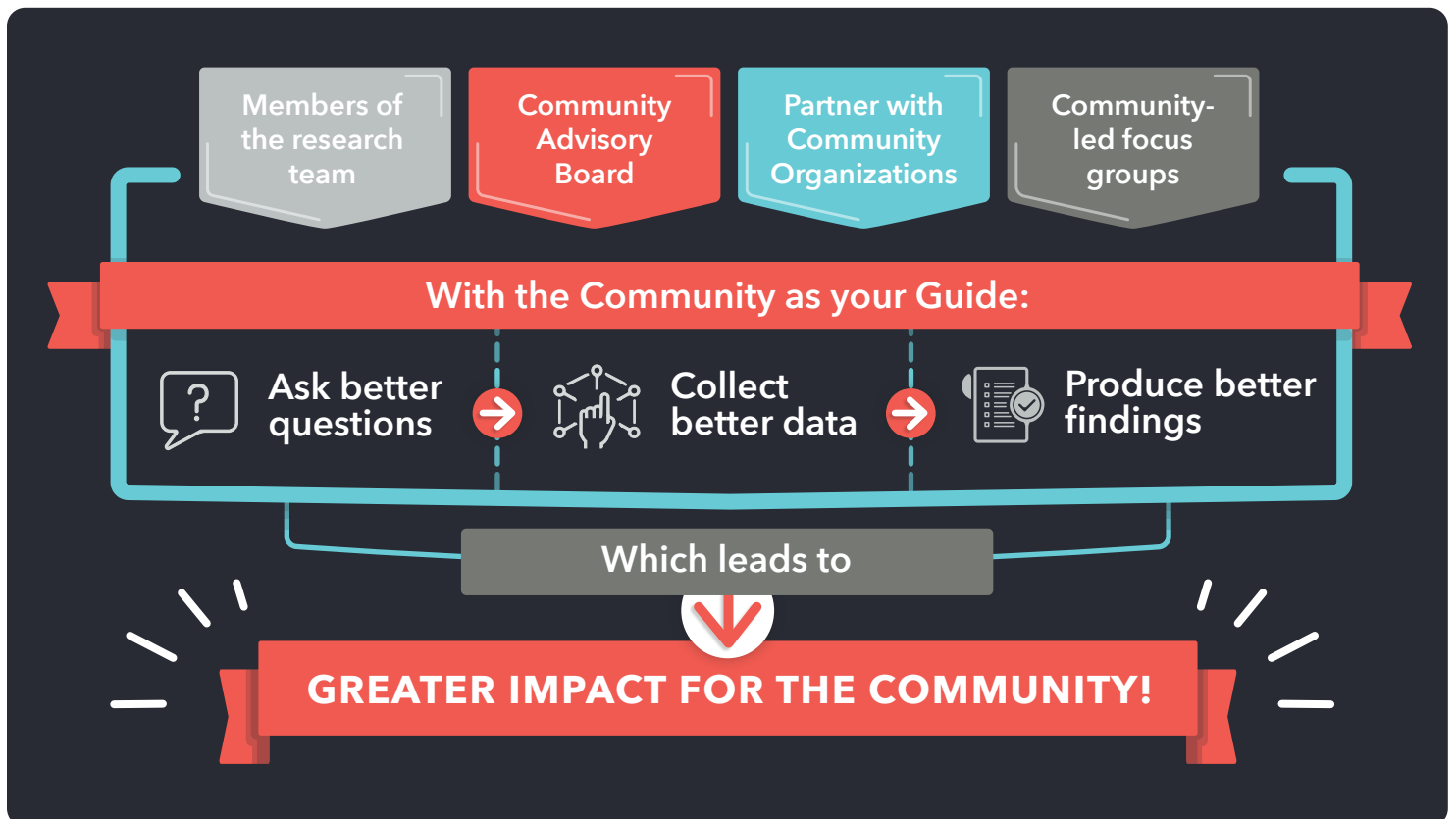


4 Analysis



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, and these recommendations are a starting point.



## Community Partners

- Always have trans/gender diverse community members on the 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

- We call on researchers to take a holistic 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.

<sup>1</sup>Cisgender: someone whose gender is aligned with the expectations associated with the sex they were assigned at birth

# Language for Gender Demographics



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 Study

Do you identify differently than the sex you were assigned at birth?

#### 1. Skip Pattern

If yes, then skip to trans-specific questions.

OR

#### 2. Non-Skip Pattern

All respondents move on to the same gender question that is trans-inclusive.

### 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

\*MI-THRAB recommended using responses from prior research's open-ended gender identity questions to guide a short list of options. The options our board offered as a start point (above) is corroborated by prior research by Transcend the Binary and our partnership with University of Michigan.

## 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 can still have value
- Meta-analysis of multiple studies can still have value



### Medical Studies

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

### 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!



# Recruitment

## Dynamic Recruitment Strategies

- Build recruitment strategies with the community
- Recruit with partners: local community organizations, affirming providers and healthcare clinics
- Recruit face-to-face at community events
- Recruit through community groups across multiple social media platforms
- Build strategies with partners to promote across email distribution and social media campaigns



### Patients' Care

It must be clear: whether or not someone participates in research, does not impact their care.

## Inclusive Recruitment Strategies

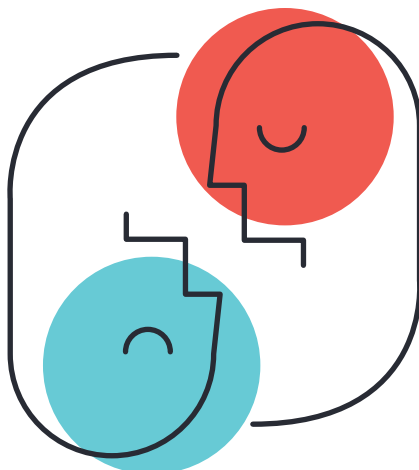
- Our community is diverse and recruitment efforts should center on the inclusion of people of color, immigrants, those living with HIV/chronic illnesses, people with disabilities, people who are neurodiverse, Veterans, youth and older adults
- Outreach should emphasize often overlooked rural areas, 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.

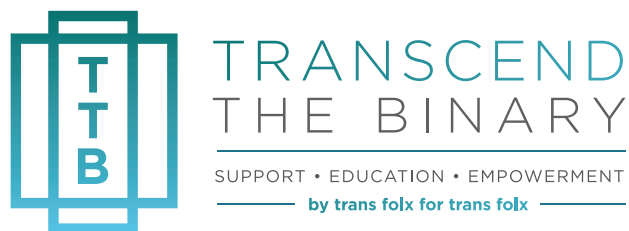
Because of this grant, all board members were compensated for their time and expertise. The report was designed and authored by community members.

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



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