Surgical Innovation

# Centering Transgender and Nonbinary Voices in Genital Gender-Affirming Surgery Research Prioritization

Geolani W. Dy, MD; Gaines Blasdel, BS; Jae M. Downing, PhD

## What Is the Innovation?

*Genital gender-affirming surgery* (GAS) is an umbrella term used to describe reconstructive procedures aimed to alleviate dysphoria related to genital anatomy for transgender and nonbinary (TGNB) individuals. Demand for GAS has grown,[1] yet research on how TGNB patients perceive quality of care and surgical outcomes is scant. Notably, existing GAS studies have lacked community engagement, which limits their utility and may perpetuate harmful research practices. High-quality comparative effectiveness research studies using a patient-centered approach are needed to inform shared decision-making, develop best techniques and perioperative management strategies, and identify gaps in payers' decisions about coverage of GAS and ancillary care.

To address these gaps, we convened the Transgender and Non-Binary Surgery Allied Research Collective (TRANS-ARC) to create a prioritized research agenda for GAS comparative effectiveness research studies from a TGNB community-centered perspective.

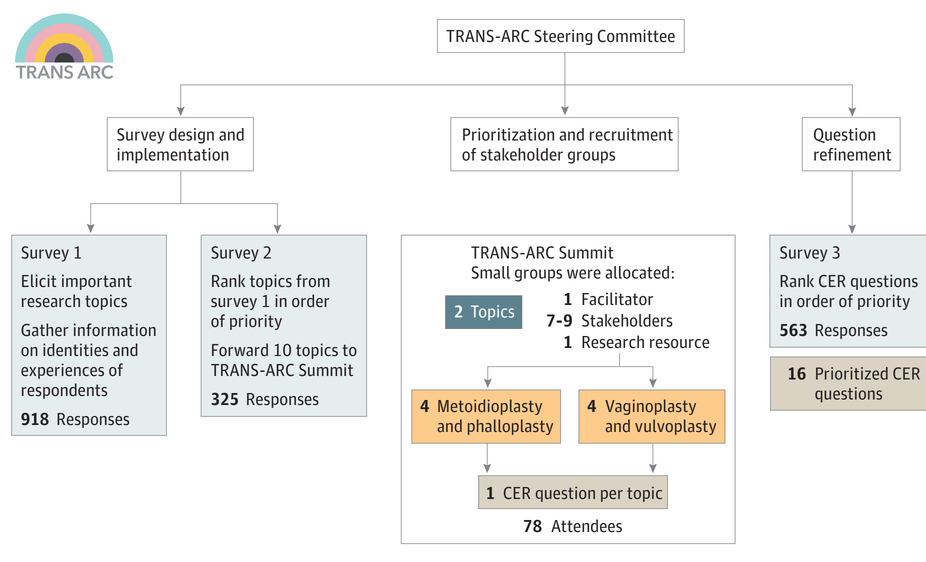
We created a steering committee of community leaders, researchers, and multidisciplinary professionals specializing in TGNB health from across the United States. Eighty percent of committee members identified as TGNB. The committee developed and guided the research prioritization process, stakeholder recruitment approach, and dissemination strategy.

The research prioritization process included a modified Delphi approach and virtual meeting (**Figure**). Recruitment activities occurred in online support groups, listservs of TGNB health professionals, and social media announcements. We invited a broad community of GAS stakeholders (eg, patients, caregivers, advocates, clinicians, researchers, and industry representatives with interest in GAS) to complete an initial online survey to share research topics of importance to them (n = 918 unique eligible responses). Responses were organized by the steering committee into 26 topics, which respondents ranked in order of priority in a second survey (n = 325). The 10 highest-priority topics included GAS outcomes and complications related to sexual health, genital sensation, urinary function, appearance satisfaction, and mental health; transphobia within health care; surgeon quality; care coordination and follow-up; goal setting for surgery; and out-of-pocket costs.

Next, we convened the 2-day virtual TRANS-ARC Summit. We used respondent-driven sampling to recruit 78 attendees, many of whom had intersectional identities across multiple stakeholder categories: TGNB people (84%); GAS patients (68%); individuals from marginalized racial and ethnic minority groups (54%); people with disabilities (24%); people involved in sex work (21%); those with history of incarceration (12%); immigrants (9%); veterans (7%); researchers (46%); surgeons (9%); other clinicians (19%); and industry representatives (7%). Stipends were offered to TGNB participants who participated outside of their professional capacity. Stakeholders were assigned to small groups, each with 7 to 9 community members, 1 facilitator, and 1 person serving as a research resource with significant comparative effectiveness research experience to answer methods questions. Each group focused on 2 priority topics for which they developed comparative effectiveness research questions using the Population, Intervention, Comparator, Outcomes, Timing, Setting framework.

After the summit, the steering committee reviewed the questions for consistency in terminology and framing. The questions were then included in a final survey available to the broader online stakeholder community, who ranked the questions in order of priority (n = 563). The final prioritized questions, available at trans-arc.org, are being disseminated to TGNB communities, researchers, and funders.

Figure. Transgender and Non-Binary Surgery Allied Research Collective (TRANS-ARC) Research Prioritization Process




Steering committee members participated in all aspects of the research prioritization process, from proposal development to dissemination. CER indicates comparative effectiveness research.



© 2022 American Medical Association. All rights reserved.

Downloaded From: https://jamanetwork.com/ Oregon Health & Science University by Geolani Dy on 05/06/2023

## What Are the Key Advantages Over Existing Approaches?

Gender-affirming surgery research has been conducted predominantly from the perspective of treating clinicians, lacking TGNB community involvement necessary for creating meaningful research processes.[2] For example, restrictive criteria for GAS candidacy (known as gatekeeping) have pushed patients to respond to clinical questionnaires used in research in a way that allows them access to GAS but may not reflect their experiences. Cisgender-defined ideals have historically determined outcomes of interest. Even when these operative ideals align with patients' goals (eg, sexuality or gendered self-image), the definition of these outcomes may not reflect culturally specific experiences within TGNB communities. Conducting studies in the setting of gatekeeping without addressing power dynamics and measuring GAS outcomes without patient input are common practices that affect the internal validity of GAS research. TRANS-ARC centered the needs and experiences of the TGNB community in the development of a research agenda to facilitate more meaningful studies on GAS outcomes.

TRANS-ARC engaged marginalized groups typically excluded from research, who experience additional barriers to GAS (ie, individuals from racial and ethnic minority backgrounds, those with lived experiences of incarceration or sex work, people with disabilities, and immigrants and/or refugees). We demonstrated that it is both possible and critically important to center TGNB community voices in creating GAS research, while also including perspectives of researchers, clinicians, and other stakeholders. By establishing an environment of mutual respect, applying a trauma-informed approach, and recognizing and representing the enormous diversity of TGNB communities, we were able to create an unprecedented space of co-learning and cross-stakeholder dialogue.

## How Will This Affect Clinical Care?

In GAS, surgical options are numerous and risks may be substantial. It is therefore crucial to understand patient priorities and perspectives. By creating and answering research questions that center patient priorities, we can better counsel and support patients seeking GAS and improve surgical care.

## Is There Evidence Supporting the Benefits of the Innovation?

Community engagement has been shown to improve research relevance, increase and diversify participation in research, improve retention in longitudinal studies, and promote community ownership of studies, which may help assuage distrust and concerns about the credibility of researchers stemming from experienced stigma within health care and health research.[3-6] Patient-centered research has potential to improve clinical care and outcomes in marginalized populations.[7]

## What Are the Barriers to Implementing This Innovation More Broadly?

These comparative effectiveness research questions require further refinement to create studies that are useful to a broad range of GAS stakeholders. Furthermore, this patient-centered research requires considerable resources, time, and leadership. Engagement processes will differ based on specific cultural, geographic, and health system contexts. TRANS-ARC identified several essential practices: sustained engagement, investment in communities beyond research, timely and equitable reimbursement, and diverse research teams. However, traditional research timelines and institutional structures do not facilitate these community-centered practices.

## In What Time Frame Will This Innovation Likely Be Applied Routinely?

We anticipate that TGNB community members, researchers, clinicians, and advocates will use this work as a foundation to build equity-focused and transparent research processes, create higher-quality evidence, and begin to answer each of these prioritized questions.

### ARTICLE INFORMATION

**Author Affiliations:** Department of Urology, Transgender Health Program, Oregon Health & Science University, Portland (Dy); Department of Urology, New York University Langone Medical Center, New York (Blasdel); Oregon Health & Science University, Portland State University School of Public Health, Portland (Downing).

**Corresponding Author:** Geolani W. Dy, MD, Department of Urology, Oregon Health & Science University, 3303 SW Bond Ave, CH-10U, Portland, OR 97239 (dy@ohsu.edu).

**Section Editor:** Justin B. Dimick, MD, MPH.

**Published Online:** May 11, 2022. doi:10.1001/jamasurg.2022.1049

**Conflict of Interest Disclosures:** None reported.

**Funding/Support:** This work was funded through a Patient-Centered Outcomes Research Institute (PCORI) Engagement Award (18835).

**Role of the Funder/Sponsor:** The funder had no role in the preparation, review, or approval of the manuscript or decision to submit the manuscript for publication.

**Disclaimer:** The statements presented in this publication are solely the responsibility of the authors and do not necessarily represent the views of PCORI or its board of governors or methodology committee.

**Additional Contributions:** We acknowledge the Transgender and Non-Binary Surgery Allied Research Collective (TRANS-ARC) steering committee for their invaluable contributions to this work, including Ina Amarillo, PhD; Cris Avery; Madeline Deutsch, MD, MPH; John Gore, MD, MS; Robin Knauerhase; Mary Marsiglio, PhD; Amy Penkin, LCSW; Sachiko Ragosta; Naiymah Sanchez; Jae Sevelius, PhD, and Liz Sage, MPH. We also thank the stakeholders who joined us in this process for trusting the TRANS-ARC steering committee to steward their experiences. The knowledge they shared of themselves and their communities is central to this article.

**Submissions:** Authors should contact Justin B. Dimick, MD, MPH, at jdimick@med.umich.edu if they wish to submit Surgical Innovation papers.

### REFERENCES

1. Canner JK, Harfouch O, Kodadek LM, et al. Temporal trends in gender-affirming surgery among transgender patients in the United States. *JAMA Surg*. 2018;153(7):609-616. doi:10.1001/jamasurg.2017.6231

2. Adams N, Pearce R, Veale J, et al. Guidance and ethical considerations for undertaking transgender health research and institutional review boards adjudicating this research. *Transgend Health*. 2017; 2(1):165-175. doi:10.1089/trgh.2017.0012

3. De las Nueces D, Hacker K, DiGirolamo A, Hicks LS. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. *Health Serv Res*. 2012;47(3 pt 2):1363-1386. doi:10.1111/j.1475-6773.2012.01386.x

4. Nápoles AM, Santoyo-Olsson J, Stewart AL. Methods for translating evidence-based behavioral interventions for health-disparity communities. *Prev Chronic Dis*. 2013;10:E193-E193. doi:10.5888/pcd10.130133

5. Siskind RL, Andrasik M, Karuna ST, et al. Engaging transgender people in NIH-funded HIV/AIDS clinical trials research. *J Acquir Immune Defic Syndr*. 2016;72(72)(suppl 3):S243-S247. doi:10.1097/QAI.0000000000001085

6. Asquith A, Sava L, Harris AB, Radix AE, Pardee DJ, Reisner SL. Patient-centered practices for engaging transgender and gender diverse patients in clinical research studies. *BMC Med Res Methodol*. 2021;21(1):202. doi:10.1186/s12874-021-01328-4

7. Sofolahan-Oladeinde Y, Mullins CD, Baquet CR. Using community-based participatory research in patient-centered outcomes research to address health disparities in under-represented communities. *J Comp Eff Res*. 2015;4(5):515-523. doi:10.2217/cer.15.31



© 2022 American Medical Association. All rights reserved.

Downloaded From: https://jamanetwork.com/ Oregon Health & Science University by Geolani Dy on 05/06/2023