

# Patient-Centered Practices for Engaging Transgender and Gender Diverse Patients in Clinical Research Studies

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## Research article

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# Abstract

**Background:** The purpose of this formative study was to assess barriers and facilitators to participation of transgender and gender diverse (TGD) patients in clinical research to solicit specific feedback on perceived acceptability and feasibility of research methods to inform creation of a multisite longitudinal cohort of primary care patients engaged in care at two community health centers.

**Method:** Between September-November 2018, four focus groups (FGs) were convened at two community health centers in Boston, MA and New York, NY (N=28 participants across all 4 groups; 11 in Boston and 17 in New York). FG guides asked about patient outreach, acceptability of study methods and measures, and ideas for study retention. FGs were facilitated by TGD study staff, lasted approximately 90 min in duration, were audio recorded, and then transcribed verbatim by a professional transcription service. Thematic analyses were conducted by two independent analysts applying a constant comparison method. Consistency and consensus were achieved across code creation and application aided by Dedoose software.

**Results:** Participants were a mean age of 33.9 years (SD 12.3; Range 18-66). Participants varied in gender identity with 4 (14.3%) being male, 3 (10.7%) female, 8 (28.6%) transgender male, 10 (35.7%) transgender female, and 3 (10.7%) nonbinary. Eight (26.6%) were Latinx, 5 (17.9%) Black, 3 (10.7%) Asian, 3 (10.7%) another race, and 5 (17.9%) multiracial. Motivators and facilitators to participation were: research creating community, research led by TGD staff, compensation, research integrated into healthcare, research applicable to TGD and non-TGD people, and research helping TGD communities. Barriers were: being research/healthcare averse, not identifying as TGD, overlooking questioning individuals, research coming from a 'cisgender lens', distrust of how the research will be used, research not being accessible to TGD people, and research being exploitative.

**Conclusion:** Though similarities emerged between the perspectives of TGD people and research citing perspectives of other underserved populations, there are barriers and facilitators to research which are unique to TGD populations. It is important for TGD people to be involved as collaborators in all aspects of research that concerns them.

## Background:

Transgender and gender diverse (TGD) people are individuals whose gender identity differs from their assigned sex at birth. TGD people are disproportionately burdened by adverse outcomes across a range of physical and mental health conditions, such as in HIV infection, mental health, and substance use, and have unmet healthcare needs compared to their cisgender (non-transgender) peers (1–6). Social marginalization and experiences of gender minority stress and stigma (7,8) have been shown to fuel health disparities for TGD people. There is a need to identify health-promoting factors to leverage for interventions to improve TGD population health. Research has found that medical gender affirmation (hormonal therapies, surgical interventions) is associated with improved psychological functioning and

health-related quality of life for TGD people (9–16), yet to our knowledge no studies have demonstrated a causal relationship between gender affirming medical care and improved HIV-related outcomes (17). Studies are needed to evaluate the impact of medical gender affirmation on HIV prevention and care, known areas of health disparity for TGD people, particularly longitudinal research to assess improved outcomes over time to inform clinical care and models of healthcare delivery.

Despite the growing evidence-base that TGD individuals suffer profound health disparities, transgender individuals may be reticent to participate in research. TGD people face many barriers to access and receipt of healthcare generally, such as lack of knowledgeable providers, experiences of violence and harassment in health settings, and financial costs (4,18,19). TGD individuals may experience apprehensions and/or similar barriers regarding participating in medical research about their health, such as lacking trust in cisgender researchers and providers due to concerns about damaging, exploitative encounters (20,21). Conversely, factors may facilitate the participation of TGD in research, such as access to needed medical care, community engagement and participation, and wanting to contribute to trans health research (21,22).

Historically, TGD people have engaged with research in the context of HIV programs and funding resources. Some prior research has been conducted to assess barriers and facilitators to TGD people participating in HIV-specific research TGD (21,23,24). Aside from HIV clinical trials, there has been little insight into the barriers and facilitators of other health outcomes research in TGD populations (25,26).

Research into barriers and facilitators to participating in research has been conducted in other marginalized populations, such as people living with HIV (27–29), men who have sex with men (MSM) (30–35) racial and ethnic minorities (32,36,37) and people who use drugs (32,37). Common barriers to participating in research for these groups have included: 1. Mistrust of researchers (38–41), 2. Feeling exploited/ having fears of being exploited (28,41), 3. Aversion to research (42), 4. Time (32,37,40,41,43), 5. Study design concerns (44), 6. Not wanting to feel like a guinea pig (29,37,38,40,44), and 7. Confidentiality concerns (40). Facilitators to research participation have included: 1. Finding meaning in the study content (38), 2. Believing the research could benefit participants and/or society/ altruism (31,32,37,39,42,43,45), 3. Financial incentive (31,32,34,37,39,46), 4. Opportunity to build and/or be part of a community (32), 5. Familiarity with the organization conducting the research (31), 6. Having a trusted person, such as a primary care provider, think it is a good idea to participate (41), and 7. Having past positive experiences with the research staff (41).

One study examined barriers and facilitators to research participation in LGBT women living with HIV in Toronto, Canada, but it was not focused specifically on the trans community. This study found that “meaningful engagement” in research, especially for marginalized communities, required listening to the voices of the research participants. Participants spoke of facilitators to participating, such as feeling the research would come back to the community or benefit them, as well as barriers, such as feeling exploited or dehumanized when participating in research (28). It is important to ascertain barriers and facilitators

that exist for TGD people in research participation, especially any barriers and facilitators that uniquely necessitate consideration for the TGD population.

The purpose of this study was to generally assess barriers and facilitators to participation of TGD patients in clinical research, and to solicit specific feedback on perceived acceptability and feasibility of research methods to inform creation of a multisite longitudinal cohort of primary care patients engaged in care at two community health centers.

## **Methods:**

### **Study Design**

This qualitative study was designed to inform the research methods, study protocol, and infrastructure of a patient-centered longitudinal cohort study of TGD adult primary care patients at two community health centers. Between September-November 2018, four focus groups (FGs) were convened, two at Fenway Health in Boston, MA and two at Callen-Lorde Community Health Center in New York, NY (N=28 participants across all 4 groups). The purpose of the FGs was to solicit community feedback, opinions, and suggestions about barriers and facilitators to research participation in TGD patients, and assess the perceived acceptability and feasibility of different research methodologies. Fenway Health and Callen-Lorde are community health centers with expertise in providing safe, competent, and informed care to LGBTQ populations (47). In the last decade, the centers have served increasing numbers of TGD primary care patients. Across both sites, approximately 10,000 TGD patients received care in 2018.

### **Participants and Procedures**

FGs were recruited using in-clinic print flyers and electronic advertisements on social media; outside recruitment was not necessary as only current health center patients were eligible. Individuals who met the following criteria were considered eligible for participation: (a) age 18 years or older, (b) have a gender identity differing from their sex assigned at birth (verified at screening via two-step method cross-categorizing natal sex and gender identity), (c) current primary care patient at Fenway Health or Callen-Lorde (defined as those who have had at least one medical visit in the prior 12 months), and (d) able to read, speak and understand English.

Participants provided verbal consent on the phone prior to attending the FG discussion. They also completed a brief demographic survey (age, gender identity, sex assigned at birth, race, ethnicity, and geographic location) prior to FG participation. FG discussions were held in-person, lasted an average of 90 minutes and were led by a primary facilitator and a supporting facilitator. Across each site, TGD-identified staff facilitated the groups. Participants were compensated with a \$25 gift card upon completion of each FG. The Fenway Institute Review Board approved all study procedures.

### **Data Collection Instruments**

A semi-structured focus group discussion guide was used to gather data across several domains: (1) research perspectives, (2) study participation, (3) study materials and communications, (4) recruitment, and (5) retention. FG guides were developed in collaboration with a multi-disciplinary team of investigators and a Community Advisory Board (CAB). FGs were audio recorded and transcribed verbatim by a professional transcription service.

## **Data Analysis**

FG transcripts were analyzed using thematic analysis and applying the constant comparative method (48). Using Dedoose 8.3.17 software, two independent analysts applied thematic codes to a subset of transcripts and constructed a codebook informed by the focus group guide. Through an iterative process, analysts independently coded each transcript, and then compared codes for codebook refinement, integrating newly emerging themes. After each of the four FG transcripts were initially coded and reviewed, finalized codes were shared, and refined further to ensure consistency and consensus. All four focus group transcripts were re-coded with the finalized codes. Findings were shared with the CAB and corroborated and cross-checked with study investigators and community members. Sample demographics from the brief survey were summarized (frequency, percent) using Excel.

## **Results:**

### **Sample Characteristics**

Twenty-eight individuals participated in all 4 focus groups with 11 (39.3%) participants in Boston and 17 (60.7%) in New York City (Table 1). Participants were a mean age of 33.9 years (SD 12.3; Range 18-66). Participants varied in gender identity with 4 (14.3%) being male, 3 (10.7%) female, 8 (28.6%) transgender male, 10 (35.7%) transgender female, and 3 (10.7%) nonbinary. Twelve (42.9%) were assigned male at birth and 16 (57.1%) were assigned female at birth. Eight (26.6%) participants were Latinx and/or Hispanic and 20 (71.4%) were not Latinx or Hispanic. Twelve (42.9%) participants were White, 5 (17.9%) Black, 3 (10.7%) Asian, 3 (10.7%) another race, and 5 (17.9%) multiracial.

### **Motivators/Facilitators to Participating in TGD Health Research**

Participants discussed a variety of motivators/facilitators to participating in TGD health research projects.

#### **Research creating community**

Participants described that TGD health research can provide them the opportunity to connect with other TGD individuals, thus creating a community of participants. They felt motivated to participate in research in order to be part of this community (Table 2 Quote 1).

#### **Research led by TGD-identified researchers**

Many participants discussed wanting to participate in research that was led and facilitated by TGD researchers. They spoke of feeling more comfortable talking about sensitive topics, such as gender affirmation and transitioning, when the researchers were TGD themselves (Table 2 Quote 2). Participants wanted TGD individuals to be involved in all levels of the research enterprise, not just as CAB members – but as leaders and part of the team to plan and develop the study research questions and protocols, collect data, conduct and interpret analyses, and publish and disseminate findings (Table 2 Quote 3).

### Compensation

Another motivator/facilitator that participants frequently spoke about was receiving compensation (Table 2 Quote 4). Participants described monetary compensation such as gift cards or cash or their time. They also spoke of payment to compensating for costs occurred to participate, such as missing work or transportation costs and time. Participants indicated that larger incentives were necessary when the risks to participate were higher, such as with blood draws or sample collection. Additionally, participants highlighted non-monetary compensation, such as referral to other studies and health, social, or community resources as facilitating participation.

### Research integrated into healthcare

Participants explained that when studies are integrated into their healthcare visit or regularly scheduled appointments, it makes participating in research easier and more feasible (Table 2 Quotes 5-6). Leveraging existing visits prevents participants from having to make a special trip to the study site, reduces the amount of time required from the study participant, and makes the study more “efficient” (Table 2 Quote 6). Likewise, this approach of combining care and research reduces barriers to participation, such as transportation and missed work.

### Relatable to TGD and cisgender people

Some participants spoke of the importance of research content being relatable to both TGD and cisgender individuals. One participant gave an example of body dysmorphia being applicable to both TGD individuals and cisgender women, since cisgender women are often sexualized and experience unhealthy ideas of body image (Table 2 Quote 7). Some participants explained that research that spans health concerns of TGD and cisgender people makes the content more relatable and can provide motivation for participation in like-minded research.

### Helping the TGD communities

Many participants spoke of being motivated to participate in TGD-identified health research in order to help the TGD community (Table 2 Quotes 8-10). Participants explained that research can help TGD individuals in similar ways to advocacy work (Table 2 Quote 10). They spoke of wanting to be a part of something that will impact their community in a positive way and to be altruistic.

## **Barriers to Participating in TGD Health Research**

### Research and healthcare averse

Some participants spoke of dislike and distrust of seeking healthcare, going to the doctor, medical environments, or participating in health research. One participant explained that they only accessed healthcare in dire situations; thus, they had never participated in research before (Table 2 Quote 11).

### Do not identify with being labeled as TGD

A few participants spoke of not liking to be referred to as or not calling themselves TGD, “trans” or “transgender.” One participant felt the word did not describe them (Table 2 Quote 12). Another explained this was not a part of their identity and they did not feel connected to or part of TGD communities (Table 2 Quote 13). Participants described that as a result they did not feel drawn to research labeled “transgender research” or studies marketed to TGD individuals.

### Overlooking individuals who are not “trans enough” or missing those who are questioning

Participants expressed concern of TGD health studies missing individuals who are questioning or not “out” as TGD due to either the studies not recognizing them as TGD or the participant not thinking they are eligible for a study recruiting TGD individuals (Table 2 Quotes 14-15). One participant explained that many different identities would fall under the TGD umbrella and could be missed (Table 2 Quote 15).

### Research from a “cisgender lens”

Participants expressed dislike of TGD health research where they had to simplify, over explain, or “dumb stuff down” for cisgender researchers (Table 2 Quotes 16-17). They also expressed being suspicious of why cisgender researchers were conducting TGD health research (Table 2 Quote 16). They felt cisgender researchers infantilize TGD people and assume that TGD people are not knowledgeable about TGD health topics (Table 2 Quote 17).

### Distrust of how the research will be used/ privacy concerns

Some participants expressed being wary of how research data will be used and not trusting researchers to give them their information (Table 2 Quotes 18-19). One participant explained it was because TGD individuals have been “burned in the past” by researchers (Table 2 Quote 18). Another individual explained that participants often never see how their efforts benefit the community (Table 2 Quote 20).

### Not accessible to TGD communities/ unaware of research opportunities

Participants expressed not knowing about health research opportunities or where to go learn about TGD studies (Table 2 Quotes 21-22). Participants also perceived that TGD communities were often unaware of research studies.

### Research that is objectifying/ exploitive

Participants described disliking research that felt opportunistic, where researchers were only conducting TGD health research because it was “the new hot thing” or publishable (Table 2 Quote 23). They also spoke of participating in research where they felt their experiences were misrepresented in research findings and disliked feeling like a subject or “put under a microscope” (Table 2 Quote 24).

### **Best Practices for Recruiting and Retaining TGD Participants**

Participants described “best practices” for recruitment and retention to meaningfully engage TGD individuals in research studies.

#### **Recruitment**

##### *Providers connecting participants to research*

Many participants spoke of wanting to be referred to studies by their medical providers. They suggested having providers give out fliers on TGD health research studies to their TGD patients (Table 3 Quote 1) or having pop-ups in provider emails to have them remind patients of study opportunities that patients may qualify for (Table 3 Quote 2).

##### *Going into TGD community spaces*

Participants also highlighted the importance of having researchers come to organizations, groups, and community spaces frequented by TGD individuals to either tell them about studies or pass out fliers (Table 3 Quotes 3-4).

##### *One-on-one contact (e.g., texts, calls, conversations)*

Participants expressed liking one-on-one contact methods. They explained this could be via texts sent out with study opportunities or having a face-to-face conversation about the study with a research staff (Table 3 Quotes 5-6).

##### *Social media to both link individuals to care and recruit participants*

A few participants suggested that social media (e.g., Facebook, Instagram) would be an effective way to enroll TGD people in studies who are not currently accessing healthcare at study sites. Reaching out about TGD research opportunities was also described as a means of getting these individuals linked to needed healthcare services (Table 3 Quote 7).

##### *Multiple modalities*

Participants expressed the importance of using multiple recruitment methods to reach TGD patients, such as telephone calls, texts, fliers, and social media (Table 3 Quote 8), especially from an accessibility standpoint (Table 3 Quote 9).

#### **Retention**

### *Providing postage*

Participants explained that providing paid postage to return surveys and other forms of study data would make it easier to participate (Table 3 Quote 10-11).

### *Reminders*

Participants expressed liking routine check-ins and contact with study staff via phone and email as reminders to participate in the surveys and visits, as well as to demonstrate to them that researchers care about their participants (Table 3 Quotes 12-13).

### *Emphasize importance of research content*

Some participants felt that research content and emphasizing how research participation will help TGD communities and society will keep participants engaged (Table 3 Quote 14).

## **Patient-Centered TGD Health Research Methods**

Participants expressed ideas for improving research methods in TGD health research.

### Survey bias in measures

Many participants spoke of surveys and other measures in TGD health research tending to focus on negative outcomes and experiences. They spoke of how asking only “negative” questions, such as about depression and risks, could paint an overly negative picture of how someone is feeling if they are not also asked about happiness, positive outcomes, or lived experiences of resiliency (Table 4 Quotes 1-2). One participant discussed the over-emphasis on gender dysphoria as an example of bias in TGD research, and wanted to learn about gender euphoria – a positive counterpart describing the feeling of self-actualization and joy in finding comfort in one’s gender identity and expression.

### Biospecimen collection as optional with consent for specific usage

Some participants expressed concern about biospecimen collection. They spoke of wanting to know what the biospecimens would be used for and wanting researchers to acquire consent for each specific use of the biospecimen (Table 4 Quote 3). Others wanted to be told the purpose of collecting a biospecimen and how the researchers were planning to use it (Table 4 Quote 4). Some desired biospecimen collection to be an optional component or research study procedure (Table 4 Quote 5).

### Interviews/focus groups as candid conversations

Participants expressed liking when interviews or focus groups felt informal and like a genuine conversation (Table 4 Quote 6). They also described the importance of transparency and comfort in these methods of data capture.

### Disseminating research findings back to the community

Participants explained that they wanted to be told of the research findings of the studies they participated in (Table 4 Quote 7). This was described as a way to build trust with communities and show respect for research participation. There was also an interest in ongoing dissemination of study findings, such as through quarterly or annual newsletters.

### Having a diverse sample

Participants talked about the importance of including a diverse sample of TGD participants in TGD health studies. They explained that the sample should be representative of how diverse TGD individuals are (Table 4 Quote 8), as well as be inclusive of individuals from different neighborhoods, of different races and ethnicities, and having diverse LGBTQ identities (Table 4 Quote 9). One participant also emphasized the importance of seeking out hard to reach TGD individuals who “are least likely to be able to” participate in order to include their experiences and voices in the research (Table 4 Quote 9).

## **Discussion:**

In discussing both facilitators and barriers to TGD health research participation, a consistent theme that emerged from this study was a strong desire from FG participants to feel connected to and engaged in the research, and being certain that the work has an impact on TGD communities. Participants highlighted that having TGD investigators and research staff leading the research would foster participant engagement and community comfort. A “participatory population perspective” has been described by Reisner et al. (2016) as vital to public health efforts with TGD populations (49). This approach entails working “with” not “on” communities in public health research, practice, and advocacy. It is a methodology grounded in the philosophical perspective that any TGD public health endeavor will only be a true success if there is meaningful input and partnership with TGD communities. Findings from the current study support the use of a participatory population perspective to conduct clinical research with TGD people, including partnering with paid staff, researchers, and community members in all aspects of the work—research methodology, recruitment and retention, data collection, analysis and interpretation, and dissemination and sharing of results—to inform and advocate for TGD health justice.

Trust was an important theme that emerged across focus groups. In the context of social stigma, many people who are members of a marginalized group, such as gender diverse populations, may feel most trusting of and comfortable interacting with people from within the same group. A barrier identified to research participation was the historical absence of TGD people on the study team to ensure the study was properly vetted and would prioritize participant safety, comfort, privacy, and trust. Participants described that lack of TGD research staff contributes to their skepticism about how the research will be valued by the researchers or how findings will be utilized. Rather than feel like collaborators, participants may feel like they are being taken advantage of or exploited (41,45).

Building upon this theme, participants expected to be fairly compensated for their time, or to otherwise have participation be low-barrier and low-effort (31,32,34,37,39,46). For a cohort that is recruited from a clinical patient population, participants identified one way to make participation low-effort is to integrate

survey measures into existing healthcare models and delivery. One example would be to not require additional visits to the clinic, if not necessary; however, there was a strong preference for compensation among participants, regardless of low-effort or streamlined survey implementation.

In addition, participants emphasized a desire for the research methods to be non-pathologizing of TGD identities. Specifically, participants requested questions that could be asked of both TGD and cisgender TGD people, so as not to pathologize learning about TGD health and medicine. Further, some TGD people do not identify with the label “TGD” and therefore wanted to feel as though the questions being asked of them could apply to all people, irrespective of TGD status. Additionally, some TGD people may still be questioning or unsure of their gender identity and may also be overlooked. Participants expressed concern that not including people in both of these categories – those not identifying as TGD and those questioning or unsure of their gender identity – would lead to survey bias and exclude data from an important segment of TGD people receiving clinical care.

Several themes that arose in the focus group discussions have important implications for recruitment and retention methods. Many revolve around the value of connection and building trusted relationships and rapport into recruitment and retention strategies. Participants spoke of wanting to be connected to research by their medical providers, a trusted party. They wanted researchers to similarly make a connection with them, either through one-on-one methods, such as telephone calls and texts, going into and showing up in TGD community spaces, or using social media networking platforms to reach out to them. This is important as we know that mistrust of researchers is a common barrier to research participation among other minority populations as well (Cottler et al., 2013; Anthea Lesch, 2006; Dhalla, 2011; Behringer-Massera, 2019). Methods that help build rapport between the community and researchers, therefore, are critical for TGD health researchers. Similarly, participants wanted to feel a connection to the study, explaining that the research content would likely keep them retained in research. Feeling they were a part of something that had impact was essential to participation, a finding that has been observed in other minority populations (Cottler et al., 2013). Therefore, this is an important consideration for recruitment strategies, with the expected impact of a study potentially being highlighted in recruitment materials.

Practicality emerged as another key theme key for recruitment and retention. Participants explained researchers needed to reach out to potential study participants via multiple modalities. This was perceived of as vital to reach participants of different identities and create a diverse and inclusive sample. It was also mentioned as an efficient way of reaching TGD participants. Ease of participation was highlighted as important for recruitment as well as to keep them retained. Methods like providing postage and reminders via telephone calls, emails, and mail-out letters were felt to make ongoing participating more realistic. Thus, TGD health researchers should foreground ways to make participation in research as convenient as possible for participants, especially as many participants will have competing needs. This was also felt to be essential and contribute to building trust with participants. Methods that communicate and show participants that researchers value their time, a barrier to research participation documented in other marginalized communities (Strauss, 2001; Buchbinder, 2004; Dhalla,

2011; Slomka, 2008; Behringer-Massera, 2019), were highly endorsed. The importance of connection, rapport, and trust in TGD health research were also thematically in common around best practices for methodology. Participants wanted qualitative research methods (e.g., focus groups, interviews) to feel candid, informal, and transparent. They also wanted research findings to be disseminated back into the community and prioritized as part of participation in the research, which can be implemented most successfully when trust and rapport have already been established between researchers and participants.

Participants were concerned that current research methodologies could be misrepresenting TGD people's experiences and identities. They spoke of survey bias and measures often focusing exclusively on the negative spectrum, such as depression, and missing the resilience of participants, such as learning and growing through hard times. The participant who described the focus on gender dysphoria at the expense of gender euphoria offered a powerful example. In TGD research, it is important that surveys capture a full spectrum of participants' experiences and feelings. Researchers should consider adding resiliency scales to their survey instruments. Participants also expressed taking care to ensure TGD research participants were not homogenous in identity, explaining the importance of having a sample diverse in race, ethnicity, geographic locales, and sexual and gender identities.

Participants also wanted options to be ingrained into research methodology, such as biospecimen collection being optional with consent required for each specific usage. Participants wanted to be explicitly told how their biospecimen would be used. Researchers should consider ways to allow participants more autonomy and control in decision-making about participating in research, including opting not to participate in some components. This further serves to communicate respect for TGD people in clinical research procedures, and re-enforces trust-building with the community.

Our findings with TGD patients corroborate findings from prior research on research participation in marginalized populations. There are common facilitators (e.g., financial incentive, altruism, positive experiences with research staff) and barriers (e.g., time, study design concerns, feeling exploited) to research participation amongst marginalized communities. However, it is also evident that there are barriers and facilitators unique to TGD populations (e.g., biased survey measures, not identifying the being labeled as TGD, overlooking individuals who are not "trans enough" or missing those who are questioning). Therefore, it is important for TGD voices to be involved in all aspects of research, including the planning of study design, recruitment, data collection, analysis and interpretation, and dissemination.

## Limitations

Interpretation of study findings should be contextualized alongside several limitations. While diverse in terms of age, gender identity, sex assigned at birth, and race, FG participants were not sampled in a representative fashion so may not reflect the patient populations of clinical sites. Additional research should be conducted with hard to reach TGD individuals, purposively sampling those who are questioning and less connected to TGD communities. Due to focus groups being conducted in-person, accessibility issues may have limited participation; multiple methods, including online participation,

should be considered for future research. Despite limitations, this study has a number of strengths, including assessment of barriers and facilitators to participating in clinical research for TGD people by asking TGD participants themselves.

## Conclusion

Although the list of barriers and facilitators identified to research participation for TGD people in this study is not exhaustive, it is a promising starting point for future researchers to consider when developing projects that engage TGD communities. More time should be spent to continue learning about and overcoming the barriers and facilitators TGD people face to participating in research, as well as how research methodologies, recruitment, and retention efforts can best engage and reach TGD individuals. Gender-affirming practices grounded in community engagement and participation, transparency, and trust are vital to TGD research. Working collaboratively in researcher-community partnerships to move TGD health research ahead should be prioritized as a strategy moving forward in TGD clinical research.

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## Tables

<b>Table 1. Descriptive Characteristics of Study Participants (N=28)</b>	
<b>Characteristic</b>	<b>% (n) or M (SD), Range</b>
Age in Years	33.9 (12.3), 18-66
<b>Gender Identity</b>	
Male	14.3 (4)
Female	10.7 (3)
Transgender Male	28.6 (8)
Transgender Female	35.7 (10)
Nonbinary	10.7 (3)
<b>Sex Assigned at Birth</b>	
Male Assigned at Birth	42.9 (12)
Female Assigned at Birth	57.1 (16)
<b>Ethnicity</b>	
Latinx/Hispanic	28.6 (8)
Not Latinx/Hispanic	71.4 (20)
<b>Race</b>	
White	42.9 (12)
Black	17.9 (5)
Asian	10.7 (3)
Another Race	10.7 (3)
Multiracial	17.9 (5)
<b>Geographic Location</b>	
Boston	39.3 (11)
New York City	60.7 (17)

**Table 2. Motivators/Facilitators and Barriers to Participating in TGD Health Research (N=28)**

<b>Motivators/Facilitators</b>	Research creating community	<p>1. "I know there's a lot of situations where a trans person can become like – can just be isolated, but I think research and things that can help form a sense of community and, like you said, there have been so many millions of us throughout the years in human history."</p> <p>-Boston</p>
	Research led by TGD researchers	<p>2. "I've done a few research things, and something I always appreciate is when they're run by trans people. I had one thing where I didn't know too much about the person that was interviewing me, and I was just, like, why is it not queer, like, not gay, not trans dude asking me all these, like, really [meaningful] questions about my transition? But then at the end, he did [say] that he was trans, and that just made me feel, like, a lot better. Because it's like, talking about your experience."</p> <p>-New York</p>
		<p>3. "In terms of research priorities of being in research studies I feel like it's a priority to have trans people and not just one token trans person but trans people as integral part of the research team designing it from the beginning. Like really there at every step."</p> <p>-New York</p>
	Compensation	<p>4. "I was going to say, the only way to truly – to get more people would probably be to give them an incentive and to give them a gift card or something, because I get surveys all the time."</p> <p>-Boston</p>
	Research integrated into healthcare	<p>5. "I think it's great that it could just be integrated into our regular visits with primary care. We don't have to really do anything super extra that would take up large chunks of our time, involve extra visits."</p> <p>-Boston</p>
		<p>6. "If you'd integrated it...that's more efficient, yeah."</p> <p>-Boston</p>
	Relatable to TGD and cisgender people	<p>7. "even a cis person, if you ask them about – something about how they relate to their body, it might get them thinking...Because I've read a lot that even with women who would consider themselves cisgender, they experience a massive amount of body dysmorphia just because of like how women – or cis women, rather, specifically, are forced to grow up and socialize and be</p>

sexualized from a young age and it creates like a really warped body image. Like, it's something that I feel like a lot of women might not notice until you ask them about how they present themselves. And like, of course this manifests in trans women too because they're still exposed to the same socialization."

-Boston

Helping the TGD community

8. "I feel good about furthering trans-health research and trans-health equity."

-Boston

9. "I would basically like to be going to the research studies, because it basically helps us trans people basically over time"

-New York

10. "Yeah. I think research can be a form of advocacy if done correctly, and I think that anyone and everyone who participates in this study is doing their community's a favor because I think data can be very powerful"

-Boston

**Barriers**

Research and healthcare averse

11. "I've never done any studies anywhere. I've been told – two years ago, I never really saw doctors or went to hospitals for anything, for any reason whatsoever. I'm the type that, to even get me to walk into an ER, the bone's got to be sticking out."

-Boston

Do not identify with being labeled at TGD

12. "It's complicated because it's like good and bad at the same time. You know what I mean? But overall it's just like – like I said there is no category for me. I don't identify as any of that. I do but I don't"

-New York

13. "I don't like to label myself as trans. You know what I mean? Like I don't even like that word...can't relate me to the community because I'm not the community. I am but I'm not. I'm just me. Don't really identify."

-New York

Overlooking individuals who are not "trans enough" or

14. "To build on that, I think maybe questioning folks may also not feel like they're included...under the study premises even if they would be."

-Boston

missing those  
who are  
questioning

15. "I would even argue that it's important for people to identify that way or are stealth or – that data is there too. So it's hard when you don't want to share that and don't identify as that but also that's many people under the umbrella who should also be represented in some way."

-New York

Research from  
a "cis lens"

16. "I tend to be instinctively kind of weary of transTGD-focused things that aren't headed at least mostly by trans people because it always feels a little bit like, "alright, so what are cis people gaining from this. Like, what is your stake in this?" And also it being lead by trans people also makes me feel like there's more of a floor to get really into the weird, granular stuff of gender experience without having –like, without the people you're serving having to like dumb stuff down basically. At least don't have to explain what trans means. [laughter] That's big."

-Boston

17. "I feel like sometimes things that are meant to be more targeted towards the trans demographic sometimes kind of still feel like they have cis-people gloves on, if that makes sense. Kind of like baby talking through, and it's like, "no, we can just talk seriously about this.""

-Boston

Distrust of  
how the  
research will  
be used/  
Privacy  
concerns

18. "it's unfortunate when you're dealing with any group of people that has been burned in the past. They just sometimes don't trust easily. So they're like, "Well, I'm not giving you my information.""

-New York

19. "I feel like there might be a chunk of people who don't want anything to do with that study. Just be like, "I don't want my information being out in the world.""

-New York

20. "people put in all these informations, and at the same time, you almost feel like it never reaches, like, people, so they can see us in a different light... So I feel like that's maybe one of the reasons why they don't want to participate."

-New York

Not accessible to the TGD community/ Unaware of research opportunities

21. "Well, again, I'm just saying, what are we supposed to be doing, like, going to transresearch.com every single day [laughter]"

-New York

22. "This was happenstance. I saw this on Facebook...I don't know that transgender people – like, where are we supposed to hear about studies that are being conducted about our community?"

-New York

Research that is objectifying/ exploitive

23. "it felt like they were doing it because it's the new hot thing and just wanted to like oh like this paper will get accepted, this is an easy project because there's nothing about trans people so we don't have to work too hard. And it really felt bad."

-New York

24. ""why are the results of this study so depressing?" Or like, "that's not what I said. Why is what I said so miscommunicated in this report?" And it feels very exploitative and it feels very like we're put under a microscope, right, as a community."

-Boston

**Table 3. Patient-Centered Approaches for Engaging TGD Participants (N=28)**

<b>Recruitment</b>	Providers connecting participants to research	1. "I think having providers mention it would be helpful... like, "Okay, well since you're here and you're one of my trans patients, you might be interested in taking part in this study. Here's a flyer." Just kind of do it like that."  -New York
		2. "What if, in terms of getting the little pop-ups in our inboxes about reminders, the providers also get little pop-ups in their inbox to remind their trans patients [of studies]."  -Boston
	Going into TGD community spaces	3. "Well, a lot of us go to a lot of organizations or groups. So if you go to different organizations that are trans-focused and go to trans groups you're going to find trans people."  -New York
		4. "But as far as getting people out I guess can also have like flyers, information at places where trans people gather. Or maybe have someone come in and describe the studies to us. And then we'll... see the person representing...so your organization must be good"  -New York
	One-on-one contact (e.g. texts, calls, conversations)	5. "text messages 'cause a lot of people are, like, always on the phone, so they'll see."  -New York
		6. "I also like this idea like sitting in person and having a conversation like face to face asking us how we feel about it."  -New York
	Social media to both link individuals to care and recruit participants	7. "Because, like, if you felt that you couldn't get enough people at Callen, some form of social media might be able to get you the non-Callen trans people of New York."  -New York
	Multiple modalities	8. "Having multiple form of communications. Not just Facebook or digital but also paper forms. Phone calls. Text messages."  -New York

9. "I think also like using like phone call...very important for patients who have disabilities. If you just put posters up then blind people will never know it exists. So making sure that everybody can access the information even if they're blind or deaf or whatever the case may be."

-New York

**Retention**

Providing postage

10. "You know, I take it if you mailed me a form, and at my convenience...Great, and the post is payed, put it in the box, that's fine."

-Boston

11. "postage, paid, returned envelope... anyone who was remotely interested in their particular subject matter would [put] it in the mail."

-Boston

Reminders  
(e.g. calls,  
emails, letters)

12. "Like an e-mail blast once a month. Nothing too aggressive. Just maybe every other month or once a month."

-New York

13. "Because it'll show us you actually care...a check-in phone call in between visits."

-New York

Emphasize  
importance of  
research  
content

14. "Compensation is great, but also just being a part of it is really great because it's for the advancement of our lives and a legacy that we can leave behind in a way. And so, maybe just the emphasis on that at the second interval."

-Boston

**Table 4. Best Practice for Research Methods (N=28)**

**Research Methods**

Survey bias in measures (e.g. quality of life scales focused on negative spectrum)

1. "Everybody was kind of nudging at this a little bit earlier and even just now, but there is a – there's like a scale for depression...I fill out this thing when I come into my PCP... there's no inverse of that, you know what I mean? There's no elation. [laughter] And I – when you say we're going to measure quality of life, I want to know how happy people are, you know?"

-Boston

2. "Also, the thing about that is like I always feel like every single time I have to go to a PCP, I have to – when I hand the tablet or whatever back to the nurse, I have to head it off with like, "I know this looks like I'm severely more depressed than I am.""

-Boston

Specimen collection as optional with consent for specific usage

3. "at the very least say, "if we're going to do something on it, we will come back to you and ask for that specific consent," to say, "this is specifically what we're going to do," instead of being like, "take my DNA,""

-Boston

4. "it's plasma; we're not going to miss it much. But I guess... probably like clarity of purpose, or like communicating ideas of what you intend to do with it would probably be a better call."

-Boston

5. "about the blood collection...if you had just had it separated in two different parts, so it's like, people that give blood and then people that don't give blood."

-Boston

Interviews/focus groups as candid conversation

6. "It was a cisgender man who identified as gay, and then me, I identify as genderfluid, and it was just, like, a candid conversation. We had never met each other, and it was us talking about health care and how we thought that things should change."

-New York

Disseminating research findings back to the community

7. "Right, and you're left wondering, "what were the results of that study?""

-Boston

Having a diverse sample

8. "I think other kinds of diversity is important. Not just like oh, it's all trans people. Making sure it's not all the same trans person. That it really represents the diversity of who we are."

-New York

9. "Well, you'd want to be able to get to multiple neighborhoods...for it to be a study that's got meaning, you can't be drawing from one strata, whether that means income strata, or one skin color...you've got to try to hit all those different rainbow colors...The people who are least likely to be able to be a part of this study are the people who you probably should want the most, in my opinion."

-Boston