



# Community-generated solutions to cancer inequity: recommendations from transgender, non-binary and intersex people on improving cancer screening and care

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## ABSTRACT

**Objective** Transgender, non-binary and intersex people are less likely to receive appropriate cancer screening for their bodies and have a higher incidence of certain cancers than cisgender people. We aimed to elicit community-generated solutions to improve cancer screening for these populations.

**Methods and analysis** We conducted six online, asynchronous focus groups in English and Spanish with transgender, non-binary, intersex and cisgender participants who were at least 15 years of age from across the USA. Participants shared their experiences with cancer screening and related conversations with healthcare providers and recommendations for making screening practices more inclusive of their bodies and experiences. Focus group data were exported into transcripts and analysed with thematic analysis.

**Results** The 23 participants represented a diversity of races, genders, sexualities, ages and geographical locations. Transgender, non-binary and intersex participants, particularly Black, Indigenous and/or people of colour, reported having to self-advocate to receive necessary care by initiating conversations about screening with their providers, requesting specific screenings and educating providers about the appropriate care for their body. Notably, no white or cisgender participants described having to request relevant screenings or initiate conversations with their providers. Participants recommended that forms ask about body parts and allow for self-identification.

**Conclusion** The ability to properly screen patients can have a direct impact on cancer outcomes. More inclusive intake forms may alleviate the need for transgender, non-binary and intersex patients to self-advocate to receive necessary care. More work should be done to educate providers on cancer risk for transgender, non-binary and intersex individuals.

## INTRODUCTION

A nascent body of research suggests that transgender, non-binary and intersex people bear a disproportionate cancer burden

### WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ A growing body of research has documented the disproportionate cancer burden among transgender, non-binary and intersex individuals, likely due to systemic inequity and under screening among these populations.
- ⇒ Little is known about the best practices for cancer screening of these populations.

### WHAT THIS STUDY ADDS

- ⇒ Our study found that transgender, non-binary and intersex participants who were also Black, Indigenous and/or people of colour had experienced conversations with healthcare providers about cancer as uncomfortable, that providers did not have answers to their questions, and they had to self-advocate by doing their own research, educating their providers or requesting that specific relevant screenings be done.
- ⇒ Participants recommended specific alterations to create inclusive and accurate screening practices such as asking about body parts, gender identity, specific sexual practices and providing content warnings before discussing potentially sensitive topics.

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Improved provider education about transgender, non-binary and intersex health needs and more inclusive screening practices may help to alleviate inequities in cancer screening and in turn improve community health outcomes for transgender, non-binary and intersex patients.

relative to cisgender people, though much of this research is made up of case studies and anecdotal evidence; some population cancer statistics fail to include these populations.<sup>1–8</sup> **Box 1** includes definitions of relevant terms modified from prior literature.<sup>9</sup> Disparities in cancer incidence may be attributable in part

**Box 1 Terms and definitions\***

Transgender is a broad term that describes a person whose gender identity (eg, man, non-binary, woman) differs from the gender commonly associated with the sex they were assigned at birth (ie, female, intersex, male).

Non-binary describes gender identities that are not limited to man or woman—they could be a combination of both or neither. Some individuals who identify as non-binary and/or gender expansive may identify as transgender as well, and some may not.

Intersex describes someone who identifies as intersex who has 'natural variations in sex characteristics that do not seem to fit typical binary notions of male or female bodies' (InterAct Advocates for Intersex Youth and Lambda Legal, 2018).

Cisgender describes someone who identifies with the gender assumed to be associated with their sex assigned at birth (eg, someone who identifies as a man and was assigned male at birth would be a cisgender man).

Endosex describes someone whose sex characteristics (hormones, anatomy, etc) from birth fit the normative medical definitions of male and female bodies.

\*Unless otherwise noted, these definitions are modified definitions from prior literature.<sup>9</sup>

to persistent and ubiquitous social inequity—a constellation of social structures and pressures that exclude and marginalise transgender, non-binary and intersex people from adequate healthcare and undermine healthy behaviours.<sup>3</sup> These inequities manifest specifically as egregious barriers to quality healthcare, including discrimination, low insurance coverage, a lack of trained providers, insufficient research evidence and outright refusals of care or even assault.<sup>2 4-6</sup>

Systemic inequities may also drive lower levels of cancer screening among transgender people compared with cisgender people. Studies have documented lower odds of transgender patients receiving relevant cancer screenings for their bodies compared with cisgender individuals: results indicate 21%–70% lower odds of receiving relevant screenings for a range of screening types, including colonoscopy, mammography and pap smears.<sup>1 2 10 11</sup> Lower screening could reflect numerous gaps in care provision, including misclassification of patient eligibility for certain cancer screening protocols. For example, misclassification may stem from screening protocols that fail to consider or integrate gender-affirming hormone use or that include assumptions about anatomy, particularly when rooted in the gender binary.<sup>2 6 12-15</sup> Indeed, the American Cancer Society's recommendations on cancer screening are based on age and binary gender categories of 'men' and 'women'.<sup>16</sup> On the other hand, the National Comprehensive Cancer Network (NCCN) guidelines for breast screening acknowledge the difference between sex and gender, stating that: 'NCCN recommendations have been developed to be inclusive of individuals of all sexual and gender identities to the greatest extent possible. On this page the terms males and females refer to sex assigned

at birth'.<sup>17</sup> A comparison of screening guidelines from major US cancer organisations can be found in [table 1](#).

However, comprehensive research, guidelines and policies for cancer screening that meaningfully include and care for transgender, non-binary and intersex people are lacking. Furthermore, the effects of these failures of current screening protocols may be compounded by lack of provider knowledge of cancer risk for transgender, non-binary and intersex patients.<sup>18</sup> These failures in screening hold epidemiological implications as earlier detection of cancer has been linked to improved care, chance of survival and quality of life, and lower treatment morbidity than later diagnosis.<sup>19</sup>

Given this evidence of failures of cancer screening for transgender, non-binary and intersex populations, we set out to elicit community-generated solutions to modifiable aspects of cancer screening processes. We conducted six focus group discussions (FGDs) to understand if and how the routine clinical intake process can be modified to improve appropriate cancer screening for transgender, non-binary and intersex people, and thus improve health outcomes for these populations.

**MATERIALS AND METHODS****Participant selection**

We recruited participants for six online, asynchronous FGDs in English and Spanish. Eligible participants included individuals age 15 years and older who resided in the USA and spoke English or Spanish as their primary language. We intentionally recruited transgender, non-binary and intersex people, and also included cisgender people as any identified recommendations for changing the intake process will need to apply for all patients to move away from siphoning all care into trans-specific clinics and because gender identity is subject to change.

Between June and October 2021, we sent recruitment emails to community-based organisations and individuals working with transgender, non-binary and intersex populations and posted study advertisements to online message boards including Discord, Craigslist and Reddit, and social media platforms including Facebook, Instagram and Twitter. Recruitment materials provided a link for interested individuals to complete a short eligibility survey. After reviewing survey submissions, the research team identified up to eight individuals for each of the six FGDs to maximise the diversity of each FGD in terms of age, geographical location, gender identity, race/ethnicity and cancer diagnoses of participants. The team then emailed selected individuals to review and complete a consent form and a short online demographic survey (online supplemental files 1–2). Those who consented were assigned to participate in an FGD that aligned with their gender group (cisgender, transgender and endosex, or transgender and intersex) and primary language so that participants could feel comfortable sharing about their personal experiences only with those who might be able to relate.

**Table 1** Current standard cancer screening guidelines from three nationally recognized institutes

| Cancer Type | American Cancer Society*  | National Comprehensive Cancer Network (NCCN)§  | US Preventative Services Taskforce (USPSTF)¶  |
|-------------|---|--|---|
| Breast      | 'Women ages 40–44 should have the choice to start annual breast cancer screening with mammograms (X-rays of the breast) if they wish to do so. Women ages 45–54 should get mammograms every year. Women 55 and older should switch to mammograms every 2 years, or can continue yearly screening.'  | 'Women with average risk between the ages of 25 and 39: The NCCN panel recommends a clinical encounter, which includes ongoing breast cancer risk assessment, risk reduction counselling, as well as a clinical breast exam every 1–3 years, and encouraging women to be aware of their breasts and promptly report any changes to their healthcare provider'. | 'The US Preventative Services Taskforce (USPSTF) recommends biennial screening mammography for women aged 50–74 years.'   |
| Cervical    | 'Cervical cancer screening should start at age 25. People under age 25 should not be tested because cervical cancer is rare in this age group. People between the ages of 25 and 65 should get a primary HPV (human papillomavirus) test* done every 5 years. If a primary human papillomavirus (HPV) test is not available, a co-test (an HPV test with a Pap test) every 5 years or a Pap test every 3 years are still good options.' |  | 'The USPSTF recommends screening for cervical cancer every 3 years with cervical cytology alone in women aged 21–29 years. For women aged 30–65 years, the USPSTF recommends screening every 3 years with cervical cytology alone, every 5 years with high-risk HPV (hrHPV) testing alone, or every 5 years with hrHPV testing in combination with cytology (cotesting).' |
| Colorectal  | 'For people at average risk for colorectal cancer, the American Cancer Society recommends starting regular screening at age 45. If you're in good health, you should continue regular screening through age 75.'  | 'It is recommended that screening for persons at average risk begin at 45 years of age after available options have been discussed.'   | 'The USPSTF recommends screening for colorectal cancer in adults aged 45–49 years.'   |
| Prostate    | 'Starting at age 50, men should talk to a healthcare provider about the pros and cons of testing so they can decide if testing is the right choice for them. If you are African American or have a father or brother who had prostate cancer before age 65, you should have this talk with a healthcare provider starting at age 45.'   | 'The panel recommends that baseline postate-specific antigen testing should be offered to healthy, well informed, average risk individuals aged 40–75 years based on the results of randomized clinical trials.'   |   |

Examples of cancer screening guidelines taken from three nationally recognised institutes.

\*Cancer Screening Guidelines | Detecting Cancer Early n.d. <https://www.cancer.org/healthy/find-cancer-early/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html> (accessed 1 March 2023).

§NCCN Clinical Practice Guidelines in Oncology: Breast Cancer 2022. ; NCCN Clinical Practice Guidelines in Oncology: Colorectal Cancer Screening 2022.; NCCN Clinical Practice Guidelines in Oncology: Prostate Cancer Early Detection 2023.

¶A and B Recommendations | United States Preventive Services Taskforce n.d. <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation-topics/uspstf-a-and-b-recommendations> (accessed 23 March 2023).

A sample size of six FGDs was set based on empirical research suggesting that 90% of qualitative themes are discoverable within 3–6 focus groups.<sup>20</sup> With concurrent review of FGD transcripts, the research team concluded that the six FGDs had sufficient information power (as an alternative to 'saturation', information power can be used to determine sample size sufficiency through assessment of the depth and quality of information available in a qualitative dataset) to warrant closing recruitment

based on the clarity of the study aim, sample specificity, quality of focus group contributions and simplicity of the analysis strategy.<sup>21</sup>

### Patient and public involvement

We recruited a community advisory board (CAB) at the start of the research project to elicit feedback from stakeholders who were transgender, non-binary and/or intersex and had relevant experience in research, cancer history,

clinical care and/or community advocacy. Together with the seven-person CAB, the research team iteratively developed a structured FGD guide, with modified versions for transgender, non-binary and/or intersex participants vs cisgender participants, including questions driven by the CAB's interests. CAB members helped to draft inclusive language for study materials and supported recruitment efforts by sharing with their networks and offering strategies to improve recruitment for hard-to-reach communities. CAB members have supported and will continue to support in providing feedback on data analysis and dissemination strategies and reviewing and coauthoring materials for their sensitivity to and inclusion of transgender, non-binary and intersex people.

### Research tool development

The FGD guide was created in English and then translated into Spanish. The FGD guides (online supplemental files 3–6) were designed to cover four core topic areas: (1) conceptualisations of gender identity, (2) healthcare experiences and disclosure, (3) review of a new screening tool and (4) recommendations for screening.

### Data collection

Once participants completed the consent form, we emailed them instructions for using the online platform FlexMR for their online asynchronous FGD. Each asynchronous online FGD took place over 4 days. On each of the 4 days, participants logged onto FlexMR to view and respond to the study questions for that day. Once a participant submitted their response to a question, they could then see and respond to all responses to that question from other participants. Study facilitators also posted follow-up questions to participants to elicit additional detail and encourage ongoing discussion. This asynchronous online format allowed participants to respond to questions on their own time with less urgency. We estimated total participation time at approximately 30 min per day, or 2 hours over the 4 days.

The FGD online platform automatically recorded all participant responses and facilitator probes in a written transcript, viewable only to the study team. This transcript included the exact text provided by each participant including any responses to follow-up questions asked by the facilitators or fellow participants. After completion of the FGD, participants received a US\$75 electronic gift card for their participation.

### Research team positionality

The first, fourth and last author jointly facilitated the FGDs. At the time of the study, these individuals were all employed by Ibis Reproductive Health in full-time research positions and had received training in FGD facilitation. The broader research team, including those involved in the study design, data analysis and drafting of this manuscript, includes university professors, a practising physician and a masters level student, who collectively identify with a range of identities including as

cisgender women, queer, transgender and non-binary, as Black, East Asian, Jewish, Latinx, South Asian, white and who speak English, Hebrew and Spanish as their primary languages.

### Analysis

We conducted a thematic analysis of the downloaded FGD text records. Two bilingual members of the research team read all transcripts and developed a codebook based on the FGD discussion guide. We a priori identified six codes that were most relevant: cancer, intake process, language, transgender, non-binary, and intersex specific health, provider communication, and recommendations. Two members of the research team independently applied these selected codes to two English transcripts to assure consistency in coding, and further refine code definitions. After adjusting the codebook accordingly, one researcher coded the full set of transcripts and organised excerpts in Excel by theme. Researchers analysed and coded all transcripts in their original languages so that meaning was not lost in translation.<sup>14 15</sup>

We drafted code summaries for each code to highlight the breadth of participant experiences reported, and to identify patterns. The research team reviewed all text files and code summaries, and convened several times to discuss ideas and core findings. In addition to narrative description of findings, we included excerpts of participants' responses to ground the findings in specific examples in the participants' own words. We list the participant age category and broad racial/ethnic identity for each excerpt as context.

## RESULTS

### Participant characteristics

Among 43 invited participants, 32 consented to participate, 25 people logged-in to an FGD and 23 (14 English-speaking and nine Spanish-speaking) responded to at least one of the questions included in these analyses. Participants identified with a diversity of genders and racial/ethnic identities (table 2). Notably, most (n=19 or 83%) participants were Black, Indigenous and/or people of colour (BIPOC), and all intersex participants (n=5) also identified as transgender, non-binary or gender expansive. Regarding access and exposure to cancer screening, most participants (n=19 or 83%) had health insurance, and most (n=17 or 74%) had received a cancer-related procedure or screening in the past 2 years.

### Patient self-advocacy in cancer screening conversations with providers

Across FGDs, transgender, non-binary and intersex participants—particularly those who were also BIPOC—described multiple ways in which self-advocacy played an influential role in their conversations with providers about cancer screening, risk or treatment. Self-advocacy included performing one's own research on individual health risks and needs, initiating conversations with

**Table 2** Participant characteristics (June–October 2021, USA), n=23

|                            | Overall (n=23) |    | TGE & endosex (n=4) |     | TGE & intersex (n=5) |     | Cisgender (n=9) |     | Unknown (n=5) |    |
|----------------------------|----------------|----|---------------------|-----|----------------------|-----|-----------------|-----|---------------|----|
|                            | n              | %  | n                   | %   | n                    | %   | n               | %   | n             | %  |
| Age in years               |                |    |                     |     |                      |     |                 |     |               |    |
| Median age                 | 25             |    | 40                  |     | 25                   |     | 25              |     | 25            |    |
| Mean age (SD)              | 29             | 11 | 40                  | 13  | 22                   | 4   | 31              | 11  | 23            | 4  |
| 18–24 years                | 4              | 17 | 0                   | 0   | 2                    | 40  | 1               | 11  | 1             | 20 |
| 25–34 years                | 12             | 52 | 1                   | 25  | 3                    | 60  | 5               | 56  | 3             | 60 |
| 35–44 years                | 3              | 13 | 1                   | 25  | 0                    | 0   | 2               | 22  | 0             | 0  |
| 45–54 years                | 2              | 9  | 1                   | 25  | 0                    | 0   | 1               | 11  | 0             | 0  |
| 55–67 years                | 2              | 9  | 1                   | 25  | 0                    | 0   | 0               | 0   | 1             | 20 |
| Primary language           |                |    |                     |     |                      |     |                 |     |               |    |
| English                    | 14             | 61 | 3                   | 75  | 5                    | 100 | 4               | 44  | 2             | 40 |
| Spanish                    | 9              | 39 | 1                   | 25  | 0                    | 0   | 5               | 56  | 3             | 60 |
| Gender identities          |                |    |                     |     |                      |     |                 |     |               |    |
| Genderqueer                | 2              | 9  | 0                   | 0   | 1                    | 20  | 0               | 0   | 1             | 20 |
| Man                        | 8              | 35 | 1                   | 25  | 2                    | 40  | 3               | 33  | 2             | 40 |
| Non-binary                 | 6              | 26 | 2                   | 50  | 1                    | 20  | 2               | 22  | 1             | 20 |
| Woman                      | 6              | 26 | 1                   | 25  | 0                    | 0   | 4               | 44  | 1             | 20 |
| Additional gender category | 3              | 13 | 0                   | 0   | 2                    | 40  | 0               | 0   | 1             | 20 |
| Género destructivo         | 1              | 4  | 0                   | 0   | 0                    | 0   | 0               | 0   | 1             | 20 |
| Gender fluid               | 1              | 4  | 0                   | 0   | 1                    | 20  | 0               | 0   | 0             | 0  |
| Trans man                  | 1              | 4  | 0                   | 0   | 1                    | 20  | 0               | 0   | 0             | 0  |
| Intersex                   |                |    |                     |     |                      |     |                 |     |               |    |
| Yes                        | 5              | 22 | 0                   | 0   | 5                    | 100 | 0               | 0   | 0             | 0  |
| No                         | 16             | 70 | 4                   | 100 | 0                    | 0   | 9               | 100 | 3             | 60 |
| Prefer not to say          | 1              | 4  | 0                   | 0   | 0                    | 0   | 0               | 0   | 1             | 20 |
| Unknown                    | 1              | 4  | 0                   | 0   | 0                    | 0   | 0               | 0   | 1             | 20 |
| Race/ethnicity             |                |    |                     |     |                      |     |                 |     |               |    |
| Black or African American  | 6              | 26 | 2                   | 50  | 1                    | 20  | 2               | 22  | 1             | 20 |
| East Asian                 | 1              | 4  | 0                   | 0   | 0                    | 0   | 0               | 0   | 1             | 20 |
| Hispanic or Latinx         | 11             | 48 | 1                   | 25  | 1                    | 20  | 7               | 78  | 2             | 40 |
| White                      | 4              | 17 | 1                   | 25  | 1                    | 20  | 2               | 22  | 0             | 0  |
| Unknown                    | 1              | 4  | 0                   | 0   | 0                    | 0   | 0               | 0   | 1             | 20 |
| Another race/ethnicity     | 2              | 8  | 0                   | 0   | 2                    | 40  | 0               | 0   | 0             | 0  |
| Health insurance coverage  |                |    |                     |     |                      |     |                 |     |               |    |
| None                       | 3              | 13 | 1                   | 25  | 0                    | 0   | 2               | 22  | 0             | 0  |
| Private health insurance   | 12             | 52 | 2                   | 50  | 2                    | 40  | 5               | 56  | 3             | 60 |
| Medicaid/medicare          | 7              | 28 | 1                   | 25  | 3                    | 60  | 2               | 22  | 1             | 20 |
| TRICARE or military        | 1              | 4  | 1                   | 25  | 0                    | 0   | 0               | 0   | 0             | 0  |
| Prefer not to say          | 1              | 4  | 0                   | 0   | 0                    | 0   | 0               | 0   | 1             | 20 |
| Health procedures had      |                |    |                     |     |                      |     |                 |     |               |    |
| Pap smear                  | 11             | 48 | 2                   | 50  | 3                    | 60  | 5               | 56  | 1             | 20 |
| Mammogram                  | 4              | 17 | 1                   | 25  | 0                    | 0   | 3               | 33  | 0             | 0  |
| Prostate exam              | 5              | 22 | 0                   | 0   | 2                    | 40  | 2               | 22  | 1             | 20 |
| Another procedure          | 3              | 13 | 1                   | 25  | 0                    | 0   | 0               | 0   | 2             | 40 |

Continued

Table 2 Continued

|                    | Overall (n=23) |    | TGE & endosex (n=4) |     | TGE & intersex (n=5) |    | Cisgender (n=9) |    | Unknown (n=5) |    |
|--------------------|----------------|----|---------------------|-----|----------------------|----|-----------------|----|---------------|----|
|                    | n              | %  | n                   | %   | n                    | %  | n               | %  | n             | %  |
| Prefer not to say  | 4              | 17 | 1                   | 25  | 0                    | 0  | 2               | 22 | 1             | 20 |
| Hysterectomy       | 1              | 4  | 1                   | 25  | 0                    | 0  | 0               | 0  | 0             | 0  |
| None of the above  | 1              | 4  | 0                   | 0   | 0                    | 0  | 0               | 0  | 1             | 20 |
| Diagnoses received |                |    |                     |     |                      |    |                 |    |               |    |
| Testicular cancer  | 3              | 13 | 0                   | 0   | 2                    | 40 | 1               | 11 | 0             | 0  |
| None of the above  | 18             | 78 | 4                   | 100 | 2                    | 40 | 8               | 89 | 4             | 80 |
| Prefer not to say  | 2              | 9  | 0                   | 0   | 1                    | 20 | 0               | 0  | 1             | 20 |
| Region             |                |    |                     |     |                      |    |                 |    |               |    |
| Midwest            | 2              | 9  | 0                   | 0   | 0                    | 0  | 2               | 22 | 0             | 0  |
| Northeast          | 7              | 30 | 2                   | 50  | 3                    | 60 | 1               | 11 | 1             | 20 |
| Southeast          | 6              | 26 | 0                   | 0   | 1                    | 20 | 4               | 44 | 1             | 20 |
| Southwest          | 4              | 17 | 2                   | 50  | 1                    | 20 | 0               | 0  | 1             | 20 |
| West coast         | 4              | 17 | 0                   | 0   | 0                    | 0  | 2               | 22 | 2             | 40 |

TGE, Transgender, Non-binary, Gender-expansive.

providers and even requesting that a necessary screening be performed. Notably, no cisgender participants mentioned having initiated a conversation about cancer with their providers. In some instances, self-advocacy shaped if and when transgender, non-binary and intersex participants received needed information about cancer screening. One participant described:

Luckily, one of my providers who only works with trans patients, is very good at explaining to me why I need a cervical cancer screening... However, with another PCP [primary care provider] I have, I am the one who has to request or bring up that I want this type of screening done. Which feels weird that it is not in my online chart or portal saying 'okay your next PAP smear is in xx months' (22-34 years old, Non-binary, nonbinary transmasculine, Black or African American, English-speaking)

Some transgender, non-binary and intersex participants described feeling forced to self-advocate when providers failed to initiate needed conversations. This failure was linked to providers lacking accurate information—or apparently the willingness to educate themselves—on current cancer screening protocols for transgender, non-binary and intersex people. One participant, for example, asked about chest cancer screening post top surgery and their provider both did not know the answer and failed to follow up about it. For others, self-advocacy stemmed from curiosity and an interest in participating actively in their own healthcare.

Notably, all participants who mentioned having to initiate these cancer screening conversations with their providers were in the English-speaking FGDs and were BIPOC (specifically, Black, East Asian, Hispanic

or Latinx, Indigenous, mixed). Conversely, white and Spanish-speaking participants who reported having had these conversations described providers initiating needed conversations, making self-advocacy less necessary. The participant below described how multiple providers initiated conversations about cancer screening and risk:

I discussed cancer risks before top surgery with my primary care physician, the surgeon doing my top surgery and a radiologist due to an abnormal mammogram. My primary care physician was first to bring it up, then the surgeon's nurse practitioner. (55-67 years old, Non-binary, White, English-speaking)

Beyond or perhaps in relation to having to self-advocate, transgender, non-binary and intersex BIPOC participants also explicitly described their conversations about cancer screening and risk with providers as uncomfortable; no cisgender or white participants described these discussions as uncomfortable. One participant internalised the idea that the need to self-advocate is because their health concerns are less important to the providers than bureaucratic factors, such as addressing insurance coverage. They described,

They never have answers for me. All they seem to care about are the steps that they need to take for insurance to cover x, y, and z. They have no idea how to address hormonal concerns. One provider even said that she wasn't sure if her clinic was open to discussing hormonal concerns because it's a women's clinic. (24-34 years old, Genderqueer, East Asian, English-Speaking)

BIPOC transgender, non-binary and intersex participants took the initiative to self-advocate in clinical

encounters with providers related to cancer screening; however, this self-advocacy caused discomfort, did not always result in the patient receiving necessary information, and occasionally served as proof of provider negligence.

### Embedding self-advocacy in the clinical intake process

Across identities, participants emphasised the importance of embedding a more inclusive and accurate self-identification system within the clinical intake process, which would ease the burden of self-advocating and correcting provider assumptions in a clinical encounter predisposed to be inaccurate based on inaccurate intake forms.

Transgender, non-binary and intersex participants overwhelmingly communicated frustration with clinical intake forms and a sense that forms were inappropriate and inaccurate for their bodies and experiences. Participants across gender identities considered forms inaccurate or inappropriate because they included only a limited number of gender options, did not ask for pronouns, failed to verify the body parts one has or hormones used, used binary language and relied only on 'assigned sex'.

Common recommendations included interventions to directly counter the limitations listed above; specifically, asking about gender identity with multiple inclusive options, asking for pronouns, asking about organs/body parts that patients have, and providing explanation for asking certain questions about sexual activity or partners. One participant expressed many of these as well as the importance of being very specific when asking about topics that could have broad and varied definitions, such as sex:

Ask for my assigned name and...how I want to be called. Ask for my pronouns. Ask for my gender identity. Ask for my sex (INCLUDING intersex identity). Allow me the option to explain my sex. Ask for my parents (not mother and father's) names and contacts. Ask how I want my body parts to be called ie. chest area rather than boobs.

Also, if you must ask for sexual identity... Try to encompass all sexualities and allow people to pick more than one because a lot of us have more than one label. I for sure do. And when you talk about sex, don't say sex when you really mean PIV [penis in vagina] or anal sex. If you want to ask what sex I have had, ask about a specific sex act because sex TO ME means intercourse (ie. nipple play, oral sex, fingering). Be SPECIFIC. (18-24 years old, Non-binary, Trans, genderfluid, intersex, Hispanic or Latinx, Mixed raced with Black, Indigenous, and European roots, English-speaking)

Similar to the quote above expressing a desire for the provider to say 'chest area' instead of 'boobs', many intersex participants recommended adding questions to the intake form to ask for the words patients use for their own body parts; rather than presuming use of medical

terms. A few participants additionally shared the importance of providing a content warning to prime patients for potentially sensitive questions on an intake form, such as questions about sexual organs and sexual partners.

Cisgender participants, conversely, tended to speak in more general and abstract terms, naming things like not making assumptions, avoiding demeaning language, privacy and treating everyone the same. For example, one participant shared,

La atención médica debe ser equitativa para todos sin importar el sexo, género.

Translation: Medical care must be equitable for all regardless of sex, gender. (25-34 years old, Cisgender woman, Hispanic or Latinx, Spanish-speaking)

In summary, participants had clear, specific and actionable suggestions for how to embed patient self-identification in the intake process, and thereby facilitate the provision of more accurate, affirming and patient-centred cancer screening and care. These recommendations have been compiled into [table 3](#). Note that while similar recommendations are highlighted in broader sexual and reproductive health research, these practice points summarise the recommendations provided by our transgender, non-binary and intersex participants.

## DISCUSSION

In this study, we present an analysis of 6 online FGDs with 23 people, conducted among transgender, non-binary, intersex and cisgender participants in English and Spanish to identify community-generated improvements to modifiable aspects of cancer risk assessment and screening. Participants expressed a need for more individualised, patient-centred care, including a proactive assessment of their gender identity and body parts by their provider. Throughout, the link between how clinicians measure patient characteristics, for instance, via intake forms, and the resulting impact on community health was clear and striking.

When examined through the lens of overlapping participant identities, transgender, non-binary and intersex BIPOC participants more frequently described having to initiate conversations with their providers about cancer risks and care, needing to request relevant screenings, and more often reported feeling uncomfortable in these conversations. This may be due to differences in social privilege, a dynamic reflected elsewhere in the literature.<sup>18 22 23</sup> Considering that cancer screening is a mandatory part of primary care practice and that the American Cancer Society recommendations for screening are provided for 'men' and 'women', and assuming cisgender and endosex patients, these findings seem particularly relevant as transgender, non-binary and intersex patients may be attempting to make up for this lack of appropriate screening recommendations through self-advocacy. However, this self-advocacy does not always

**Table 3** Practice points for individualised care

| Practice point   | Examples  |
|--|---|
| More inclusive and specific language on intake forms   | <ul style="list-style-type: none"> <li>▶ Ask about gender identity and pronouns with ‘check all that apply’ options, as well as a write-in option</li> <li>▶ Ask about which body parts people have and hormones used rather than assuming, but only ask when relevant</li> <li>▶ Ask about intersex identity and details of intersex diagnosis</li> <li>▶ Avoid binary language and assumptions about patients’ bodies or sexual activity</li> </ul>   |
| Consent  | <ul style="list-style-type: none"> <li>▶ Ask permission before discussing topics with patients and letting patient know why that topic will be discussed (Eg, if a patient asks about STI-testing, ‘In order to gauge which tests to order, may I ask some questions about your recent sexual history?’)</li> <li>▶ On intake forms, provide preface before asking about sensitive topics (eg, To introduce our organ inventory we included: ‘To ensure that you are screened in a way that is appropriate for you, we ask ALL people about which body parts you CURRENTLY have.’)</li> <li>▶ Ask what name and pronouns a patient would like to use (and provide opportunities to change this information at each visit)</li> <li>▶ Allow patients to provide the words they want providers to use for their bodies</li> </ul> |
| Education/attitude   | <ul style="list-style-type: none"> <li>▶ Provider education on trans-inclusive care (eg, knowledge about breast cancer risk for individuals who have had top surgery; knowledge about impact of hormones in area of expertise)</li> <li>▶ Willingness to look for answers to questions of transgender and intersex patients and follow-up when unsure of answer</li> </ul>  |
| Stream-lined medical records system  | <ul style="list-style-type: none"> <li>▶ Prior to each appointment, provide the option for patients to complete screening forms online re their body parts, hormone-use, and surgery history</li> <li>▶ Patient form is accessible to provider during the patient visit and should prompt provider to initiate relevant conversations (eg, if patient is over 21 years old and has a cervix and has not had a pap smear in 3 years, medical record system should prompt provider to initiate that conversation)</li> </ul>  |
| Community-generated recommendations for clinical intake and screening processes that are more inclusive of and relevant to the experiences of transgender, non-binary and intersex people. |   |

sufficiently compensate for the lack in provider knowledge on cancer screening protocols, especially for transgender, non-binary and intersex patients.

### Consistency with other literature

Understanding patients’ wishes can help clinicians lay a foundation for affirming patient–provider interactions through a quick assessment of the patient’s gender identity, correct pronouns and name. Participants described the discomfort they experienced when intake forms and the providers they spoke with made assumptions instead of asking about their patient’s gender identity, body parts, sexual activity or language. This mirrors past research that has documented the discomfort caused by gendered language and provider assumptions in clinic settings and how that discomfort can lead transgender and non-binary individuals to avoid seeking care.<sup>24 25</sup> A previous study with transgender and gender-diverse participants in the Washington DC area reported that trust in one’s provider is an important factor in health seeking, and that participants were much more likely to seek cancer

screening if receiving a relevant recommendation from their provider.<sup>26</sup> This along with our findings suggests that improved trust through more affirming intake processes could improve care-seeking behaviours and overall community health of transgender, non-binary and intersex individuals.

Intersex participants specifically mentioned wanting to be asked about their body parts and about the anatomical terms they are comfortable using (eg, using the term ‘chest’ rather than ‘breasts’). This highlights a need uniquely important to the population of intersex individuals, whose healthcare experiences have been understudied. A recent national survey of intersex individuals reveals that intersex individuals report worse health status than expected for their age, which may be related to difficulty accessing high-quality, intersex-aware healthcare.<sup>27</sup>

BIPOC transgender, non-binary and intersex participants reported needing to self-advocate to receive relevant care. Previous studies have reported that Black and Latinx individuals are less likely to bring up health



information they sought outside of the clinical setting with their provider, while also more likely to use this information to change their approach to maintaining their health.<sup>28–30</sup> This difference in patient self-advocacy, however, has been employed by transgender, non-binary and gender-expansive individuals as a strategy to mitigate healthcare discrimination and stigma.<sup>31</sup> It is, therefore, imperative for clinicians to facilitate discussions around cancer screening with their patients using best practices in patient-centred care, including screening beyond the American Cancer Society recommended categories to ensure that all patients receive relevant screenings without bearing the burden of self-advocacy.

### Strengths and limitations

Our study has some unique strengths. Study participants represent a range of gender and racial/ethnic identities, and primary languages. Our study sample includes both English and Spanish participants and is inclusive of intersex individuals, who are often an invisible group, rarely represented in studies assessing healthcare needs. Further, asynchronous online FGDs have been shown to facilitate research participation for people that might otherwise face insurmountable barriers to research participation (eg, travel distance, time off from work or childcare) and to increase participant comfort expressing their views in detail, given the anonymity conferred by the online forum.<sup>32 33</sup> The online asynchronous platform format also reduces the time and cost of conducting in-person FGDs as well as the potential for errors generated from translating spoken word into written word during transcription.<sup>34 35</sup>

Our study also has some important limitations. Most participants in this study did not have a previous diagnosis of cancer, and thus we cannot determine whether experiences differ based on cancer history. Participants in the study, while being inclusive of different demographics, were mostly young (median age=25, range=18–67), and had to have online access and feel comfortable communicating in a written format to participate. Despite screening recommendations that prioritise older populations, most of the participants ages 18–34 had received a cancer screening; whether they had been screened did not correlate with having a recommendation, or the nature of the recommendation. Future studies should intentionally recruit participants in older age brackets who may have more experience with different kinds of cancer screening, possibly by recruiting in person rather than online. Though participants joined from all US census regions, half resided in only three states (California, New York and New Mexico), which make up for less than 19% of the US population.<sup>36</sup> Additionally, some comparisons may be hard to attribute to one identity factor or another as many participants held multiple marginalised identities. Finally, we did not ask about factors that influenced their level of self-advocacy or discomfort with provider conversations. Additional research in these areas is warranted.

### CONCLUSIONS

Transgender, non-binary and intersex participants who were BIPOC reported facing unique challenges to care, including reporting greater discomfort with conversations about cancer while also reporting a greater need for initiating these conversations. In interactions with their healthcare provider, participants wanted to be respected and to be asked directly about their gender identity, pronouns and—notably for intersex individuals—about their body parts. Efforts to educate providers on cancer screening and care specific to transgender, non-binary and intersex patients are critical to advancing health equity by alleviating the burden of self-advocacy. Recognising the diversity of bodies, genders and behaviours offers a path for providers to actively improve transgender, non-binary and intersex individuals' health and will ultimately contribute to more equitable cancer screening, treatment and overall community health.

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