



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.^{1–8} **Box 1** includes definitions of relevant terms modified from prior literature.⁹ 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.⁹

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.³ 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.^{2 4-6}

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.^{1 2 10 11} 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.^{2 6 12-15} Indeed, the American Cancer Society's recommendations on cancer screening are based on age and binary gender categories of 'men' and 'women'.¹⁶ 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'.¹⁷ 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.¹⁸ 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.¹⁹

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.²⁰ 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.²¹

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.^{14 15}

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.^{18 22 23} 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"> ▶ Ask about gender identity and pronouns with ‘check all that apply’ options, as well as a write-in option ▶ Ask about which body parts people have and hormones used rather than assuming, but only ask when relevant ▶ Ask about intersex identity and details of intersex diagnosis ▶ Avoid binary language and assumptions about patients’ bodies or sexual activity
Consent	<ul style="list-style-type: none"> ▶ 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?’) ▶ 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.’) ▶ Ask what name and pronouns a patient would like to use (and provide opportunities to change this information at each visit) ▶ Allow patients to provide the words they want providers to use for their bodies
Education/attitude	<ul style="list-style-type: none"> ▶ 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) ▶ Willingness to look for answers to questions of transgender and intersex patients and follow-up when unsure of answer
Stream-lined medical records system	<ul style="list-style-type: none"> ▶ Prior to each appointment, provide the option for patients to complete screening forms online re their body parts, hormone-use, and surgery history ▶ 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)
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.^{24 25} 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.²⁶ 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.²⁷

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.^{28–30} 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.³¹ 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.^{32 33} 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.^{34 35}

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.³⁶ 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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Patient consent for publication Not applicable.

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Supplemental file 1: English-language: Demographic questionnaire for Focus Group Discussion participants

A. INTRODUCTION

Thank you for your interest in our study. This study has been designed by a diverse team of sexual and reproductive health researchers including individuals who identify as transgender, nonbinary, gender-expansive, and cisgender and are of various sexual orientations.

For most healthcare services and research studies, whether you can participate or not depends on your gender or sex. However, in this study, we will explore new ways of figuring out whether someone is eligible for healthcare and research. These new questions do not rely on gender or sex assigned at birth. Your answers will help us understand when these new questions should be asked, if at all. The goal is to design questions that will better identify who is eligible for types of clinical care and individual research studies, leading to more accurate and inclusive clinical care and research, better science, and better health outcomes for all people.

This survey should take about 5 minutes to complete. Please remember to close your browser window after submitting your responses to prevent anyone from seeing your responses.

B. FOCUS GROUP DISCUSSION ALIAS

0. To protect your confidentiality, what name would you like participants to see during the focus group discussion? This name will be your “alias”, or the name that appears in the focus group online chat that other participants will see. Many people prefer to use a fake name so that their responses remain anonymous.
-

C. GENDER

1. A person's gender is an important, inner concept of self which can include girl/woman, boy/man, a blend of both, neither, and many more. Gender is how each person thinks of themselves and what they call themselves. One's gender can be consistent with, or different than, the gender commonly assumed for their sex assigned at birth. The words a person uses to talk about their gender can change over time.

What is your gender/how do you describe your gender?

2. If you had to choose from the list below, although we acknowledge that these categories may not be ideal, which of the below best describe(s) your current gender? (Select all that apply)
 - Agender
 - Genderqueer
 - Man
 - Nonbinary
 - Two-Spirit (feel free to include your tribe's specific language for your identity, if you would like) _____
 - Woman
 - Additional gender category, please specify: _____

- Prefer not to say
3. Are you transgender, or of transgender experience?
- Yes
 No
 Don't know
 Prefer not to say
4. Do you identify as intersex?
- No
 Yes
 Prefer not to say
5. Has a healthcare provider ever told you that you are intersex or that you have what is sometimes referred to as either a "difference of sex development" or a "disorder of sex development" (DSD)?
- No
 Yes
 I don't know
 Prefer not to say
6. Can you tell us more about what your health care provider told you about your specific diagnosis? (The diagnosis of being intersex or having a DSD)
-
-
-

D. HEALTH HISTORY. These next few questions will ask about health related services or screenings that you may have had.

7. In the past TWO YEARS, please select any and all procedures that you have had:
- Pap smear (A pap smear is a procedure that involves a clinician collecting cells from the cervix to test for signs of cervical cancer)
 Mammogram (A mammogram is an x-ray picture of breast/chest tissue to detect breast cancer)
 Prostate exam (A prostate exam involves a clinician sticking a gloved finger inside the rectum to feel for an enlarged prostate, a sign of potential prostate cancer)
 Another: _____
 Prefer not to say
8. In your LIFETIME, have you ever been diagnosed with the following?
- Human Immunodeficiency Virus (HIV)
 Breast cancer
 Cervical cancer
 Ovarian cancer
 Prostate cancer
 Testicular cancer
 Another cancer: _____
 None of the above
 I don't know
 Prefer not to say

E. SOCIODEMOGRAPHIC CHARACTERISTICS. In this last section, we will ask a few more questions to help us understand more about you. Your responses to these questions will give us a better understanding of who is included in this study.

9. What state do you currently live in? _____
10. How old are you today? _____
11. Which pronouns do you use (select all that apply)
- He/him/his
 - She/her/her
 - They/them/theirs
 - No pronouns, I only use my name.
 - Another: _____
 - Prefer not to say
12. Do you consider yourself to be: (select all that apply)
- Asexual
 - Bisexual
 - Gay
 - Lesbian
 - Pansexual
 - Queer
 - Questioning
 - Same-gender loving
 - Straight/heterosexual
 - Another sexual orientation (please specify): _____
13. What is the highest level of school that you have completed?
- Some high school or less
 - High school degree or GED
 - Trade or technical school and no degree
 - Trade or technical school degree
 - Some college and no degree
 - College degree
 - Graduate or professional study and no graduate degree
 - Graduate or professional degree
14. Which categories best describe you? (select all that apply)
- American Indian or Alaska Native - What tribe(s) are you affiliated with?

 - Black or African American
 - Central Asian
 - East Asian
 - Hispanic or Latinx
 - Middle Eastern or North African
 - Native Hawaiian and Pacific Islander
 - South Asian
 - South East Asian
 - White
 - Unknown
 - Not listed, please tell us: _____
 - None of these

15. What type of health insurance do you have? (select all that apply)
- None
 - Private health insurance (from employer, or that you or someone else pays for)
 - Medicaid
 - Medicare
 - TRICARE or military health insurance
 - Indian Health Service
 - Other (please specify) _____
 - I don't know
40. How would you describe your work status right now?
- Employed full time (40 hours or more per week) and not a student
 - Employed part-time (Up to 39 hours per week) and not a student
 - Employed full-time (40 hours or more per week) and in school
 - Employed part-time (Up to 39 hours per week) and in school
 - Full-time or part-time student, not employed
 - Self-employed
 - Unemployed
 - Retired
 - Unable to work
 - Not listed (please specify): _____
 - None of these
16. Are you a parent? This includes parenting children who are now adults, are deceased, or are not biologically related to you.
- Yes
 - No
 - Prefer not to say
17. Please indicate how you became a parent. **Select all that apply.**
- The egg was fertilized through sexual activity with another parent of the child
 - I carried the child through a pregnancy and was also the egg source for the child
 - I carried the child through a pregnancy but was NOT the egg source for the child
 - I provided the egg for the child that another person carried through the pregnancy
 - I provided the sperm for the child
 - I adopted the child
 - I used donor (anonymous) sperm for the child
 - I used donor (known) sperm for the child
 - I underwent a second parent adoption of my partner's biological child
 - I worked with a surrogate to carry the child
 - I worked with an egg donor to provide the egg source for the child
 - I am a step parent to the child
 - I am a foster parent to the child
 - I became a parent through another method (please specify): _____
 - None of these

END OF SURVEY:

Thank you so much for your participation in this study. We will email or call you soon with detailed log-in information for your online focus group discussion. We look forward to your participation.

If you have questions about this survey or your participation in this study, please contact Anu Manchikanti Gómez at 510-642-0722 or anugomez@berkeley.edu.

Supplemental file 2: Spanish: Demographic survey for focus group discussion participants

A. INTRODUCCIÓN

Gracias por su interés en nuestro estudio. Este estudio ha sido diseñado por un equipo diverso de investigadores de salud sexual y reproductiva que incluye personas que se identifican como transgénero, no binario, de género expansivo y cisgénero y tienen diversas orientaciones sexuales.

Para la mayoría de los servicios de salud y estudios de investigación, si puede participar o no depende de su género o sexo. Sin embargo, en este estudio, exploraremos nuevas formas de determinar si alguien es elegible para recibir atención médica o participar en una investigación. Estas nuevas preguntas no dependen del género o el sexo asignado al nacer. Sus respuestas nos ayudarán a comprender cuándo se deben hacer estas nuevas preguntas, si es que se deben hacer. El objetivo es diseñar preguntas que identifiquen mejor quién es elegible para tipos de atención clínica y estudios de investigación, lo que conducirá a una atención clínica e investigaciones más precisas e inclusivas, mejor ciencia y mejores resultados de salud para todas las personas.

Esta encuesta debería tardar unos 5 minutos en completarse. Recuerde cerrar la ventana de su navegador después de enviar sus respuestas para evitar que alguien vea sus respuestas.

B. ALIAS PARA LA DISCUSIÓN DEL GRUPO FOCAL

0. Para proteger su confidencialidad, ¿qué nombre le gustaría que vieran los participantes durante la discusión del grupo focal? Este nombre será su "alias", o el nombre que aparece en el chat del grupo focal en línea que verán otros participantes. Muchas personas prefieren usar un nombre falso para que sus respuestas permanezcan anónimas.

C. GÉNERO

1. El género de una persona es un concepto interno importante de sí mismo que puede incluir chica / mujer, chico / hombre, una combinación de ambos, ninguno y muchos más. El género es cómo cada persona piensa de sí misma y cómo se llama a sí misma. El género de una persona puede ser consistente o diferente al género comúnmente asumido para su sexo asignado al nacer. Las palabras que una persona usa para hablar sobre su género pueden cambiar con el tiempo.

¿Cuál es su género / cómo describe su género?

2. Si tuviera que elegir de la lista a continuación, aunque reconocemos que estas categorías pueden no ser ideales y que el género no es necesariamente una identidad fija y puede cambiar con el tiempo, ¿cuál de las siguientes describe mejor su género actual? (Seleccione todas las que correspondan)
 - Agénero (sin género)
 - Genderqueer
 - Hombre
 - No binario
 - Two-Spirit (puede incluir el idioma específico de su tribu para su identidad, si lo desea) _____

- Mujer
 - Categoría de género adicional, especifique: _____
 - Prefiero no responder
3. ¿Se identifica como transgénero y / o se considera una persona de experiencia transgénero?
- Sí
 - No
 - No lo sé
 - Prefiero no responder
4. ¿Se identifica como intersexual?
- No
 - Sí
 - Prefiero no responder
5. ¿Alguna vez un proveedor de atención médica le ha dicho que es intersexual o que tiene lo que a veces se denomina "diferencia en el desarrollo sexual" o "trastorno del desarrollo sexual" (TDS)?
- No
 - Sí
 - No sé
 - Prefiero no responder
6. ¿Puede decirnos más sobre lo que le dijo su proveedor de atención médica sobre su diagnóstico específico? (El diagnóstico de ser intersexual o tener un TDS)
- _____
- _____
- _____

D. HISTORIAL DE SALUD. Las siguientes preguntas se referirán a los servicios relacionados con la salud o las pruebas de detección que puede haber tenido.

7. En los últimos DOS AÑOS, seleccione todos y cada uno de los procedimientos que haya tenido:
- Prueba de Papanicolaou (una prueba de Papanicolaou es un procedimiento en el que un médico recolecta células del cuello uterino para detectar signos de cáncer de cuello uterino)
 - Mamografía (una mamografía es una imagen de rayos X del tejido de la mama / pecho para detectar el cáncer de mama)
 - Examen de próstata (un examen de próstata implica que un médico introduzca un dedo enguantado dentro del recto para palpar el agrandamiento de la próstata, un signo de posible cáncer de próstata)
 - Otro: _____
 - Prefiero no responder
8. En su VIDA, ¿alguna vez le han diagnosticado lo siguiente?

- Virus de inmunodeficiencia humana (VIH)
- Cáncer de mama
- Cáncer de cuello uterino
- Cáncer de ovarios
- Cáncer de próstata
- Cáncer testicular
- Otro tipo de cáncer: _____
- Ninguna de las anteriores
- No sé
- Prefiero no responder

E. **CARACTERÍSTICAS SOCIODEMOGRÁFICAS.** En esta última sección, haremos algunas preguntas más para ayudarnos a comprender más sobre usted. Sus respuestas a estas preguntas nos darán una mejor comprensión de quiénes están incluidos en este estudio.

9. ¿En qué estado vive actualmente? _____

10. ¿Qué edad tiene hoy? _____

11. ¿Qué pronombres usa (selecciona todos los que correspondan)?

- Él
- Ella
- Elle
- No uso pronombres, solo uso mi nombre.
- Otro: _____
- Prefiero no responder

12. ¿Usted se considera: (seleccione todo lo que corresponda)...?

- Asexual
- Bisexual
- Gay
- Lesbiana/e
- Pansexual
- Queer
- Cuestionándose
- Amante del mismo género
- Heterosexual
- Otra orientación sexual (especifique): _____

13. ¿Cuál es el nivel más alto de la escuela que ha completado?

- Alguna escuela secundaria o menos
- Título de escuela secundaria o GED
- Escuela técnica o comercial, sin título
- Título de escuela técnica o comercial
- Algo de Universidad, sin título
- Título universitario
- Estudios de posgrado o profesionales, sin título de posgrado
- Licenciatura posgrada o título profesional

14. ¿Qué categorías describe mejor su raza? (seleccione todas las que correspondan)
- Indígena americana o nativa de Alaska: ¿a qué tribu (s) está afiliado? _____
 - Negra o afroamericana
 - De descendencia centroasiática
 - De descendencia asiática oriental
 - Hispana o Latina
 - De descendencia del medio oriente o norteafricana
 - Nativa de Hawaii o de las Islas Pacificas
 - De descendencia surasiática
 - De descendencia asiática del sudeste
 - Blanca
 - Desconocida
 - No incluida (especifique): _____
 - Ninguna de las anteriores
15. ¿Qué tipo de seguro médico tiene? (seleccione todas las que correspondan)
- Ninguno
 - Seguro médico privado (del empleador o que usted u otra persona pague)
 - Medicaid
 - Medicare
 - TRICARE o seguro médico militar
 - Indian Health Service
 - Otro (especifique) _____
 - No sé
40. ¿Cómo describiría su situación laboral en este momento?
- Empleade a tiempo completo (40 horas o más por semana) y no soy estudiante
 - Empleade a tiempo parcial (hasta 39 horas por semana) y no soy estudiante
 - Empleade a tiempo completo (40 horas o más por semana) y soy estudiante
 - Empleade a tiempo parcial (hasta 39 horas por semana) y soy estudiante
 - Estudiante a tiempo completo o parcial, no empleade
 - Trabajo por cuenta propia
 - Desempleade
 - Retirade
 - Incapaz de trabajar
 - No incluido (especifique): _____
 - Ninguna de las anteriores
16. ¿Usted es xadre? Esto incluye la crianza de hijos que ahora son adultes, han fallecido o no están relacionadas biológicamente con usted.
- Sí
 - No
 - Prefiero no responder
17. Indique cómo se convirtió en xadre. **Seleccione todas las que correspondan.**
- El óvulo fue fertilizado a través de la actividad sexual con otre xadre del niño
 - Llevé a le niño por un embarazo y también fui la fuente de óvulos para le niño

- Llevé a la niña durante un embarazo, pero NO fui la fuente de óvulos
- Le proporcioné el óvulo para el embarazo que otra persona llevó.
- Le proporcioné el esperma
- Adopté a la niña
- Utilicé esperma de donante (anónimo)
- Utilicé esperma de donante (conocido)
- Me sometí a la adopción por una segunda madre de la hija biológica de mi pareja.
- Trabajé con una sustituta para llevar el embarazo
- Trabajé con una donante de óvulos para proporcionar la fuente de óvulos para el embarazo
- Soy madre de la niña
- Soy una madre adoptiva (foster parent) de la niña
- Me convertí en madre a través de otro método
(especifique): _____
- Ninguna de las anteriores

FIN DE LA ENCUESTA:

Muchas gracias por su participación en este estudio. Le enviaremos un correo electrónico o le llamaremos pronto con información detallada de inicio de sesión para la discusión de su grupo focal en línea. Esperamos su participación.

Si tiene preguntas sobre esta encuesta o su participación en este estudio, comuníquese con Anu Manchikanti Gómez al 510-642-0722 o anugomez@berkeley.edu.

Online FGD guide: Cisgender participants, English-language

Supplemental file 3: English: Online focus group discussion guide, cisgender participants

FGD Facilitator: Explain discussion purpose and guidelines

Taking part in this online group discussion will take an estimated 30 minutes per day over four days, for a total of 2 hours. Each day during the four days, you will log in to this website. Each day we will post a new set of questions related to your gender, your body, your healthcare experiences, and your reactions to a new set of questions about body organs or anatomy that you may have. Each day, you can respond to that day's questions, add to your responses from prior days, and respond to responses from other participants. The facilitator may also ask you follow-up questions based on your previous day's responses. You can respond to these follow-up questions the next time you log in.

On day three of this online discussion, we will be showing you a new set of questions called an "organ inventory" – this is a form that patients and medical staff can use to identify what body parts a patient has that might be important when receiving medical care. We hope to hear from you about your opinions on the content of the organ inventory, how we can improve it, and when/how the questions could be used.

There are no right or wrong answers for this discussion. Please feel free to share your opinions and reactions honestly and freely. We are interested in hearing your point of view even if it is different from what others might express, or even if you are unsure or feel conflicted about your opinion(s) on the form or the questions we ask. You can skip any questions that you do not want to answer.

Privacy/confidentiality information

The responses written during this focus group discussion will be saved and shared with the researchers. To protect your privacy, we will only be using the alias name that you choose to provide. The only name the other participants in the focus group discussion will see will be this alias name that you choose to provide. They will not know anything else about you, other than what you choose to share.

Please remember you do not need to answer any questions you feel uncomfortable with and you can leave the focus group at any time.

Also, it is important that this discussion remains private; please do not discuss or share information from this conversation with others. Please remember to close your browser window after submitting your responses to prevent anyone from seeing your responses.

When mentioning people you know in this space, please do not mention their name(s). If a name is mentioned, it will not be included in the transcript.

If you have any questions about the study, the questions, or your rights as a participant in this research, you can contact Professor Anu Manchikanti Gómez at 510-642-0722 or anugomez@berkeley.edu.

I. Day 1: Conceptualizations of Gender

Thank you again for agreeing to participate in this discussion. To get started, I'd like to learn a bit about your thoughts and opinions about gender in general, and your own gender.

Online FGD guide: Cisgender participants, English-language

1. Are there specific words or language you use to describe your own gender?
 - a. Does the way you describe your gender change based on the people around you or where you are? If so, can you tell us about that?
2. How long have you identified in this way?
3. How often do people perceive you as this gender?
4. In what situations do you choose to share your gender?
5. In what situations do you feel you don't have a choice in sharing this information?
6. What feels important for you to share about your gender for us to understand what it means to you?
7. What does the phrase "sex assigned at birth" mean to you? Are there specific words or language you use to describe your sex assigned at birth?
 - a. Are there any circumstances or situations in which this changes? If so, can you tell us about that?
8. In the short survey you completed for this focus group, we asked you the following two questions about gender:

If you had to choose from the list below, although we acknowledge that these categories may not be ideal, which of the below best describe(s) your current gender? (Select all that apply)

- Agender
- Genderqueer
- Man
- Nonbinary
- Two-Spirit (feel free to include your tribe's specific language for your identity, if you would like) _____
- Woman
- Additional gender category, please specify: _____
- Prefer not to say

Are you transgender, or of transgender experience?

- Yes
- No
- Don't know
- Prefer not to say

What do you think of the phrasing of the gender list question?

- a. What do you think of the option to "select all that apply", versus an option to select just one?
- b. How would only being able to select one vs all that apply affect how you respond?
- c. How do you feel about the gender options listed?

Online FGD guide: Cisgender participants, English-language

9. What do you think about the question that asks about being transgender?
 - a. How would you change the phrasing, if at all?
10. How do you feel about having the question about transgender experience asked separately, rather than listing “transgender” as a gender option in the multiple choice gender list question?
11. After asking about gender, we then asked you about being or identifying as intersex. Specifically, we asked: Do you identify as intersex?
 - No
 - Yes
 - Prefer not to say

Followed by: Has a healthcare provider ever told you that you are intersex or that you have what is sometimes referred to as either a “difference of sex development” or a “disorder of sex development” (DSD)?

- No
- Yes
- I don’t know
- Prefer not to say

How do you feel about these two questions asked together? Do you prefer one over the other? Why or why not?

- a. How might you improve the question(s)?

II. Day 2: Healthcare Experiences and Disclosure

Now we’d like to ask you a few questions about your experiences in a healthcare setting.

12. Do your healthcare providers know your gender?
13. What does support look and feel like to you within a healthcare setting?
14. What does it look and feel like to not have support within a healthcare setting?
15. How do you manage or navigate barriers to care?
16. Have any of your providers discussed cancer risk, screening, or treatment such as a pap test or prostate exam with you? If so, who generally brings up the subject?
17. How comfortable do you feel having these conversations with your provider?
18. What are the most important features of a medical intake process for you?
 - a. What features should be AVOIDED in a medical intake process for you?
19. Have you ever chosen to not share part(s) of your relevant medical history with certain healthcare providers? Why or why not?

Online FGD guide: Cisgender participants, English-language

20. Do the intake forms at your healthcare provider's office feel as if they have appropriate and accurate language about your gender, body, and behaviors?
21. Do you have any recommendations for creating medical forms that better reflect your gender, body, and behaviors?
22. If you were to need screening or medical care, how would you choose a specific clinic or provider?
23. If you were to need screening or medical care, how would you choose a specific procedure? Would you ask your provider or friends?
24. What types of information would you want your provider to know before starting this conversation?
25. What impact (if any) do the attitudes of providers have on your desire to seek out healthcare?

III. Day 3: Review of the Inventory

Please take the next five minutes to read through this form. After you have finished reviewing the form, please respond to the next set of questions about your experience with the inventory.

ORGAN INVENTORY FORM

To ensure that you are screened in a way that is appropriate for your body and your experience, we ask ALL people (regardless of gender or sex assigned at birth) about which body parts you currently have. For each body part, we start with using the medical term, although we know that these terms may not be the words you use for your body. You will be able to write-in the words you use for these body parts in a later question. However, for the sake of clarity, we use the medical terms as a starting point.

From the below list of body parts, please check the box next to any body part that you CURRENTLY have. For organs that come in pairs, please select the box if you have ANY tissue from that organ. **SELECT ALL THAT APPLY.**

- Breasts or breast tissue**
Breasts are soft organs on the chest of teenagers and adults.
- Colon**
The colon is an organ in the lower torso area that helps with food absorption. The longest part of the large intestine.
- Uterus**
The uterus is an organ that sits in the pelvic area. Monthly bleeding comes from the uterus, and it is where a pregnancy grows.
- Ovaries**
The ovary is an organ that makes human eggs and also hormones. There are usually two of them, and they are in the pelvic region of the body.
- Fallopian tubes**
The fallopian tubes connect the ovaries to the uterus.

Online FGD guide: Cisgender participants, English-language

- Cervix**
The **cervix** is the opening to the uterus, at the back end of the vagina.
- Prostate**
The **prostate** is a gland inside the body, below the bladder and between the rectum and urethra at the base of the penis.
- Penis**
The **penis** is a phallus that is a part of the body near the groin, used by some people for sexual activity, and also by some people for releasing urine and sperm from the body.
- Vagina**
The **vagina** is a frontal genital opening, used by some people for sexual activity, and also by some people for releasing menstrual blood or giving birth.
- Testicles**
The testicles (also called **testes**) are reproductive glands that sit outside the body and are contained within the scrotum. There are usually two of them, and they produce sperm and androgens.
- Anus**
The **anus** is the opening through which solid waste leaves the body, also used by some people for sexual activity.
- None of the above**
- Prefer not to say**
- Please feel free to share additional information about the organs that you have now, or that you used to have, that might be important for your healthcare providers to know.
- _____
- _____
- _____

If you checked penis, vagina, or testicles on the list above, please check the option below that applies to you. Understanding what surgeries you may have had and/or what hormone therapy you have used may help your provider determine what health screening they recommend. **SELECT ALL THAT APPLY.**

Were you born with this vagina or was it developed through surgery and/or gender-affirming hormone therapy (GAHT)/hormone replacement therapy (HRT)?

- Born with
- Surgery
- GAHT/HRT
- I do not have this organ
- Prefer not to say

Were you born with this penis, or was it developed through surgery and/or gender-affirming hormone therapy (GAHT)/hormone replacement therapy (HRT)?

- Born with
- Surgery

Online FGD guide: Cisgender participants, English-language

- GAHT/HRT
- I do not have this organ
- Prefer not to say

Were you born with testicles, or were they developed through surgery and/or gender affirming hormone therapy (GAHT) or hormone replacement therapy (HRT)?

- Born with
- Surgery
- GAHT/HRT
- I do not have this organ
- Prefer not to say

Have you had either of the surgeries below? We are asking about your history of surgery because it may help your provider decide what kind of health screening they recommend. **SELECT ALL THAT APPLY.**

Mastectomy

A mastectomy is surgery to remove all breast tissue from a breast as a way to treat or prevent breast cancer. A mastectomy may involve one or both breasts.

Top surgery

A surgical procedure to remove breast tissue. It is also called masculinizing chest surgery. Top surgery involves more than a mastectomy for the treatment of breast cancer. Special techniques may be used to contour and reduce the chest wall, position the nipples and areola, and minimize scarring.

26. What did you think when you first read through the form?

Probe:

- a. How did you feel?
- b. What did you like? Not like?
- c. What surprised you?
- d. Other comments:

27. How did you feel reading through the options on this form?

Probe:

- a. Warm? Cold? Medical? Personal?
- b. What felt difficult to understand?
- c. What felt easy to understand?
- d. Other comments:

28. What information was relevant or not relevant for your gender, body, or experience?

Probe:

- a. Why/why not?
- b. What information was the most important?
- c. What information was missing?
- d. Other comments:

29. How easy or how difficult was it to figure out how to fill out this form?

30. Who do you think this form is intended for? Why?

Online FGD guide: Cisgender participants, English-language

31. How do you think a healthcare provider should use this form? When (if ever) do you think it is appropriate for a healthcare provider to use this form?
32. After participants respond to the organ inventory, we will give them the option to tell their provider what language they use to talk about their body. See below for an example.

Would you like to tell your provider what language you use to describe your body parts?

- Yes
 No → Skip to end

If yes, please check the box next to the box that applies to your experience. When answering these questions, please consider what terms you might use when talking with your provider in the medical setting.

Do you use the word “breasts”?

- Yes, I use the word “breasts.”
 No, I use a different word. The word I use instead of “breasts” is: _____
 Prefer not to say

Do you use the word “cervix”?

- Yes, I use the word “cervix.”
 No, I use a different word. The word I use instead of “cervix” is: _____
 Prefer not to say

Do you use the term “fallopian tubes”?

- Yes, I use the term “fallopian tubes.”
 No, I use a different word. The word I use instead of “fallopian tubes” is: _____
 Prefer not to say

Do you use the word “ovaries”?

- Yes, I use the word “ovaries.”
 No, I use a different word. The word I use instead of “ovaries” is: _____
 Prefer not to say

Do you use the word “penis”?

- Yes, I use the word “penis.”
 No, I use a different word. The word I use instead of “penis” is: _____
 Prefer not to say

Do you use the word “prostate”?

- Yes, I use the word “prostate.”
 No, I use a different word. The word I use instead of “prostate” is: _____
 Prefer not to say

Online FGD guide: Cisgender participants, English-language

Do you use the word “testicles”?

- Yes, I use the word “testicles.”
- No, I use a different word. The word I use instead of “testicles” is: _____
- Prefer not to say

Do you use the word “uterus”?

- Yes, I use the word “uterus.”
- No, I use a different word. The word I use instead of “uterus” is: _____
- Prefer not to say

Do you use the word “vagina”?

- Yes, I use the word “vagina.”
- No, I use a different word. The word I use instead of “vagina” is: _____
- Prefer not to say

Do you use the word “colon”?

- Yes, I use the word “colon.”
- No, I use a different word. The word I use instead of “colon” is: _____
- Prefer not to say

Do you use the word “anus”?

- Yes, I use the word “anus.”
- No, I use a different word. The word I use instead of “anus” is: _____
- Prefer not to say

33. What is your reaction to this option to share the words you use to talk about your own body?
34. What could this information on word-use be used for?
35. Do you have any concerns with how this information might be used?
36. Any recommendations to improve how we ask people about the words that they use for these body parts?
 - a. How would you feel about adding an answer option for each term that read “I would prefer not to talk about this body part with a provider”?

IV. Day 4: Recommendations

We are interested in your opinions about recommendations for improving this form.

37. Who do you think would benefit most from using this form? Why?
38. Who would benefit least? Why?

Online FGD guide: Cisgender participants, English-language

39. What could be improved?
40. Are there any situations or settings in which this form should not be used? What are possible alternatives that could be used in that situation or setting?
41. Do you have any other thoughts that you would like to share that might help us as we think about changes to the form?
42. Are there any things you think it would be important for the research team to know that we haven't asked you about?
43. Thank you so much for your participation in this study! In order to send you the \$75 Amazon gift card as a thank you for participating, we will need to collect your contact information. If you would like to receive a \$75 Amazon gift card as a thank you for participating, please select "yes" below.
- YES, I would like to receive a \$75 gift card
 - NO, I do not want a gift card
44. For a ~15 minute online survey, would you be more likely to participate if participation offered:
- A raffle to win one \$50 gift card (you would have about a 1 in 10 chance of winning)
 - A guaranteed \$5 gift card
 - Equally likely to participate with either
 - I don't know
45. Below, we would like you to choose a four-digit passcode. Please choose a number that you can easily remember. After you enter your passcode and click the NEXT button, you will be directed to another website to complete a form with your passcode and contact information. By entering this information in a separate survey, we can make sure that your name and contact information are not directly connected to your answers to the questions in this focus group. **If you do not wish to enter your information, you can log-out of the focus group session and close your browser now to protect your privacy.**

END OF FOCUS GROUP DISCUSSION

Online FGD guide: Cisgender participants, English-language

NEW SURVEY FOR INCENTIVE DISTRIBUTION

Thank you for participating in a research study with the University of California, Berkeley and Ibis Reproductive Health. Please answer the following questions so we can send you the \$75 gift card as a thank you for participating. By entering this information in a separate survey, we can make sure that your name and contact information are not directly connected to your answers to the questions in this survey. **If you do not wish to enter your information, you can close your browser now to protect your privacy.**

1. Please enter your four-digit passcode.

2. Would you like us to email you a \$75 gift card or text you a \$75 gift card?
 EMAIL – I would like to receive a \$75 gift card via email
 PHONE – I would like to receive a \$75 gift card via text message
3. [If selects “email” above →] Please provide the email address where you would like to have your gift card sent:

4. [If selects “phone” above →] Please provide the phone number where you would like to have your gift card sent:

5. Would you like us to send you results of this study (a fact sheet, FAQ, or other type of summary) by email?
 Yes, please email me results at this email address: _____
 No, do not send me results.

Thank you for participating! We will send your gift card to the email or phone number that you gave us. If you do not receive your card within two weeks, please contact the research lead, Professor Anu Manchikanti Gómez at 510-642-0722 or anugomez@berkeley.edu.

Please click the arrow to submit your information. Please close your browser window after submission.

END OF INCENTIVE SURVEY

Online FGD guide: Cisgender participants, Spanish-language

Supplemental file 4: Spanish: Online focus group discussion guide for cisgender participants

FGD Facilitator: Explain discussion purpose and guidelines

La participación en esta discusión grupal en línea tomará aproximadamente 30 minutos por día durante cuatro días, 2 horas en total. Cada día durante los cuatro días, iniciará sesión en este sitio web. Cada día publicaremos un nuevo conjunto de preguntas relacionadas con su identidad de género, su cuerpo, sus experiencias de atención médica y sus reacciones a un nuevo conjunto de preguntas sobre los órganos corporales que pueda tener. Cada día, puede responder a las preguntas de ese día, así como agregar a sus respuestas de días anteriores y responder a las respuestas de otros participantes. Le facilitadore también puede hacerle preguntas de seguimiento basadas en las respuestas del día anterior. Puede responder a estas preguntas de seguimiento la próxima vez que inicie sesión.

El tercer día de esta discusión en línea, le mostraremos un nuevo conjunto de preguntas llamado "inventario de órganos": este es un formulario que los pacientes y el personal médico pueden usar para identificar qué partes del cuerpo tiene un paciente que podrían ser importantes al recibir atención médica. Esperamos conocer sus opiniones sobre el contenido del inventario de órganos, cómo podemos mejorarlo y cuándo y cómo se podrían utilizar las preguntas.

No hay respuestas correctas o incorrectas en esta discusión. No dude en compartir sus opiniones y reacciones con honestidad y libertad. Estamos interesados en escuchar su punto de vista incluso si es diferente de lo que otros podrían expresar, o incluso si no está seguro o se siente en conflicto acerca de su (s) opinión (es) en el formulario o las preguntas que le hacemos. Puede omitir cualquier pregunta que no desee responder.

Información de privacidad/ confidencialidad

Las respuestas escritas durante esta discusión de grupo focal se guardarán y compartirán con los investigadores. Para proteger su privacidad, solo usaremos el nombre de alias que elija proporcionar. El único nombre que verán los demás participantes en la discusión del grupo focal será este nombre de alias que usted elija proporcionar. Ellos no sabrán nada más sobre ti, aparte de lo que elijas compartir.

Recuerde que no es necesario que responda a ninguna pregunta con la que se sienta incómodo y que puede abandonar el grupo focal en cualquier momento.

Además, es importante que esta discusión sea privada; por favor no discuta ni comparta información de esta conversación con otros. Recuerde cerrar la ventana de su navegador después de enviar sus respuestas para evitar que alguien vea sus respuestas.

Cuando mencione a personas que conoce, no use sus nombres. Si se usa un nombre, no será incluido en la transcripción.

Si tiene alguna pregunta sobre el estudio, las preguntas o sus derechos como participante en esta investigación, puede comunicarse con Profesora Anu Manchikanti Gómez al 510-642-0722 o anugomez@berkeley.edu.

I. 1r Día: Conceptualizaciones de la identidad de género

Gracias nuevamente por aceptar participar en esta discusión. Para comenzar, me gustaría aprender un poco sobre sus pensamientos y opiniones sobre el género en general y sobre su propia identidad de género.

Online FGD guide: Cisgender participants, Spanish-language

1. ¿Hay palabras específicas o lenguaje específico que usa para describir su propia identidad de género?
 - a. ¿La forma en que describe su género cambia en función de las personas que le rodean o del lugar donde se encuentra? Si es así, ¿puedes contarnos sobre eso?
2. ¿Por cuánto tiempo se ha identificado de esta forma?
3. ¿Con qué frecuencia la gente le percibe con esta identidad de género?
4. ¿En qué espacios elige compartir su identidad de género?
5. ¿En qué espacios cree que no tiene opción a compartir o no compartir esta información?
6. ¿Qué le parece importante compartir sobre su género para que entendamos lo que significa para usted?
7. ¿Qué significa para usted la frase sexo asignado al nacer? ¿Hay palabras o lenguaje específico que usa para describir su sexo asignado al nacer?
 - a. ¿Existen circunstancias o situaciones en las que esto cambie? Si es así, ¿puedes contarnos sobre eso?
8. En la breve encuesta que completó para este grupo de enfoque, le hicimos las siguientes dos preguntas sobre género:

Si tuviera que elegir de la lista a continuación, aunque reconocemos que estas categorías pueden no ser ideales, ¿cuál de las siguientes describe mejor su género actual? (Seleccione todas las que correspondan)

- Agénero (sin género)
- Genderqueer
- Hombre
- No binarie
- Two-Spirit (puede incluir el idioma específico de su tribu para su identidad, si lo desea) _____
- Mujer
- Categoría de género adicional, especifique: _____
- Prefiero no responder

¿Se identifica como transgénero y / o se considera una persona de experiencia transgénero?

- Sí
- No
- No lo sé
- Prefiero no responder

¿Qué opina de la redacción de la pregunta de la lista de género?

Online FGD guide: Cisgender participants, Spanish-language

- a. ¿Qué opina de la opción de "seleccione todas las que correspondan", frente a la opción de seleccionar solo uno?
- b. ¿Cómo afectaría su respuesta al poder seleccionar solo uno frente a todas las que correspondan?
- c. ¿Cómo se siente acerca de las opciones de género enumeradas?
9. ¿Qué opina de la pregunta sobre ser transgénero?
- a. ¿Cómo cambiaría la redacción, si es que la cambiaría?
10. ¿Cómo se siente al que se le haga la pregunta sobre la experiencia transgénero por separado, en lugar de incluir "transgénero" como una opción de género en la pregunta de la lista de género de opción múltiple?
11. Después de preguntarle sobre el género, le preguntamos si es o se identifica como intersexual. Específicamente, preguntamos: Se identifica como intersexual?
- No
- Sí
- Prefiero no responder
- Seguido por: ¿Alguna vez un proveedor de atención médica le ha dicho que es intersexual o que tiene lo que a veces se denomina "diferencia en el desarrollo sexual" o "trastorno del desarrollo sexual" (TDS)?
- No
- Sí
- No sé
- Prefiero no responder
- ¿Cómo se siente acerca de estas dos preguntas formuladas juntas? ¿Prefiere una más que otra?
- ¿Por qué o por qué no?
- a. ¿Cómo podría mejorar la (s) pregunta (s)?

II. 2do Día: Experiencias y divulgación de atención médica

Ahora nos gustaría hacerle algunas preguntas sobre sus experiencias en un entorno de atención médica.

12. ¿Conocen sus proveedores de atención médica su género?
13. ¿Cómo se ve y se siente el apoyo para usted en un entorno de atención médica?
14. ¿Cómo se ve y se siente no tener apoyo dentro de un entorno de atención médica?
15. ¿Cómo maneja o supera las barreras de la atención?
16. ¿Alguno de sus proveedores ha hablado con usted sobre el riesgo de cáncer, las pruebas de detección o el tratamiento como una prueba de Papanicolaou o examen de próstata? Si es así, ¿quién suele mencionar el tema?

Online FGD guide: Cisgender participants, Spanish-language

17. ¿Qué tan cómodo se siente al tener estas conversaciones con su proveedor?
18. ¿Cuáles son las características más importantes de un proceso de admisión médica para usted?
 - a. ¿Qué características deben EVITARSE en un proceso de admisión médica para usted?
19. ¿Alguna vez ha optado por no compartir parte (s) de su historial médico relevante con ciertos proveedores de atención médica? ¿Por qué o por qué no?
20. ¿Los formularios de admisión en el consultorio de su proveedor de atención médica se sienten como si tuvieran un lenguaje apropiado y preciso sobre su género, cuerpo y comportamientos?
21. ¿Tiene alguna recomendación para crear formularios médicos que reflejen mejor su identidad, cuerpo y comportamientos?
22. Si necesitara un examen de detección o atención médica, ¿cómo determinaría una preferencia por una clínica o un proveedor específico?
23. Si necesitara un examen de detección o atención médica, ¿cómo determinaría una preferencia por un procedimiento específico? ¿Le preguntaría a su proveedor o amigos?
24. ¿Qué tipo de información le gustaría que su proveedor supiera antes de comenzar esta conversación?
25. ¿Qué impacto (si lo hay) tienen las actitudes de los proveedores en su deseo de buscar atención médica?

III. 3r: Revisión del inventario

Tómese los próximos cinco minutos para leer este formulario. Responda a la siguiente serie de preguntas cuando haya terminado de revisar el formulario.

FORMULARIO DE INVENTARIO DE ÓRGANOS

Para asegurarnos de que se le realice un examen de detección apropiado para su cuerpo y su experiencia, le preguntamos a TODAS las personas (independientemente del género o sexo asignado al nacer) sobre qué partes del cuerpo tiene actualmente. Para cada parte del cuerpo, comenzamos usando el término médico, aunque sabemos que estos términos pueden no ser las palabras que usa para su cuerpo. Podrá escribir las palabras que usa para estas partes del cuerpo en una pregunta posterior. Sin embargo, en aras de la claridad, utilizamos los términos médicos como punto de partida.

De la siguiente lista de partes del cuerpo, marque la casilla junto a cualquier parte del cuerpo que tenga ACTUALMENTE. Para los órganos que vienen en pares, seleccione la casilla si tiene CUALQUIER tejido de ese órgano. **SELECCIONE TODAS LAS QUE CORRESPONDAN.**

Senos o tejido mamario

Los **senos** son órganos blandos en el pecho de adolescentes y adultos.

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- Colon**
El **colon** es un órgano en la zona inferior del torso que ayuda con la absorción de alimentos. La parte más larga del intestino grueso.
- Útero**
El **útero** es un órgano que se encuentra en el área pélvica. El sangrado mensual proviene del útero y es donde crece el embarazo.
- Ovarios**
Los **ovarios** son órganos que producen óvulos humanos y también hormonas. Suelen haber dos de ellos y se encuentran en la región pélvica del cuerpo.
- Trompas de Falopio**
Las **trompas de Falopio** conectan los ovarios al útero.
- Cuello uterino**
El **cuello uterino** es la abertura del útero, en la parte posterior de la vagina.
- Próstata**
La **próstata** es una glándula dentro del cuerpo, debajo de la vejiga y entre el recto y la uretra en la base del pene.
- Pene**
El **pene** es un falo que es una parte del cuerpo cerca de la ingle, utilizado por algunas personas para la actividad sexual y también por algunas personas para soltar orina y esperma del cuerpo.
- Vagina**
La **vagina** es una abertura genital frontal, utilizada por algunas personas para la actividad sexual y también por algunas personas para soltar sangre menstrual o dar a luz.
- Testículos**
Los testículos (también llamados **testes**) son glándulas reproductoras que se encuentran fuera del cuerpo y están contenidas dentro del escroto. Por lo general, hay dos y producen espermatozoides y andrógenos.
- Ano**
El **ano** es la abertura a través de la cual los desechos sólidos salen del cuerpo, también utilizada por algunas personas para la actividad sexual.
- Ninguna de las anteriores**
- Prefiero no responder**
- No dude en compartir información adicional sobre los órganos que tiene ahora o que solía tener, que podría ser importante que sus proveedores de atención médica la sepan.

Si marcó pene, vagina o testículos en la lista anterior, marque la opción a continuación que se aplique a usted. Comprender qué cirugías puede haber tenido y / o qué terapia hormonal ha utilizado puede ayudar

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a su proveedor a determinar qué exámenes de salud recomiendan. **SELECCIONE TODAS LAS QUE CORRESPONDAN.**

¿Nació con esta vagina o se desarrolló mediante cirugía y / o terapia hormonal de afirmación de género (THAG) / terapia de reemplazo hormonal (TRH)?

- Nací con una vagina
- Cirugía
- GAHT/TRH
- No tengo este órgano
- Prefiero no responder

¿Nació con este pene o se desarrolló mediante cirugía y / o terapia hormonal de afirmación de género (THAG) / terapia de reemplazo hormonal (TRH)?

- Nací con una vagina
- Cirugía
- GAHT/TRH
- No tengo este órgano
- Prefiero no responder

¿Nació con testículos o se desarrollaron mediante cirugía y / o terapia hormonal de afirmación de género (THAG) / terapia de reemplazo hormonal (TRH)?

- Nací con una vagina
- Cirugía
- GAHT/TRH
- No tengo este órgano
- Prefiero no responder

¿Ha tenido alguna de las siguientes cirugías? Le preguntamos sobre su historial de cirugía porque puede ayudar a su proveedor a decidir qué tipo de examen de salud recomienda. **SELECCIONE TODAS LAS QUE CORRESPONDAN.**

Mastectomía

Una mastectomía es una cirugía para extirpar todo el tejido mamario de una mama como una forma de tratar o prevenir el cáncer de mama. Una mastectomía puede involucrar uno o ambos senos.

Top surgery

Procedimiento quirúrgico para extraer tejido mamario. También se llama cirugía de tórax masculinizante. La cirugía superior implica más que una mastectomía para el tratamiento del cáncer de mama. Se pueden usar técnicas especiales para contornear y reducir la pared torácica, colocar los pezones y la areola y minimizar las cicatrices.

26. ¿Qué pensó cuando leyó el formulario por primera vez?

Probe:

- a. ¿Cómo se sintió?
- b. ¿Qué le gustó? ¿Qué no le gustó?
- c. ¿Qué le sorprendió?
- d. Otros comentarios:

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27. ¿Cómo se sintió leer las opciones de este formulario?

Probe:

- ¿Cálido? ¿Frío? ¿Médico? ¿Personal?
- ¿Qué le pareció difícil de entender?
- ¿Qué se sintió fácil de entender?
- Otros comentarios:

28. ¿Qué información fue relevante o no relevante para su género, cuerpo o experiencia?

Probe:

- ¿Por qué por qué no?
- ¿Qué información fue la más importante?
- ¿Qué información faltaba?
- Otros comentarios:

29. ¿Qué tan fácil o difícil fue averiguar cómo llenar este formulario?

30. ¿A quién cree que va dirigido este formulario? ¿Por qué?

31. ¿Cómo cree que un proveedor de atención médica debería usar este formulario? ¿Cuándo (si alguna vez) cree que es apropiado que un proveedor de atención médica use este formulario?

32. Después de que los participantes respondan al inventario de órganos, les daremos la opción de decirle a su proveedor qué lenguaje usar para hablar sobre su cuerpo. Vea a continuación un ejemplo.

¿Le gustaría decirle a su proveedor qué lenguaje usar para describir las partes de su cuerpo?

- Sí
 No → Saltar al final

En caso afirmativo, marque la casilla junto a la casilla que se aplica a su experiencia. Al responder a estas preguntas, considere qué términos podría utilizar al hablar con su proveedor en el ámbito médico.

¿Usa la palabra "senos"?

- Sí, uso la palabra "senos."
 No, uso otra palabra. La palabra que uso en vez de "senos" es: _____
 Prefiero no responder

¿Usa la palabra "cuello uterino"?

- Sí, uso la palabra "cuello uterino."
 No, uso otra palabra. La palabra que uso en vez de "cuello uterino" es: _____
 Prefiero no responder

¿Usa la palabra "trompas de Falopio"?

- Sí, uso la palabra "trompas de Falopio."
 No, uso otra palabra. La palabra que uso en vez de "Trompas de Falopio" es:

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Prefiero no responder

¿Usa la palabra "ovarios"?

Sí, uso la palabra "ovarios."

No, uso otra palabra. La palabra que uso en vez de "ovarios" es: _____

Prefiero no responder

¿Usa la palabra "pene"?

Sí, uso la palabra "pene."

No, uso otra palabra. La palabra que uso en vez de "pene" es: _____

Prefiero no responder

¿Usa la palabra "próstata"?

Sí, uso la palabra "próstata."

No, uso otra palabra. La palabra que uso en vez de "próstata" es: _____

Prefiero no responder

¿Usa la palabra "testículos"?

Sí, uso la palabra "testículos."

No, uso otra palabra. La palabra que uso en vez de "testículos" es: _____

Prefiero no responder

¿Usa la palabra "útero"?

Sí, uso la palabra "útero."

No, uso otra palabra. La palabra que uso en vez de "útero" es: _____

Prefiero no responder

¿Usa la palabra "vagina"?

Sí, uso la palabra "vagina."

No, uso otra palabra. La palabra que uso en vez de "vagina" es: _____

Prefiero no responder

¿Usa la palabra "colon"?

Sí, uso la palabra "colon."

No, uso otra palabra. La palabra que uso en vez de "colon" es: _____

Prefiero no responder

¿Usa la palabra "ano"?

Sí, uso la palabra "ano."

No, uso otra palabra. La palabra que uso en vez de "ano" es: _____

Prefiero no responder

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33. ¿Cuál es su reacción a esta opción de compartir las palabras que usa para hablar sobre su propio cuerpo?
34. ¿Para qué podría usarse esta información sobre el uso de palabras?
35. ¿Tiene alguna inquietud sobre cómo se podría utilizar esta información?
36. ¿Alguna recomendación para mejorar la forma en que preguntamos a las personas sobre las palabras que usan para estas partes del cuerpo?
 - a. ¿Cómo se sentiría si agregáramos una opción de respuesta para cada término que diga “Preferiría no hablar de esta parte del cuerpo con un proveedor”?

IV. 4o Día: Recomendaciones**Nos interesan sus opiniones sobre las recomendaciones para mejorar este formulario.**

37. ¿Quién cree que se beneficiaría más al utilizar este formulario? ¿Por qué?
38. ¿Quién se beneficiaría menos? ¿Por qué?
39. ¿Qué se podría mejorar?
40. ¿Hay situaciones o entornos en los que no se deba utilizar este formulario? ¿Cuáles son las posibles alternativas que podrían utilizarse en esa situación o entorno?
41. ¿Tiene alguna otra idea que le gustaría compartir y que podría ayudarnos a pensar en los cambios en el formulario?
42. ¿Hay algo que crea que sería importante que el equipo de investigación supiera que no le hayamos preguntado?
43. ¡Muchas gracias por su participación en este estudio! Para poder enviarle la tarjeta de regalo de Amazon de \$ 75 como agradecimiento por participar, necesitaremos recopilar su información de contacto. Si desea recibir una tarjeta de regalo de Amazon de \$ 75 como agradecimiento por participar, seleccione "sí" a continuación.
 - SÍ, me gustaría recibir una tarjeta de regalo de \$ 75
 - NO, no quiero una tarjeta regalo
44. Para una encuesta en línea de ~ 15 minutos, ¿sería más probable que participara si se le ofreciera participación?:
 - Un sorteo para ganar una tarjeta de regalo de \$ 50 (tendría una probabilidad de 1 en 10 de ganar)
 - Una tarjeta de regalo de \$ 5 garantizada
 - Es igualmente probable que participe con cualquier opción
 - No lo sé

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45. A continuación, nos gustaría que eligiera un código de acceso de cuatro dígitos. Elija un número que pueda recordar fácilmente. Después de ingresar su contraseña y hacer clic en el botón SIGUIENTE, será dirigido a otro sitio web para completar un formulario con su contraseña e información de contacto. Al ingresar esta información en una encuesta separada, podemos asegurarnos de que su nombre e información de contacto no estén directamente relacionados con sus respuestas a las preguntas de esta encuesta. **Si no desea ingresar su información, puede cerrar su navegador ahora para proteger su privacidad.**

FIN DE LA DISCUSIÓN DE GRUPO FOCAL

NEW SURVEY FOR INCENTIVE DISTRIBUTION

Gracias por participar en un estudio de investigación con la Universidad de California, Berkeley e Ibis Reproductive Health. Por favor, responda las siguientes preguntas para que podamos enviarle la tarjeta de regalo de Amazon de \$ 75 como agradecimiento por participar. Al ingresar esta información en una encuesta separada, podemos asegurarnos de que su nombre e información de contacto no estén directamente relacionados con sus respuestas a las preguntas de esta encuesta. **Si no desea ingresar su información, puede cerrar su navegador ahora para proteger su privacidad.**

1. Ingrese su contraseña de cuatro dígitos.

2. ¿Le gustaría que le enviemos por correo electrónico una tarjeta de regalo de Amazon de \$ 75 o le enviemos un mensaje de texto con una tarjeta de regalo de Amazon de \$ 75?
 CORREO ELECTRÓNICO: me gustaría recibir una tarjeta de regalo de \$ 75 por correo electrónico
 TELÉFONO: me gustaría recibir una tarjeta de regalo de \$ 75 por mensaje de texto

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3. [Si selecciona "correo electrónico" arriba →] Proporcione la dirección de correo electrónico a la que le gustaría que le enviemos su tarjeta de regalo:

4. [Si selecciona "teléfono" arriba →] Proporcione el número de teléfono al que le gustaría que le enviemos su tarjeta de regalo:

5. ¿Le gustaría que le enviemos los resultados de este estudio (una hoja informativa, preguntas frecuentes u otro tipo de resumen) por correo electrónico?
 Sí, envíeme un correo electrónico con los resultados a esta dirección de correo electrónico: _____
 No, no quiero que me envíen los resultados.

¡Gracias por participar! Enviaremos su tarjeta de regalo de Amazon al correo electrónico o al número de teléfono que nos proporcionó. Si no recibe su tarjeta en dos semanas, comuníquese con la líder de la investigación, Profesora Anu Manchikanti Gómez al 510-642-0722 o anugomez@berkeley.edu.

Haga clic en la flecha para enviar su información. Cierre su navegador después de enviar sus respuestas.

FIN DE LA ENCUESTA DE INCENTIVOS

Online FGD guide: TGE and/or intersex participants, English-language

Supplemental file 5: English: Online focus group discussion guide for transgender, nonbinary, gender-expansive, and intersex participants

FGD Facilitator: Explain discussion purpose and guidelines

Taking part in this online group discussion will take an estimated 30 minutes per day over four days, for a total of 2 hours. Each day during the four days, you will log in to this website. Each day we will post a new set of questions related to your gender, your body, your healthcare experiences, and ask for your reactions to a new set of questions about body organs or anatomy that you may have. Each day, you can respond to that day's questions, add to your responses from prior days, and respond to responses from other participants. The facilitator may also ask you follow-up questions based on your previous day's responses. You can respond to these follow-up questions the next time you log in.

On day three of this online discussion, we will be showing you a new set of questions called an "organ inventory" – this is a form that patients and medical staff can use to identify what body parts a patient has that might be important when receiving medical care. We hope to hear from you about your opinions on the content of the organ inventory, how we can improve it, and when/how the questions could be used.

There are no right or wrong answers for this discussion. Please feel free to share your opinions and reactions honestly and freely. We are interested in hearing your point of view even if it is different from what others might express, or even if you are unsure or feel conflicted about your opinion(s) on the form or the questions we ask. You can skip any questions that you do not want to answer.

Privacy/confidentiality information

The responses written during this focus group discussion will be saved and shared with the researchers. To protect your privacy, we will only be using the alias name that you choose to provide. The only name the other participants in the focus group discussion will see will be this alias name that you choose to provide. They will not know anything else about you, other than what you choose to share.

Please remember you do not need to answer any questions you feel uncomfortable with, and you can leave the focus group at any time.

Also, it is important that this discussion remains private; please do not discuss or share information from this conversation with others. Please remember to close your browser window after submitting your responses to prevent anyone from seeing your responses.

When mentioning people you know in this space, please do not mention their name(s). If a name is mentioned, the study team will remove it from the transcript.

If you have any questions about the study, the questions, or your rights as a participant in this research, you can contact Professor Anu Manchikanti Gómez at 510-642-0722 or anugomez@berkeley.edu.

I. Day 1: Conceptualizations of Gender

Thank you again for agreeing to participate in this discussion. To get started, I'd like to learn a bit about your thoughts and opinions about gender in general, and your own gender.

1. Are there specific words or language you use to describe your own gender?

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Online FGD guide: Transgender and nonbinary participants, English-language

- a. Does the way you describe your gender change based on the people around you or where you are? If so, can you tell us about that?
2. How long have you identified in this way?
3. How often do people perceive you as this gender?
4. In what situations do you choose to share your gender?
5. In what situations do you feel you don't have a choice in sharing this information?
6. What feels important for you to share about your gender for us to understand what it means to you?
7. What does the phrase "sex assigned at birth" mean to you? Are there specific words or language you use to describe your sex assigned at birth?
 - a. Are there any circumstances or situations in which this changes? If so, can you tell us about that?
 - a. As a transgender, gender-expansive, nonbinary, gender non-conforming and/or intersex person, how well do you feel that sex assigned at birth captures important information about your identity or healthcare needs?
8. In what spaces or situations do you choose to share information about your sex assigned at birth?
9. In what spaces or situations do you feel you don't have a choice in sharing this information?
10. In the short survey you completed for this focus group, we asked you the following two questions about gender:
 - If you had to choose from the list below, although we acknowledge that these categories may not be ideal, which of the below best describe(s) your current gender? (Select all that apply)
 - Agender
 - Genderqueer
 - Man
 - Nonbinary
 - Two-Spirit (feel free to include your tribe's specific language for your identity, if you would like) _____
 - Woman
 - Additional gender category, please specify: _____
 - Prefer not to say
 - Are you transgender, or of transgender experience?
 - Yes
 - No
 - Don't know
 - Prefer not to say

What do you think of the phrasing of the gender list question?

- a. What do you think of the option to "select all that apply", versus an option to select just one?

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- b. How would only being able to select one vs all that apply affect how you respond?
 - c. How do you feel about the gender options listed?
11. What do you think about the question that asks about being transgender?
- a. How would you change the phrasing, if at all?
12. How do you feel about having the question about transgender experience asked separately, rather than listing “transgender” as a gender option in the multiple choice gender list question?
13. After asking about gender, we then asked you about being or identifying as intersex. Specifically, we asked: Do you identify as intersex?
- No
 - Yes
 - Prefer not to say

Followed by: Has a healthcare provider ever told you that you are intersex or that you have what is sometimes referred to as either a “difference of sex development” or a “disorder of sex development” (DSD)?

- No
- Yes
- I don’t know
- Prefer not to say

How do you feel about these two questions asked together? Do you prefer one over the other? Why or why not?

- a. How might you improve the question(s)?

II. Day 2: Healthcare Experiences and Disclosure

Now we’d like to ask you a few questions about your experiences in a healthcare setting.

14. Do your healthcare providers know your gender? (Aka, are you “out” to your providers about your gender?)
15. What does support look and feel like to you as a transgender, nonbinary, gender-expansive (TGE), and/or intersex individual within a healthcare setting?
16. What does it look and feel like to not have support as a TGE and/or intersex individual within a healthcare setting?
17. How do you manage or navigate barriers to care?

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18. How do you see other TGE or intersex individuals manage or navigate these barriers to care?
19. Has your provider shared with you their qualifications for working with TGE and/or intersex individuals?
20. Have any of your providers discussed cancer risk, screening, or treatment such as a pap test or prostate exam with you? If so, who generally brings up the subject?
21. How comfortable do you feel having these conversations with your provider?
22. Has a provider not been able to answer your questions about cancer risk, screening, or treatment related to TGE and/or intersex individuals?
23. What are the most important features of a medical intake process for you and TGE and/or intersex individuals you know?
 - a. What features should be AVOIDED in a medical intake process for you and TGE and/or intersex individuals you know?
24. Has your experience as a TGE and/or intersex individual changed your relationship to disclosing your medical history to your healthcare providers over time?
25. Do the intake forms at your healthcare provider's office feel as if they have appropriate and accurate language about your gender, body, and behaviors?
26. Do you have any recommendations for creating medical forms that better reflect your gender, body, and behaviors?
27. If you were to need screening or medical care, how would you choose a specific clinic or provider?
28. If you were to need screening or medical care, how would you choose a specific procedure
Would you ask your provider or friends?
29. What types of information would you want your provider to know before starting this conversation?
30. How knowledgeable have healthcare providers you've seen been about caring for TGE and/or intersex people?
 - a. If not knowledgeable, have you been supported with referrals for accessing care that's appropriate for you?
31. What impact (if any) do the attitudes of providers have on your desire to seek out healthcare?

III. Day 3: Review of the Inventory

Please take the next five minutes to read through this form. After you have finished reviewing the form, please respond to the set of questions about your experience with the inventory.

ORGAN INVENTORY

Online FGD guide: Transgender and nonbinary participants, English-language

To ensure that you are screened in a way that is appropriate for your body and your experience, we ask ALL people (regardless of gender or sex assigned at birth) about which body parts you CURRENTLY have. For each body part, we start with using the medical term, although we know that these terms may not be the words you use for your body. You will be able to write-in the words you use for these body parts in a later question. However, for the sake of clarity, we use the medical terms as a starting point.

From the below list of body parts, please check the box next to any body part that you CURRENTLY have. For organs that come in pairs, please select the box if you have ANY tissue from that organ. **SELECT ALL THAT APPLY.**

- Breasts or breast tissue**
Breasts are soft organs on the chest of teenagers and adults.
- Colon**
The colon is an organ in the lower torso area that helps with food absorption. The longest part of the large intestine.
- Uterus**
The uterus is an organ that sits in the pelvic area. Monthly bleeding can come from the uterus, and it is where a pregnancy grows.
- Ovaries**
The ovary is an organ that makes human eggs and also hormones. There are usually two of them, and they are in the pelvic region of the body.
- Fallopian tubes**
The fallopian tubes connect the ovaries to the uterus.
- Cervix**
The cervix is the opening to the uterus, at the back end of the vagina.
- Prostate**
The prostate is a gland inside the body, below the bladder and between the rectum and urethra at the base of the penis.
- Penis**
The penis is a phallus that is a part of the body near the groin, used by some people for sexual activity, and also by some people for releasing urine and sperm from the body.
- Vagina**
The vagina is a frontal genital opening, used by some people for sexual activity, and also by some people for releasing menstrual blood or giving birth.
- Testicles**
The testicles (also called testes) are reproductive glands that sit outside the body and are contained within the scrotum. There are usually two of them, and they produce sperm and androgens.
- Anus**

Online FGD guide: Transgender and nonbinary participants, English-language

The **anus** is the opening through which solid waste leaves the body, also used by some people for sexual activity.

- None of the above**
- Prefer not to say**
- Please feel free to share additional information about the organs that you have now, or that you used to have, that might be important for your healthcare providers to know.

If you checked penis, vagina, or testicles on the list above, please check the option below that applies to you. Understanding what surgeries you may have had and/or what hormone therapy you have used may help your provider determine what health screening they recommend. **SELECT ALL THAT APPLY.**

Were you born with this vagina or was it developed through surgery and/or gender-affirming hormone therapy (GAHT)/hormone replacement therapy (HRT)?

- Born with
- Surgery
- GAHT/HRT
- I do not have this organ
- Prefer not to say

Were you born with this penis, or was it developed through surgery and/or gender-affirming hormone therapy (GAHT)/hormone replacement therapy (HRT)?

- Born with
- Surgery
- GAHT/HRT
- I do not have this organ
- Prefer not to say

Were you born with testicles, or were they developed through surgery and/or gender affirming hormone therapy (GAHT) or hormone replacement therapy (HRT)?

- Born with
- Surgery
- GAHT/HRT
- I do not have this organ
- Prefer not to say

Have you had either of the surgeries below? We are asking about your history of surgery because it may help your provider decide what kind of health screening they recommend. **SELECT ALL THAT APPLY.**

- Mastectomy**
A mastectomy is surgery to remove all breast tissue from a breast as a way to treat or prevent breast cancer. A mastectomy may involve one or both breasts.
- Top surgery**

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A surgical procedure to remove breast tissue. It is also called masculinizing chest surgery. Top surgery involves more than a mastectomy for the treatment of breast cancer. Special techniques may be used to contour and reduce the chest wall, position the nipples and areola, and minimize scarring.

32. What did you think when you first read through the form?

Probe:

- a. How did you feel?
- b. What did you like? Not like?
- c. What surprised you?
- d. Other comments:

33. How did you feel reading through the options on this form?

Probe:

- a. Warm? Cold? Medical? Personal?
- b. What felt difficult to understand?
- c. What felt easy to understand?
- d. Other comments:

34. What information was relevant or not relevant for your gender, body, or experience?

Probe:

- a. Why/why not?
- b. What information was the most important?
- c. What information was missing?
- d. Other comments:

35. How easy or how difficult was it to figure out how to fill out this form?

36. Who do you think this form is intended for? Why?

37. How do you think a healthcare provider should use this form? When (if ever) do you think it is appropriate for a healthcare provider to use this form?

38. After participants respond to the organ inventory, we will give them the option to tell their provider what language they use to talk about their body. See below for an example.

Would you like to tell your provider what language you use to describe your body parts?

- Yes
 No → Skip to end

If yes, please check the box next to the box that applies to your experience. When answering these questions, please consider what terms you might use when talking with your provider in the medical setting.

Do you use the word “breasts”?

- Yes, I use the word “breasts.”
 No, I use a different word. The word I use instead of “breasts” is: _____
 Prefer not to say

Online FGD guide: Transgender and nonbinary participants, English-language

Do you use the word “cervix”?

- Yes, I use the word “cervix.”
- No, I use a different word. The word I use instead of “cervix” is: _____
- Prefer not to say

Do you use the term “fallopian tubes”?

- Yes, I use the term “fallopian tubes.”
- No, I use a different word. The word I use instead of “fallopian tubes” is: _____
- Prefer not to say

Do you use the word “ovaries”?

- Yes, I use the word “ovaries.”
- No, I use a different word. The word I use instead of “ovaries” is: _____
- Prefer not to say

Do you use the word “penis”?

- Yes, I use the word “penis.”
- No, I use a different word. The word I use instead of “penis” is: _____
- Prefer not to say

Do you use the word “prostate”?

- Yes, I use the word “prostate.”
- No, I use a different word. The word I use instead of “prostate” is: _____
- Prefer not to say

Do you use the word “testicles”?

- Yes, I use the word “testicles.”
- No, I use a different word. The word I use instead of “testicles” is: _____
- Prefer not to say

Do you use the word “uterus”?

- Yes, I use the word “uterus.”
- No, I use a different word. The word I use instead of “uterus” is: _____
- Prefer not to say

Do you use the word “vagina”?

- Yes, I use the word “vagina.”
- No, I use a different word. The word I use instead of “vagina” is: _____
- Prefer not to say

Do you use the word “colon”?

- Yes, I use the word “colon.”

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No, I use a different word. The word I use instead of “colon” is: _____

Prefer not to say

Do you use the word “anus”?

Yes, I use the word “anus.”

No, I use a different word. The word I use instead of “anus” is: _____

Prefer not to say

39. What is your reaction to this option to share the words you use to talk about your own body?

40. What could this information on word-use be used for?

41. Do you have any concerns with how this information might be used?

42. Any recommendations to improve how we ask people about the words that they use for these body parts?

a. How would you feel about adding an answer option for each term that read “I would prefer not to talk about this body part with a provider”?

IV. Day 4: Recommendations

We are interested in your recommendations for improving this form.

43. Who do you think would benefit most from using this form? Why?

44. Who would benefit least? Why?

45. What could be improved?

46. Are there any situations or settings in which this form should not be used? What are possible alternatives that could be used in that situation or setting?

47. Do you have any other thoughts that you would like to share that might help us as we think about changes to the form?

48. Are there any things you think it would be important for the research team to know that we haven't asked you about?

49. Thank you so much for your participation in this study! In order to send you the \$75 gift card as a thank you for participating, we will need to collect your contact information. If you would like to receive a \$75 gift card as a thank you for participating, please select "yes" below.

YES, I would like to receive a \$75 gift card

NO, I do not want a gift card

50. For a ~15 minute online survey, would you be more likely to participate if participation offered:

a. A raffle to win one \$50 gift card (you would have about a 1 in 10 chance of winning)

b. A guaranteed \$5 gift card

c. Equally likely to participate with either

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d. I don't know

- 51.** Below, we would like you to choose a four-digit passcode. Please choose a number that you can easily remember. After you enter your passcode and click the NEXT button, you will be directed to another website to complete a form with your passcode and contact information. By entering this information in a separate survey, we can make sure that your name and contact information are not directly connected to your answers to the questions in this focus group. **If you do not wish to enter your information, you can log-out of the focus group session and close your browser now to protect your privacy.**
-

END OF FOCUS GROUP DISCUSSION

NEW SURVEY FOR INCENTIVE DISTRIBUTION

Thank you for participating in a research study with the University of California, Berkeley and Ibis Reproductive Health. Please answer the following questions so we can send you the \$75 gift card as a thank you for participating. By entering this information in a separate survey, we can make sure that your name and contact information are not directly connected to your answers to the questions in this survey. **If you do not wish to enter your information, you can close your browser now to protect your privacy.**

1. Please enter your four-digit passcode.

2. Would you like us to email you a \$75 gift card or text you a \$75 gift card?
 EMAIL – I would like to receive a \$75 gift card via email
 PHONE – I would like to receive a \$75 gift card via text message
3. [If selects “email” above →] Please provide the email address where you would like to have your gift card sent:

4. [If selects “phone” above →] Please provide the phone number where you would like to have your gift card sent:

5. Would you like us to send you results of this study (a fact sheet, FAQ, or other type of summary) by email?
 Yes, please email me results at this email address: _____
 No, do not send me results.

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Thank you for participating! We will send your gift card to the email or phone number that you gave us. If you do not receive your card within two weeks, please contact the research lead, Professor Anu Manchikanti Gómez at 510-642-0722 or anugomez@berkeley.edu.

Please click the arrow to submit your information. Please close your browser after submitting your responses.

END OF INCENTIVE SURVEY

Online FGD guide: Transgender and nonbinary participants, Spanish-language

Supplemental file 6: Spanish: Online focus group discussion guide for transgender, nonbinary, gender-expansive, and intersex participants

FGD Facilitator: Explain discussion purpose and guidelines

La participación en esta discusión grupal en línea tomará aproximadamente 30 minutos por día durante cuatro días, 2 horas en total. Cada día durante los cuatro días, iniciará sesión en este sitio web. Cada día publicaremos un nuevo conjunto de preguntas relacionadas con su identidad de género, su cuerpo, sus experiencias de atención médica y sus reacciones a un nuevo conjunto de preguntas sobre los órganos corporales que pueda tener. Cada día, puede responder a las preguntas de ese día, así como agregar a sus respuestas de días anteriores y responder a las respuestas de otros participantes. Le facilitador también puede hacerle preguntas de seguimiento basadas en las respuestas del día anterior. Puede responder a estas preguntas de seguimiento la próxima vez que inicie sesión.

El tercer día de esta discusión en línea, le mostraremos un nuevo conjunto de preguntas llamado "inventario de órganos": este es un formulario que los pacientes y el personal médico pueden usar para identificar qué partes del cuerpo tiene un paciente que podrían ser importantes al recibir atención médica. Esperamos conocer sus opiniones sobre el contenido del inventario de órganos, cómo podemos mejorarlo y cuándo y cómo se podrían utilizar las preguntas.

No hay respuestas correctas o incorrectas en esta discusión. No dude en compartir sus opiniones y reacciones con honestidad y libertad. Estamos interesadas en escuchar su punto de vista incluso si es diferente de lo que otros podrían expresar, o incluso si no está segura o se siente en conflicto acerca de su (s) opinión (es) en el formulario o las preguntas que le hacemos. Puede omitir cualquier pregunta que no desee responder.

Privacy/confidentiality information

Las respuestas escritas durante esta discusión de grupo focal se guardarán y compartirán con los investigadores. Para proteger su privacidad, solo usaremos el nombre de alias que elija proporcionar. El único nombre que verán los demás participantes en la discusión del grupo focal será este nombre de alias que usted elija proporcionar. Ellos no sabrán nada más sobre ti, aparte de lo que elijas compartir.

Recuerde que no es necesario que responda a ninguna pregunta con la que se sienta incómodo y que puede abandonar el grupo focal en cualquier momento.

Además, es importante que esta discusión sea privada; por favor no discuta ni comparta información de esta conversación con otros. Recuerde cerrar la ventana de su navegador después de enviar sus respuestas para evitar que alguien vea sus respuestas.

Cuando mencione a personas que conoce, no use sus nombres.

Si tiene alguna pregunta sobre el estudio, las preguntas o sus derechos como participante en esta investigación, puede comunicarse con Profesora Anu Manchikanti Gómez al 510-642-0722 o anugomez@berkeley.edu.

I. 1r Día: Conceptualizaciones de la identidad de género

Gracias nuevamente por aceptar participar en esta discusión. Para comenzar, me gustaría aprender un poco sobre sus pensamientos y opiniones sobre el género en general y sobre su propia identidad de género.

Online FGD guide: Transgender and nonbinary participants, Spanish-language

1. ¿Hay palabras específicas o lenguaje que usa para describir su propia identidad de género?
 - a. ¿Existen circunstancias o situaciones en las que esto cambie? Si es así, ¿puede contarnos sobre eso?
2. ¿Por cuánto tiempo se ha identificado de esta forma?
3. ¿Con qué frecuencia la gente le percibe con esta identidad de género?
4. ¿En qué situaciones elige compartir esta información?
5. ¿En qué situaciones cree que no tiene opción a compartir o no compartir esta información?
6. ¿Qué le parece importante compartir sobre su identidad de género para que entendamos lo que significa para usted?
7. ¿Qué significa para usted la frase sexo asignado al nacer? ¿Hay palabras o lenguaje específico que usa para describir su sexo asignado al nacer?
 - a. ¿Existen circunstancias o situaciones en las que esto cambie? Si es así, ¿puede contarnos sobre eso?
 - b. Como persona transgénero, de género expansivo, no binario, de género expansivo y / o intersexual, ¿qué tan bien cree que el sexo asignado al nacer captura información importante sobre su identidad o necesidades de atención médica?
8. ¿En qué espacios eliges compartir información sobre tu sexo asignado al nacer?
9. ¿En qué espacios cree que no tiene opción a compartir o no compartir esta información?
10. En la breve encuesta que completó para este grupo de enfoque, le hicimos las siguientes dos preguntas sobre género:

Si tuviera que elegir de la lista a continuación, aunque reconocemos que estas categorías pueden no ser ideales, ¿cuál de las siguientes describe mejor su género actual? (Seleccione todas las que correspondan)

- Agénero (sin género)
- Genderqueer
- Hombre
- No binario
- Two-Spirit (puede incluir el idioma específico de su tribu para su identidad, si lo desea) _____
- Mujer
- Categoría de género adicional, especifique: _____
- Prefiero no responder

¿Se identifica como transgénero y / o se considera una persona de experiencia transgénero?

- Sí
- No
- No lo sé
- Prefiero no responder

Online FGD guide: Transgender and nonbinary participants, Spanish-language

¿Qué opina de la redacción de la pregunta de la lista de género?

a. ¿Qué opina de la opción de "seleccione todas las que correspondan", frente a la opción de seleccionar solo una?

b. ¿Cómo afectaría su respuesta al poder seleccionar solo una frente a todas las que correspondan?

c. ¿Cómo se siente acerca de las opciones de género enumeradas?

11. ¿Qué opina de la pregunta sobre ser transgénero?

a. ¿Cómo cambiaría la redacción, si es que la cambiaría?

12. ¿Cómo se siente al que se le haga la pregunta sobre la experiencia transgénero por separado, en lugar de incluir "transgénero" como una opción de género en la pregunta de la lista de género de opción múltiple?

13. Después de preguntarle sobre el género, le preguntamos si es o se identifica como intersexual. Específicamente, preguntamos: ¿Se identifica como intersexual?

No

Sí

Prefiero no responder

Seguido por: ¿Alguna vez un proveedor de atención médica le ha dicho que es intersexual o que tiene lo que a veces se denomina "diferencia en el desarrollo sexual" o "trastorno del desarrollo sexual" (TDS)?

No

Sí

No sé

Prefiero no responder

¿Cómo se siente acerca de estas dos preguntas formuladas juntas? ¿Prefieres una más que otra?
¿Por qué o por qué no?

a. ¿Cómo podría mejorar la (s) pregunta (s)?

II. 2do Día: Experiencias y divulgación de atención médica

Ahora nos gustaría hacerle algunas preguntas sobre sus experiencias en un entorno de atención médica.

14. ¿Conocen sus proveedores de atención médica su género? (Aka, ¿está "fuera" con sus proveedores acerca de su género?)

15. ¿Cómo se ve y se siente el apoyo para usted como persona TGE en un entorno de atención médica?

Online FGD guide: Transgender and nonbinary participants, Spanish-language

16. ¿Cómo se ve y se siente no tener apoyo como persona TGE dentro de un entorno de atención médica?
17. ¿Cómo maneja o supera las barreras de la atención?
18. ¿Cómo ve a otras personas TGE manejar o superar estas barreras para la atención?
19. ¿Ha compartido su proveedor con usted sus calificaciones para trabajar con las personas TGE?
20. ¿Alguno de sus proveedores ha hablado con usted sobre el riesgo de cáncer, las pruebas de detección o el tratamiento? Si es así, ¿quién suele mencionar el tema?
21. ¿Qué tan cómodo se siente al tener estas conversaciones con su proveedor?
22. ¿Un proveedor no ha podido responder sus preguntas sobre el riesgo de cáncer, las pruebas de detección o el tratamiento relacionado con las personas TGE?
23. ¿Cuáles son las características más importantes de un proceso de admisión médica para usted y las personas TGE que conoce?
 - a. ¿Qué características deben EVITARSE en un proceso de admisión médica para usted?
24. ¿Ha cambiado su identidad como persona TGE su relación con la divulgación de su historial médico a sus proveedores de atención médica a través del tiempo?
25. ¿Los formularios de admisión en el consultorio de su proveedor de atención médica se sienten como si tuvieran un lenguaje apropiado y preciso sobre su identidad, cuerpo y comportamientos?
26. ¿Tiene alguna recomendación para crear formularios médicos que reflejen su género, cuerpo y comportamientos?
27. Si necesitara un examen de detección o atención médica, ¿cómo determinaría una preferencia por una clínica o un proveedor específico?
28. Si necesitara un examen de detección o atención médica, ¿cómo determinaría una preferencia por un procedimiento específico? ¿Le preguntaría a su proveedor o amigos?
29. ¿Qué tipo de información le gustaría que su proveedor supiera antes de comenzar esta conversación?
30. ¿Qué tan informados han estado los proveedores de atención médica que ha visto sobre el cuidado de las personas TGE?
 - a. Si no tan informados, ¿ha recibido apoyo con referencias para acceder a la atención adecuada para usted?
31. ¿Qué impacto (si lo hay) tienen las actitudes de los proveedores en su deseo de buscar atención médica?

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III. 3r Día: Revisión del inventario

Tómese los próximos cinco minutos para leer este formulario. Responda a la siguiente serie de preguntas cuando haya terminado de revisar el formulario.

FORMULARIO DE INVENTARIO DE ÓRGANOS

Para asegurarnos de que se le realice un examen de detección apropiado para su cuerpo y su experiencia, le preguntamos a TODAS las personas (independientemente del género o sexo asignado al nacer) sobre qué partes del cuerpo tiene actualmente. Para cada parte del cuerpo, comenzamos usando el término médico, aunque sabemos que estos términos pueden no ser las palabras que usa para su cuerpo. Podrá escribir las palabras que usa para estas partes del cuerpo en una pregunta posterior. Sin embargo, en aras de la claridad, utilizamos los términos médicos como punto de partida.

De la siguiente lista de partes del cuerpo, marque la casilla junto a cualquier parte del cuerpo que tenga ACTUALMENTE. Para los órganos que vienen en pares, seleccione la casilla si tiene CUALQUIER tejido de ese órgano. **SELECCIONE TODAS LAS QUE CORRESPONDAN.**

- Senos o tejido mamario**
Los **senos** son órganos blandos en el pecho de adolescentes y adultos.
- Colon**
El **colon** es un órgano en la zona inferior del torso que ayuda con la absorción de alimentos. La parte más larga del intestino grueso.
- Útero**
El **útero** es un órgano que se encuentra en el área pélvica. El sangrado mensual proviene del útero y es donde crece el embarazo.
- Ovarios**
Los **ovarios** son órganos que producen óvulos humanos y también hormonas. Suelen haber dos de ellos y se encuentran en la región pélvica del cuerpo.
- Trompas de Falopio**
Las **trompas de Falopio** conectan los ovarios al útero.
- Cuello uterino**
El **cuello uterino** es la abertura del útero, en la parte posterior de la vagina.
- Próstata**
La **próstata** es una glándula dentro del cuerpo, debajo de la vejiga y entre el recto y la uretra en la base del pene.
- Pene**
El **pene** es un falo que es una parte del cuerpo cerca de la ingle, utilizado por algunas personas para la actividad sexual y también por algunas personas para soltar orina y esperma del cuerpo.
- Vagina**
La **vagina** es una abertura genital frontal, utilizada por algunas personas para la actividad sexual y también por algunas personas para soltar sangre menstrual o dar a luz.
- Testículos**

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Los testículos (también llamados **testes**) son glándulas reproductoras que se encuentran fuera del cuerpo y están contenidas dentro del escroto. Por lo general, hay dos y producen espermatozoides y andrógenos.

- Ano**
El **ano** es la abertura a través de la cual los desechos sólidos salen del cuerpo, también utilizada por algunas personas para la actividad sexual.
- Ninguna de las anteriores**
- Prefiero no responder**
- No dude en compartir información adicional sobre los órganos que tiene ahora o que solía tener, que podría ser importante que sus proveedores de atención médica la sepan. _____

Si marcó pene, vagina o testículos en la lista anterior, marque la opción a continuación que se aplique a usted. Comprender qué cirugías puede haber tenido y / o qué terapia hormonal ha utilizado puede ayudar a su proveedor a determinar qué exámenes de salud recomiendan. **SELECCIONE TODAS LAS QUE CORRESPONDAN.**

¿Nació con esta vagina o se desarrolló mediante cirugía y / o terapia hormonal de afirmación de género (THAG) / terapia de reemplazo hormonal (TRH)?

- Nací con una vagina
- Cirugía
- GAHT/TRH
- No tengo este órgano
- Prefiero no responder

¿Nació con este pene o se desarrolló mediante cirugía y / o terapia hormonal de afirmación de género (THAG) / terapia de reemplazo hormonal (TRH)?

- Nací con una vagina
- Cirugía
- GAHT/TRH
- No tengo este órgano
- Prefiero no responder

¿Nació con testículos o se desarrollaron mediante cirugía y / o terapia hormonal de afirmación de género (THAG) / terapia de reemplazo hormonal (TRH)?

- Nací con una vagina
- Cirugía
- GAHT/TRH
- No tengo este órgano
- Prefiero no responder

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¿Ha tenido alguna de las siguientes cirugías? Le preguntamos sobre su historial de cirugía porque puede ayudar a su proveedor a decidir qué tipo de examen de salud recomienda. **SELECCIONE TODAS LAS QUE CORRESPONDAN.**

Mastectomía

Una mastectomía es una cirugía para extirpar todo el tejido mamario de una mama como una forma de tratar o prevenir el cáncer de mama. Una mastectomía puede involucrar uno o ambos senos.

Top surgery

Procedimiento quirúrgico para extraer tejido mamario. También se llama cirugía de tórax masculinizante. La cirugía superior implica más que una mastectomía para el tratamiento del cáncer de mama. Se pueden usar técnicas especiales para contornear y reducir la pared torácica, colocar los pezones y la areola y minimizar las cicatrices.

32. ¿Qué pensó cuando leyó el formulario por primera vez?

Probe:

- ¿Cómo se sintió?
- ¿Qué te gustó? ¿Qué no te gustó?
- ¿Qué te sorprendió?
- Otros comentarios:

33. ¿Cómo se sintió leer las opciones de este formulario?

Probe:

- ¿Cálido? ¿Frío? ¿Médico? ¿Personal?
- ¿Qué te pareció difícil de entender?
- ¿Qué se sintió fácil de entender?
- Otros comentarios:

34. ¿Qué información fue relevante o no relevante para su género, cuerpo o experiencia?

Probe:

- ¿Por qué por qué no?
- ¿Qué información fue la más importante?
- ¿Qué información faltaba?
- Otros comentarios:

35. ¿Qué tan fácil o difícil fue averiguar cómo llenar este formulario?

36. ¿A quién cree que va dirigido este formulario? ¿Por qué?

37. ¿Cómo cree que un proveedor de atención médica debería usar este formulario? ¿Cuándo (si alguna vez) cree que es apropiado que un proveedor de atención médica use este formulario?

38. . Después de que los participantes respondan al inventario de órganos, les daremos la opción de decirle a su proveedor qué lenguaje usar para hablar sobre su cuerpo. Vea a continuación un ejemplo.

¿Le gustaría decirle a su proveedor qué lenguaje usar para describir las partes de su cuerpo?

- Sí
 No → Saltar al final

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En caso afirmativo, marque la casilla junto a la casilla que se aplica a su experiencia. Al responder a estas preguntas, considere qué términos podría utilizar al hablar con su proveedor en el ámbito médico.

¿Usa la palabra "senos"?

- Sí, uso la palabra “senos.”
- No, uso otra palabra. La palabra que uso en vez de “senos” es: _____
- Prefiero no responder

¿Usa la palabra "cuello uterino"?

- Sí, uso la palabra “cuello uterino.”
- No, uso otra palabra. La palabra que uso en vez de “cuello uterino” es: _____
- Prefiero no responder

¿Usa la palabra "trompas de Falopio"?

- Sí, uso la palabra “trompas de Falopio.”
- No, uso otra palabra. La palabra que uso en vez de “Trompas de Falopio” es: _____
- Prefiero no responder

¿Usa la palabra "ovarios"?

- Sí, uso la palabra “ovarios.”
- No, uso otra palabra. La palabra que uso en vez de “ovarios” es: _____
- Prefiero no responder

¿Usa la palabra "pene"?

- Sí, uso la palabra “pene.”
- No, uso otra palabra. La palabra que uso en vez de “pene” es: _____
- Prefiero no responder

¿Usa la palabra "próstata"?

- Sí, uso la palabra “próstata.”
- No, uso otra palabra. La palabra que uso en vez de “próstata” es: _____
- Prefiero no responder

¿Usa la palabra "testículos"?

- Sí, uso la palabra “testículos.”
- No, uso otra palabra. La palabra que uso en vez de “testículos” es: _____
- Prefiero no responder

¿Usa la palabra "útero"?

- Sí, uso la palabra “útero.”
- No, uso otra palabra. La palabra que uso en vez de “útero” es: _____
- Prefiero no responder

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¿Usa la palabra "vagina"?

- Sí, uso la palabra "vagina."
- No, uso otra palabra. La palabra que uso en vez de "vagina" es: _____
- Prefiero no responder

¿Usa la palabra "colon"?

- Sí, uso la palabra "colon."
- No, uso otra palabra. La palabra que uso en vez de "colon" es: _____
- Prefiero no responder

¿Usa la palabra "ano"?

- Sí, uso la palabra "ano."
- No, uso otra palabra. La palabra que uso en vez de "ano" es: _____
- Prefiero no responder

39. ¿Cuál es su reacción a esta opción de compartir las palabras que usa para hablar sobre su propio cuerpo?
40. ¿Para qué podría usarse esta información sobre el uso de palabras?
41. ¿Tiene alguna inquietud sobre cómo se podría utilizar esta información?
42. ¿Alguna recomendación para mejorar la forma en que preguntamos a las personas sobre las palabras que usan para estas partes del cuerpo?
- a. ¿Cómo se sentiría si agregáramos una opción de respuesta para cada término que diga "Preferiría no hablar de esta parte del cuerpo con un proveedor"?

IV. 4o Día: Recomendaciones

Nos interesan sus opiniones sobre las recomendaciones para mejorar este formulario.

43. ¿Quién cree que se beneficiaría más al utilizar este formulario? ¿Por qué?
44. ¿Quién se beneficiaría menos? ¿Por qué?
45. ¿Qué se podría mejorar?
46. ¿Hay situaciones o entornos en los que no se deba utilizar este formulario? ¿Cuáles son las posibles alternativas que podrían utilizarse en esa situación o entorno?
47. ¿Tiene alguna otra idea que le gustaría compartir y que podría ayudarnos a pensar en los cambios en el formulario?
48. ¿Hay algo que cree que sería importante que el equipo de investigación supiera que no le habíamos preguntado?

Online FGD guide: Transgender and nonbinary participants, Spanish-language

49. ¡Muchas gracias por su participación en este estudio! Para poder enviarle la tarjeta de regalo de Amazon de \$ 75 como agradecimiento por participar, necesitaremos recopilar su información de contacto. Si desea recibir una tarjeta de regalo de Amazon de \$ 75 como agradecimiento por participar, seleccione "sí" a continuación.
- SÍ, me gustaría recibir una tarjeta de regalo de \$ 75
 - NO, no quiero una tarjeta regalo
50. Para una encuesta en línea de ~ 15 minutos, ¿sería más probable que participara si se le ofreciera participación?:
- Un sorteo para ganar una tarjeta de regalo de \$ 50 (tendría una probabilidad de 1 en 10 de ganar)
 - Una tarjeta de regalo de \$ 5 garantizada
 - Es igualmente probable que participe con cualquier opción
 - No lo sé
51. A continuación, nos gustaría que eligiera un código de acceso de cuatro dígitos. Elija un número que pueda recordar fácilmente. Después de ingresar su contraseña y hacer clic en el botón SIGUIENTE, será dirigido a otro sitio web para completar un formulario con su contraseña e información de contacto. Al ingresar esta información en una encuesta separada, podemos asegurarnos de que su nombre e información de contacto no estén directamente relacionados con sus respuestas a las preguntas de esta encuesta. **Si no desea ingresar su información, puede cerrar su navegador ahora para proteger su privacidad.**
-

FIN DE LA DISCUSIÓN DE GRUPO FOCAL

NEW SURVEY FOR INCENTIVE DISTRIBUTION

Gracias por participar en un estudio de investigación con la Universidad de California, Berkeley e Ibis Reproductive Health. Por favor, responda las siguientes preguntas para que podamos enviarle la tarjeta de regalo de Amazon de \$ 75 como agradecimiento por participar. Al ingresar esta información en una encuesta separada, podemos asegurarnos de que su nombre e información de contacto no estén directamente relacionados con sus respuestas a las preguntas de esta encuesta. **Si no desea ingresar su información, puede cerrar su navegador ahora para proteger su privacidad.**

1. Ingrese su contraseña de cuatro dígitos.

2. ¿Le gustaría que le enviemos por correo electrónico una tarjeta de regalo de Amazon de \$ 75 o le enviemos un mensaje de texto con una tarjeta de regalo de Amazon de \$ 75?
 - CORREO ELECTRÓNICO: me gustaría recibir una tarjeta de regalo de \$ 75 por correo electrónico

Online FGD guide: Transgender and nonbinary participants, Spanish-language

- TELÉFONO: me gustaría recibir una tarjeta de regalo de \$ 75 por mensaje de texto
3. [Si selecciona "correo electrónico" arriba →] Proporcione la dirección de correo electrónico a la que le gustaría que le enviemos su tarjeta de regalo:

4. [Si selecciona "teléfono" arriba →] Proporcione el número de teléfono al que le gustaría que le enviemos su tarjeta de regalo:

5. ¿Le gustaría que le enviemos los resultados de este estudio (una hoja informativa, preguntas frecuentes u otro tipo de resumen) por correo electrónico?
- Sí, envíeme un correo electrónico con los resultados a esta dirección de correo electrónico: _____
- No, no quiero que me envíen los resultados.

¡Gracias por participar! Enviaremos su tarjeta de regalo de Amazon al correo electrónico o al número de teléfono que nos proporcionó. Si no recibe su tarjeta en dos semanas, comuníquese con la líder de la investigación, Profesora Anu Manchikanti Gómez al 510-642-0722 o anugomez@berkeley.edu.

Haga clic en la flecha para enviar su información. Cierre su navegador después de enviar sus respuestas.

FIN DE LA ENCUESTA DE INCENTIVOS