

*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](mailto: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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- 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**

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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**

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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.

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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

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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.**
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**END OF FOCUS GROUP DISCUSSION*****NEW SURVEY FOR INCENTIVE DISTRIBUTION***


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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](mailto:anugomez@berkeley.edu).

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

**END OF INCENTIVE SURVEY**