PCR218

# Gender is not binary: An online survey to improve inclusivity in sex and gender demographic questions

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## Introduction

- Historically, **sex and gender demographic characteristics have not been collected consistently or inclusively** within clinical studies/health research, due to the use of singular questions with binary response options. For example, only asking about gender, with binary response options of "male" and "female".[1–3]
- It is important that **sex** *(biological construct based on anatomy, physiology, genetics, and hormones)*[4] **and gender** *(multidimensional construct that encompasses gender identity and expression, as well as social and cultural expectations)*[4] **demographic information is collected appropriately in clinical studies,** to ensure the accurate collection of this data and inclusion of commonly marginalized groups, such as the transgender community.[5]
  - Transgender individuals are more likely to participate in health research if it is perceived as inclusive and diverse, with research from a cisgender *(gender identity corresponds to sex assigned at birth)* lens being a barrier to participation.[6]
- **The U.S. Food and Drug Administration (FDA) recognizes sex differences in the safety and efficacy of medical products**, and acknowledge sex and gender are separate concepts that should be collected in clinical studies.[7,8]
- As part of the diversity plan, the FDA also advises that clinical trial sponsors should **seek diversity in clinical trial** enrolment, beyond populations defined by race and ethnicity, **including sex and gender identity.**[9] Despite this, there lacks specific guidance regarding how sex and gender demographic questions should be collected in clinical studies.
  - Moreover, current research exploring understanding and preferences of how sex and gender demographic questions are asked is limited.

**Objective: To explore the understanding of word preferences of sex and gender demographic questions within both the general population and the LGBTQ+ community through an online survey.**

## Methods

A **literature review was conducted** exploring inclusive language to use when collecting demographic information on sex and gender to inform a **survey developed** by Adelphi Values' Diversity, Equity, Inclusivity and Belonging team.

The survey consisted of two sections using both closed and open-ended questions that gathered:
Section 1: Participant demographic information.
Section 2: **Understanding, preferences and opinions on terminology across three sex and gender demographic question options** (Figures 1-3).

The survey was **hosted on Prolific** (an online research hosting website) and targeted **US respondents**.

Quantitative data were analyzed using **descriptive statistics** and open-ended data were analyzed using **thematic analysis.**[10]

**Option 1:**

1. What sex were you assigned at birth, such as an original birth certificate? (Please select one box)
   - ☐1 Male
   - ☐2 Female
   - ☐3 Intersex
2. Is your gender identity the same as the sex you were assigned at birth? (Please select one box)
   - ☐1 Yes
   - ☐2 No, please describe ______________________

Figure 1. Sex and gender demographic questions option 1

**Option 2:**

1. What is your current sex? (Please select one box)
   - ☐1 Male
   - ☐2 Female
   - ☐3 Intersex
2. What best describes your gender identity? (Please select one box)
   - ☐1 Male
   - ☐2 Female
   - ☐3 Transgender male
   - ☐4 Transgender female
   - ☐5 Gender neutral/non-binary
   - ☐6 Not listed, please specify ______________

Figure 2. Sex and gender demographic questions option 2

**Option 3:**

1. How would you describe yourself? (Please select one box)
   - ☐1 Male
   - ☐2 Female
   - ☐3 Transgender male
   - ☐4 Transgender female
   - ☐5 Gender neutral/non-binary
   - ☐6 Not listed, please specify ______________

Figure 3. Sex and gender demographic questions option 3

## Results

### Participant demographic characteristics

- N=300* respondents (Mean age = 37; Range 18-82).
  - *n=1 participant's data were removed due to failing data checks, resulting in an **analyzable sample of N=299 participants**.
- **60% identified as members of the LGBTQIA+** *(Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual/Aromantic, + indicating other sexualities and gender identities exist)* community.
- **56% sex was assigned female at birth**, 44% male.
- 81% gender identity was the same as their sex assigned at birth, with **19% self-identifying a different gender identity to their sex assigned at birth** (Figure 4).

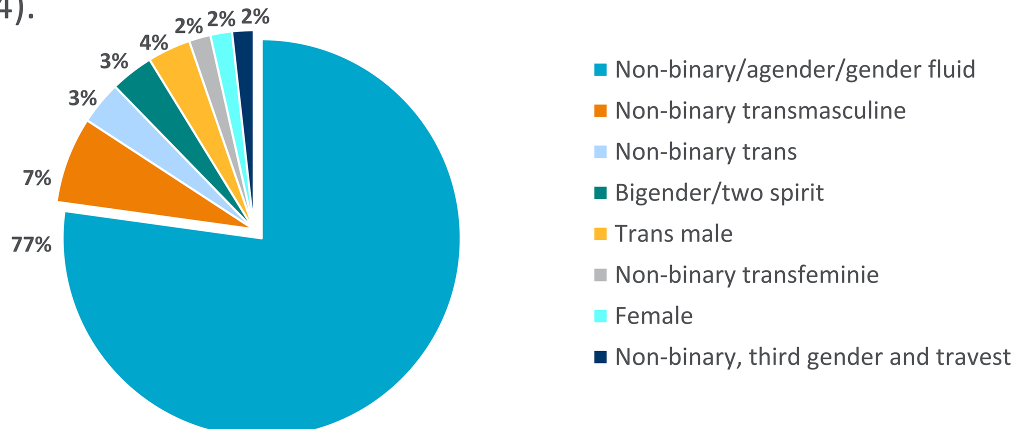


Figure 4. Self-identified gender identities for respondents who indicated their gender identity does not match their sex assigned at birth

### Understanding

- **Most participants (84%) noted that they understood all aspects** of the three sex and gender questions.
- 4% noted they didn't understand an aspect of the options:
  - 8 participants were unsure of what intersex meant;
  - 2 participants were unsure of how to answer "no, please describe";
  - 1 participant thought sex and gender were the same.
- 12% either did not answer the question or did not provide an appropriate answer.
- When asked to respond to the three options based on hypothetical scenarios, **the majority of participants responded as intended for Options 1-3**, with slightly higher proportions for Options 1 (87%) and 3 (86%), compared to Option 2 (80%).

*"The wording on all three options is clear and easy to navigate and understand."*

### Preferences

- **Option 1 was most commonly ranked as the most preferable option,** with Option 3 following closely behind.

| Options | Most preferable 1 | 2 | 3 | 4 | Least preferable 5 |
|---|---|---|---|---|---|
| Option 1 | 104 | 91 | 85 | 10 | 9 |
| Option 2 | 59 | 116 | 96 | 23 | 5 |
| Option 3 | 98 | 72 | 97 | 18 | 14 |
| None of these options are preferable to me | 24 | 11 | 10 | 203 | 51 |
| I do now know how to rank these options | 14 | 9 | 11 | 45 | 220 |

*"Option 1 seems best IF the questioner needs to know one's sex at birth (like for medical purposes), and it is nice that it provides a field for the person to fill in what they perceive as their gender identity."*

*"Option 1 has the clearest delineation between past and present, allowing for the clearest results in a clinical settings. Option 3 … leaves space for other possibilities, but it may not lead to clear answers in certain contexts that Option 1 would provide."*

### Opinions on terminology

- **Most participants (73%) felt a response option of 'prefer not to say' should be included** within sex and gender demographic questions.
  - 13% of participants reported that 'prefer not to say' should not be listed as a response option and 15% did not know.
- **56% of participants noted they would like to specify their gender** if it was not listed, with a slight preference for the term 'not listed' (36%) over 'other' (30%).
- Participants highlighted the importance of identifying and using inclusive language to ensure people from the LGBTQIA+ community are respected.
  - Allowing people to self-identify, in their own terms, was felt to be a successful method of achieving this.
- Participants also **suggested providing definitions of response options and randomizing the order gender identities are listed** so that 'Male' and 'Female' are not always listed first.

*"Sex and gender are deeply personal for a lot of us, so giving more space to self-identify instead of trying to include every single identity separately is always going to feel more inclusive."*

## Conclusions

- This study highlighted **the importance of identifying and using inclusive language** to ensure the LGBTQIA+ community are inclusively and accurately represented within clinical studies, to allow for sex and gender differences in clinical studies to be explored.
- **All three options of the sex and gender demographic questions were well understood**, with a slight **preference towards Option 1** and a **preference for self-describing gender identity**.
  - It is recommended that the purpose of sex and gender demographic questions, including how they will be used in analysis of any health data, are considered before determining how to ask these questions. Consideration may also depend on disease area, anticipated sex or gender differences, and plans for sub-group analyses by sex and/or gender.
- The results from this survey are **applicable to clinical studies being conducted in the US**, future research should examine understanding and preferences of demographic questions in other countries.

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ISPOR US, Atlanta, GA, 5th-8th May 2024