

# Inclusion of LGBTQ persons in research related to pregnancy risk: a cognitive interview study

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## ABSTRACT

**Introduction** Recently, researchers have begun considering whether and how to include lesbian, gay, bisexual, transgender and queer (LGBTQ) people in research about abortion and contraception care. Including LGBTQ people in research about abortion and contraception care, as well as the risk for unintended pregnancy more broadly, requires accurate assessment of risk for unintended pregnancy, which involves different considerations for LGBTQ people.

**Methods** We created a survey with existing sexual orientation and gender identity measures, new reproductive anatomy questions to guide skip patterns, gender neutral terminology in sexual and behavioural risk questions, and existing contraception and pregnancy intentions questions that were modified to be gender neutral. We then assessed the appropriateness of these measures through cognitive interviews with 39 individuals aged 18–44 years who were assigned female at birth and identified as LGBTQ. Participants were recruited in the San Francisco Bay Area of California, Baltimore, Maryland and other cities.

**Results** Existing demographic questions on sexual orientation and gender identity were well received by participants and validating of participant reported identities. Participants responded positively to new reproductive anatomy questions and to gender neutral terminology in sexual behaviour and pregnancy risk questions. They felt skip patterns appropriately removed them out of inappropriate items (eg, use of contraception to avoid unintended pregnancy); there was some question about whether pregnancy intention measures were widely appropriate or should be further restricted.

**Conclusions** This study provides guidance on ways to appropriately evaluate inclusion of LGBTQ people in abortion and contraception research.

## Key messages

- ▶ Researchers interested in including lesbian, gay, bisexual, transgender and queer (LGBTQ) people in studies about pregnancy risk need to consider unique anatomical and behavioural factors in survey development.
- ▶ LGBTQ people may feel validated by expanded gender identity options and sexual and reproductive health survey items that use gender neutral terminology.
- ▶ Commonly used pregnancy intention, pregnancy risk and sexual behaviour questions should be adapted for use among LGBTQ people.

## INTRODUCTION

There is growing awareness that lesbian, gay, bisexual, transgender or queer (LGBTQ) individuals may have unique reproductive health needs, experiences or challenges<sup>1–3</sup> not typically addressed in research.<sup>4</sup> Researchers have begun comparing reproductive health across sexual orientation,<sup>5</sup> mostly among LGB youth.<sup>6</sup> While some research examines sexual health of<sup>7,8</sup> and pregnancy among transgender men,<sup>9</sup> there is little research about needs or experiences of transgender or gender non-conforming individuals in relation to abortion, contraception and unintended pregnancy.

Most studies of abortion and contraception do not assess gender identity,<sup>10</sup> assuming all participants are cisgender—when gender identity matches sex assigned at birth.<sup>11</sup> Abortion and contraception researchers have begun exploring the possibility of adding questions about sexual orientation and gender identity to questionnaires<sup>12</sup> to document how many LGBTQ people have abortions, for



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example. However, measurement has been inconsistent. Consistent and intentional assessment of sexual orientation and gender identity (SOGI) can help document the unique needs or experiences of LGBTQ people in relation to abortion and contraception care. While best practices for including sexual orientation,<sup>13–15</sup> gender identity measures,<sup>16 17</sup> or both,<sup>18</sup> exist, little to no guidance exists for inclusion of LGBTQ individuals in abortion and contraception research, unlike more extensive work in sexual health.<sup>19 20</sup> Additionally, little guidance exists for reproductive health researchers on assessing the appropriateness of LGBTQ inclusion based on the relevance of the research question to LGBTQ people and the researcher's ability to properly enlist enough participants to evaluate LGBTQ specific findings.

Including LGBTQ people in research about risk for unintended pregnancy more broadly is not as simple as just adding questions about SOGI to the demographics section of a survey. Not assessing the specific and relevant measures of sexual behaviour and reproductive anatomy can lead to asking LGBTQ individuals inappropriate questions (eg, asking a cisgender woman who only has sex with other cisgender women about the type of contraception she is using to prevent pregnancy, or asking a transgender man who has had a hysterectomy about his pregnancy risk). Due to misconceptions about pregnancy risk among researchers, clinicians and LGBTQ people themselves, LGBTQ people have historically not been included in research about abortion and contraception. In addition to general SOGI measures and making existing survey questions gender neutral, new questions to assess sexual behaviour and reproductive anatomy are needed in order to sensitively include LGBTQ people in abortion and contraception research.

## METHODS

The study involved two steps. First, we developed a survey. This involved: (a) identifying existing sexual orientation, gender identity, sexual behaviour and reproductive health survey questions; (b) adapting existing sexual behaviour and reproductive health questions to make them gender neutral; (c) developing additional anatomy and sexual behaviour questions to measure characteristics and behaviour relevant to pregnancy risk; and (d) developing skip patterns to ensure people only got questions relevant to their sexual behaviour and anatomy. Then we conducted cognitive interviews<sup>21</sup> with LGBTQ individuals about these survey items and skip patterns.

### Survey development

#### Measures

Survey items assessed participant demographics, sexual orientation, gender identity, pregnancy risk (from questions about sexual behaviour and reproductive anatomy, and from direct questions), contraception,

pregnancy status, retrospective and prospective pregnancy intentions, and pregnancy history. Demographic characteristics included age, education, employment and race/ethnicity.

SOGI measures were used to assess demographic characteristics, determine study eligibility and to help assess pregnancy risk. We used SOGI survey items from the Williams Institute<sup>13 16</sup> (see figure 1 for response options). Sexual orientation was assessed in three ways: current sexual identity, past year sexual behaviour and current sexual attraction.

We assessed pregnancy risk in two ways: sexual behaviour and self-perceived risk. First, we developed new self and partner anatomy and sexual partner gender identity measures to determine skip patterns. Figure 1 illustrates the survey logic for pregnancy risk assessment. Cisgender women, transgender men and gender queer/gender non-conforming individuals with a uterus who had sex with someone who had sperm were considered at risk of pregnancy based on biological plausibility (presence of uterus/ovaries and sperm). Individuals who only had sex with someone else who did not have sperm were not considered at risk of pregnancy.

Secondly, we also asked a self-perceived pregnancy risk question: "Do you think you can become pregnant?". Those who said no or who reported being unsure were asked a follow-up question with a close ended list of possible reasons, including medical diagnoses (eg, infertility or menopause), procedures (eg, hysterectomy or participant/partner sterilisation), sexual behaviour (sex during certain times of the month) or other miscellaneous items (eg, breastfeeding). Answers to these reasons questions did not impact on survey order or skip patterns.

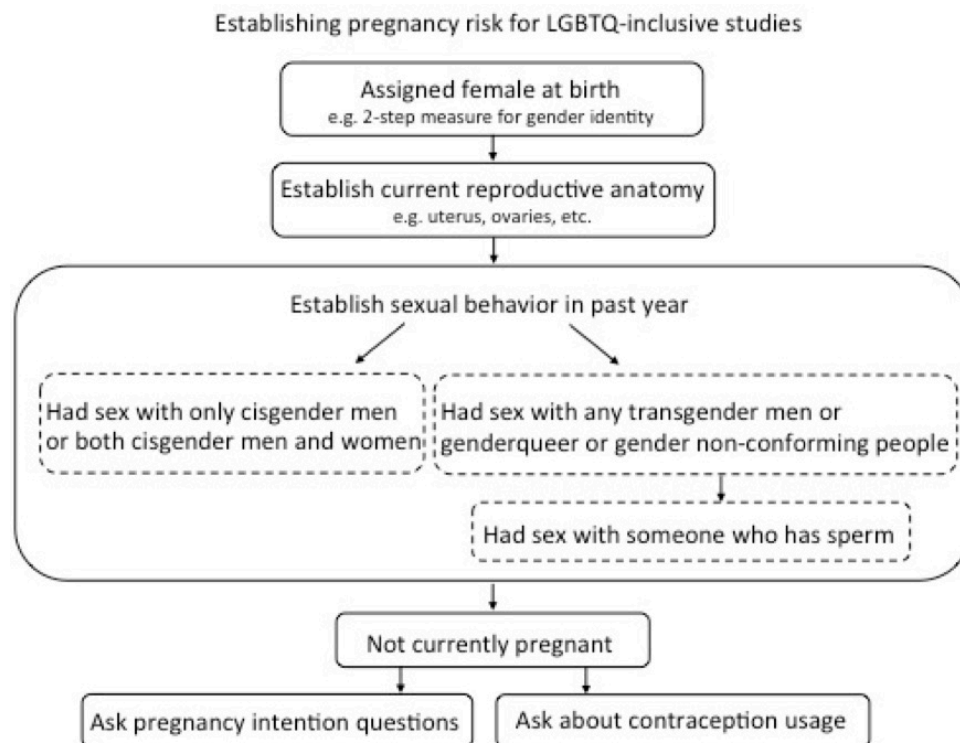
We asked participants considered at risk of pregnancy about contraception and unprotected sex, current pregnancy status, retrospective pregnancy intentions (have you wanted to be pregnant in the past),<sup>22</sup> prospective pregnancy intentions (do you want to be pregnant in the future)<sup>23</sup> and pregnancy history. We slightly modified the retrospective pregnancy intentions measure to use gender neutral language for romantic partners (eg, partner vs boyfriend) and used gender neutral language in the prospective pregnancy intentions measure (eg, becoming a 'parent' rather than a 'mother').

Participants whose sex assigned at birth and sexual behaviour responses indicated that they were not at risk of pregnancy, but who had anatomy to be or become pregnant, were skipped out of contraception (methods used) and unprotected sex questions, but asked other pregnancy related questions.

### Cognitive interviews

#### Sampling and recruitment

This study recruited people who identified as LGBTQ, were assigned female at birth and were



**Figure 1** Skip pattern logics for establishing pregnancy risk. LGBTQ, lesbian, gay, bisexual, transgender or queer.

aged 18–44 years. After obtaining human subjects' approval, we recruited individuals through LGBTQ organisations, e-mail, social media websites and local Craigslist postings in the San Francisco Bay Area of California and Baltimore, Maryland, and through snowball sampling. Interested individuals took a short screening survey that included demographic, gender identity and sexual orientation questions to determine eligibility. We described the study as one looking for LGBTQ people assigned female at birth focused on reproductive health.

#### Procedure

Eligible participants scheduled in person, video or telephone interviews after completing the online screening form. Participants reviewed informed consent materials, gave verbal consent and then completed an electronic survey on a tablet or personal computer. Following survey completion, cognitive interviews<sup>21</sup> were then conducted using the recall talk-aloud protocol, in which participants talked through their thought processes while answering survey items and determining answer selection.<sup>21</sup> All interviews were recorded with participant permission and transcribed. Transcripts were uploaded to Dedoose (V.7.6.6).

#### Data analysis

Analysis included both deductive and inductive coding. Following previous cognitive interview studies,<sup>10 21</sup> coding focused on participant interpretations and reactions to each question. Deductive coding focused on reproductive health question sets (eg, contraception

use, pregnancy intentions). The study team developed matrices around broad question areas (eg, gender identity, sexual orientation, sexual behaviour, contraception) to ensure inclusion of all participant perspectives. Participant reactions to questions were also coded as positive (participant liked the question), neutral (participant had no specific feelings about the question) or negative (participant did not like the questions) to quickly assess overall reactions.

#### Patient and public involvement

The research question and measures were informed by previous literature on LGBTQ patient experiences of exclusion in reproductive healthcare. Patients were not involved directly in the design or analysis of the study. However, participants in the study were asked to refer other participants as part of snowball sampling within the community. Results will be disseminated to community members and researchers through scholarly publication and publicly available measurement recommendations.

## RESULTS

Participant characteristics (n=39) are shown in [table 1](#). [Figure 2](#) details participant reactions to measures categorised into positive, negative, neutral or mixed responses; detailed qualitative responses to specific items are detailed in the following sections.

#### Existing SOGI measures

Participants responded positively to most existing SOGI measures.<sup>13 16</sup> The two step method for gender

**Table 1** Participant demographics

| Characteristic                                       | No of participants (%) (n=39) |
|--|-------------------------------|
| Age (years) (mean (range))                           | 29.9 (18–44)                  |
| Race/ethnicity (n (%))                               |                               |
| White  | 57 (22)                       |
| Black or African American                            | 15 (6)                        |
| Asian  | 5 (2)                         |
| Bi-racial  | 8 (3)                         |
| Hispanic   | 15 (6)                        |
| Sexual orientation (n (%))                           |                               |
| Gay or lesbian                                       | 13 (5)                        |
| Bisexual   | 18 (7)                        |
| Queer  | 64 (25)                       |
| Other  | 5 (2)                         |
| Gender identity (n (%))                              |                               |
| Male   | 5 (2)                         |
| Female   | 54 (21)                       |
| Trans man/trans male                                 | 13 (5)                        |
| Gender queer/gender non-conforming                   | 33 (13)                       |
| Education (n (%))                                    |                               |
| Less than high school                                | 2 (1)                         |
| High school graduate/general educational development | 2 (1)                         |
| Some college   | 10 (4)                        |
| Associates degree                                    | 2 (1)                         |
| College graduate                                     | 38 (15)                       |
| Postgraduate degree                                  | 45 (18)                       |
| Employment status (n (%))                            |                               |
| Employed full time                                   | 54 (21)                       |
| Employed part time                                   | 13 (5)                        |
| Unemployed   | 13 (5)                        |
| Homemaker  | 2 (1)                         |
| Other  | 18 (7)                        |

identity—sex assigned at birth and gender identity—was well received. Participants reported that flexibility was important for SOGI questions, noting that the ability to ‘select all that apply’ for multiple genders was preferable to selecting only one. Several participants were pleased to see ‘queer’ as a sexual orientation option, as most surveys they had seen only listed heterosexual, lesbian/gay and bisexual; this was also reflected in 64% of participants identifying as queer. Participants critiqued modifier inconsistency in gender identity measures, specifically the lack of ‘cisgender’ in the gender identity categories. However, two transgender male participants related most intimately to male as a standalone term and said they often check ‘male’ on forms or would check both male and transgender male if they could select multiple options.

Many participants also critiqued the sexual attraction measure. While other survey items used both gender binary (man/woman) and non-binary language (gender queer, some other gender identity), the sexual attraction question asked participants to describe their attraction as only toward men and women. A bi-racial, gender queer, queer participant said the sexual attraction item felt ‘limiting’ because they are attracted to ‘all different kinds of people’ so they chose ‘not sure’ as their response. Another participant, a white queer woman, found the attraction question difficult to answer, asking how to quantify ‘mostly attracted’ for her answer. Others were confused by what feelings were encompassed under ‘attraction’ (eg, romantic vs sexual).

**Pregnancy risk**

Participants responded positively to gender neutral language for sexual behaviour questions that focused on anatomy versus identity (see table 2). A white queer woman said the question about whether her sexual partner(s) had sperm was her ‘favourite question’ and found it ‘crucial’ that the survey assessed anatomical pregnancy risk. There was some concern about whether asking about vaginal sex might trigger gender dysphoria for some transgender participants, but no transgender participants in this study reported this.

In general, participants were unfazed by the skip pattern that started with a question about having sex with a transgender or gender queer/non-binary person. They acknowledged that the longer list of options could be confusing for those outside of the LGBTQ community. A couple of participants dissented, saying everyone should see the longer list to normalise language around identities. One South Asian transgender male participant noted that “if you’re not someone who engages with trans people... I think it would be legitimately more confusing to think through all these (other terms), and people might get hung up on it”. He also suggested including a definition for ‘cisgender’. A few expressed concern about how to best answer the sexual behaviour question in cases where their partner had multiple gender identities or if they had multiple partners.

Almost all participants interpreted the self-perceived pregnancy risk question to mean physical or biological capability rather than sexual behaviour that could lead to pregnancy. A white bisexual woman said she felt she was physically capable of becoming pregnant “even though I don’t have any partners right now who are capable of impregnating someone”. A second question asking participants why they felt they could not get pregnant also had mixed reactions; one participant with a history of miscarriages felt the question was triggering for those struggling with infertility, while others said they wanted to see items about sexual behaviour as response options (eg, I do not have sex with people who have sperm) in that list as well.

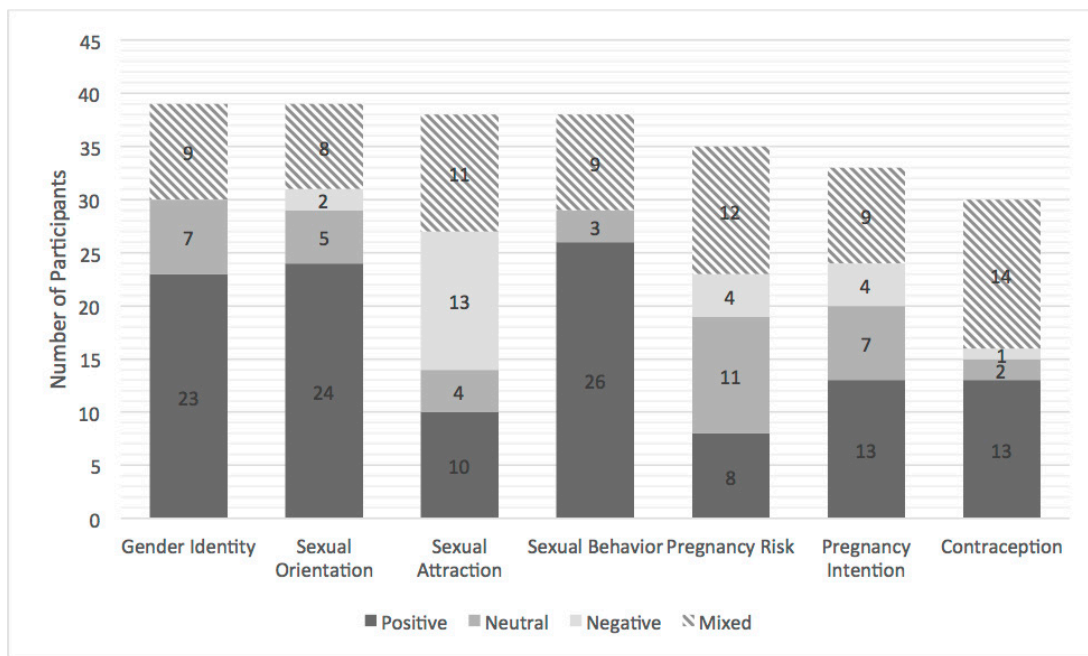


Figure 2 Participant item response ratings.

**Contraception and pregnancy intentions**

Participant responses to contraception and pregnancy intentions items were mixed. One-third responded positively to both sets of questions and more responded negatively to pregnancy intentions. Many participants (n=25) were skipped out of contraception and pregnancy intentions questions. However, several participants reported using contraception for uses outside of pregnancy prevention, indicating that skip patterns based on current pregnancy risk may exclude potentially important contraception use information from this population. One bi-racial queer woman said, “I’m not particularly using an IUD for pregnancy prevention, so this question... about what contraceptive method...feel[s] funny to me because...I’m kind of using it off label”. Transgender participants expected hormone replacement therapies as a response option when asked about contraception. Some, however, said they had mixed information on whether testosterone should be considered a contraceptive. Prospective pregnancy intentions items were asked to most participants (n=34). Very few desired to become pregnant or have children in the near future and several noted that any pregnancy would be unintended; a few noted that the only way they could see becoming pregnant was by means of sexual assault. Some, who were not at risk of

pregnancy (eg, cisgender women who have sex with other cisgender women) felt the framing of pregnancy intentions questions did not reflect their experiences.

**DISCUSSION**

This study provides guidance on ways to evaluate LGBTQ inclusion in abortion and contraception research related to pregnancy risk. Overall, existing demographic SOGI questions were well received and validating of participant reported identities. The one exception was the sexual attraction measure, which most viewed negatively. In studies set in pregnancy focused contexts, it would be appropriate to include SOGI measures in a demographics section and use gender neutral language to improve cultural sensitivity. In settings where someone’s pregnancy status is unknown, researchers can use SOGI questions about sexual behaviour and sex assigned at birth to screen people into/out of the study. Survey approaches developed for this study can allow for inclusion of LGBTQ people in research while avoiding asking them inappropriate questions. However, we do note that if the sample in abortion care settings is not large enough to have an adequate number of LGBTQ participants for a complete analysis of their needs or experiences,

| Table 2 Gender neutral framing   |   |
|--|---|
| Traditional framing approach   | Gender neutral approach   |
| In the next question, we ask about the <i>man</i> who you became pregnant with. This <i>man</i> might be your <i>husband</i> , a partner you live with, a <i>boyfriend</i> or someone you’ve had sex with once or twice. | In the next question, we ask about the <i>person</i> who you became pregnant with. This <i>person</i> might be your <i>spouse</i> , a <i>romantic and/or domestic partner</i> , or someone you’ve had sex with once or twice. |
| In terms of becoming a <i>mother</i> , I feel it happened at the...  | In terms of becoming a <i>parent</i> , I feel it happened at the...   |

it may be more appropriate to screen them out rather than increase participant burden if their data will not be used.

Because abortion and contraception studies set in the general population typically focus on the needs of cisgender heterosexual women, they may not identify the needs most relevant for LGBTQ people. For example, they may not investigate whether and to what extent hormone replacement therapies may prevent pregnancy, a topic still under debate by medical researchers.<sup>24</sup> Researchers who want to include LGBTQ individuals in research about abortion and contraception should make sure their studies are able to deepen understanding of the needs and experiences of LGBTQ individuals and ways to meet these needs. This may mean creation and validation of new items to assess shifting gender identities,<sup>25</sup> sexual attraction measures that account for a wider variety of relationship configurations (eg, non-monogamy or polyamory), sexual fluidity across the lifespan or types of pregnancy risk (biological, behavioural or other). This also means that factors known to impact reproductive health decision making, such as socioeconomic status and disability status,<sup>26</sup> are also key demographic factors to consider in future surveys.

There are several limitations to generalisability. While this study included LGBTQ individuals from multiple states, participants were recruited through convenience sampling and resided primarily in California and Maryland based on the physical location of the two primary research staff. Participants were highly educated and many worked in LGBTQ or reproductive health, indicating potentially higher levels of knowledge or consideration of demographic and reproductive health terminology. We did not assess whether SOGI questions, revised items, newly developed anatomy questions or the skip patterns they informed are suitable for cisgender heterosexual women. We only used items in English. Survey items assessing intersex or difference/disorder of sex development<sup>27 28</sup> were not assessed. Future studies should also test these items. Additionally, unlike recent measures developed specifically for transgender populations,<sup>17</sup> we did not assess for indigenous gender identities or sexual orientations. Future research should assess local terminology for SOGI items and with cisgender heterosexual women to ensure more accurate data collection.<sup>29</sup> Finally, this study was designed primarily to inform the work of reproductive health researchers rather than provide direct guidance on assessing pregnancy risk or contraceptive use in a clinical context. Time constraints in clinical interactions make pregnancy risk assessment even more challenging. Future research should explore how these survey items could be adapted into shorter assessments for clinical application.

Culturally sensitive inclusion or exclusion of LGBTQ individuals should be a priority for reproductive health researchers. The survey items and approaches

described here should facilitate this and lead to opportunities to improve the reproductive health of LGBTQ people.

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**Competing interests** None declared.

**Patient consent** Not required.

**Ethics approval** The study was approved by the UCSF Committee on Human Research.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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