



Asking sexual orientation and gender identity on health surveys: Findings from cognitive interviews in the United States across sexual orientations and genders

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1. Introduction

Sexual orientation and gender identity (SOGI) represent fundamental parts of a person's identity, yet these important demographic characteristics are not consistently asked on U.S.-based health surveys (Patterson et al., 2017). As a result of inconsistent survey practices, sexual and gender minority (SGM) people – including but not limited to lesbian, gay, bisexual, transgender and queer (LGBTQ+) people – are often rendered invisible despite growing evidence of health disparities and differences, as well as differences in resilience patterns among these populations (Blosnich et al., 2014; Bockting et al., 2013; Cahill et al., 2016; Fredriksen-Goldsen et al., 2014; Institute of Medicine (US) Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2011; Jaffee et al., 2016; Patterson et al., 2017). Gender minority people are transgender and gender diverse individuals whose gender identities or expressions differ from those commonly associated with their sex assigned at birth (SAAB) (American Psychological Association, 2015). Cisgender people, conversely, have gender identities and/or expressions that are consistent with those commonly associated with their SAAB. Sexual minority people are not heterosexual and may include lesbian, gay, and bisexual people as well as people of other sexual orientations (e.g., asexual, demi-sexual, pansexual). As part of national efforts to improve public

health infrastructure and services, *Healthy People 2030* called for an increase in the number of surveys that collect data on LGBTQ+ populations (Office of Disease Prevention and Health Promotion, 2020). Moreover, the National Academy of Sciences' Committee on Measuring Sex, Gender Identity, and Sexual Orientation evaluated current SOGI measures and recommended standardized federal data collection after identifying heterogeneous practices that contribute to inaccurate categorization and/or undercounting of SGM people (The National Academies of Sciences, 2022). SOGI dimensions are multipronged and complex; they encompass sexual identity, sexual attraction, sexual behavior, gender identity, and gender expression. Each are distinct from SAAB. The multiplicity of questions necessary to ascertain these various dimensions poses a challenge to health researchers in balancing accuracy and survey burden when considering non-SGM and SGM populations in large-scale surveys.

Many studies about SOGI questions on health surveys have focused primarily on the preferences and experiences of SGM people (Holzberg et al., 2019; Moseson et al., 2020; Suen et al., 2020, 2022). Although some early work, such as cognitive testing of the National Health and Nutrition Examination Survey (NHANES) performed by the National Center for Health Statistics included non-SGM and SGM participants, this effort focused only on sexual orientation. Findings from NHANES testing suggested that sexual identity, like racial identity, is a complex

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phenomenon and respondents may not understand answer options on questions about sexual orientation (Miller, 2011). Relevant contributions were made by the National Health Interview Survey (NHIS), which began collecting information about the sexual orientation of adult respondents in 2013. However, NHIS's sexual identity item focused on response rates based on the mode of administration (e.g., computer-based survey with or without audio) rather than respondent preferences; no response differences based on mode were found. Akin to NHANES work, NHIS variables and analyses were limited to sexual orientation and did not consider comprehensive gender identity (i.e., including methods to identify transgender and gender diverse people explicitly) (Dahlhamer et al., 2019).

An important aspect of accurately measuring SOGI is addressing missing data. Studies using Behavioral Risk Factor Surveillance System (BRFSS) data have shown less than 5% of item-level SOGI data were missing, which suggests that the majority of respondents are willing to answer SOGI questions (Jesdale, 2021). Cognitive interviews performed by the U.S. Census Bureau demonstrated that LGBTQ+ and non-LGBTQ+ respondents were generally willing to answer SOGI questions in the context of a federal employment survey (Ellis et al., 2018). Moreover, findings from the California Health Interview Survey and the U.S. Census Bureau's Household Pulse Survey have found considerable proportions of less definitive responses (e.g., something else, don't know, none of these) or non-responders. This highlights an important gap in understanding why survey respondents do not answer SOGI questions and whether factors like comfort, acceptability, and appropriateness of language may affect the response (File & Scherer, 2022; Jans, 2022; Jans et al., 2015).

Limited research has explored how non-SGM and SGM people want to be asked about SOGI in the context of a federal health survey and how these groups compare regarding their concerns for disclosure. The purpose of this qualitative study was to explore how people across various sexual orientations and gender identities preferred to be asked about SOGI on U.S.-based health surveys (Office of Disease Prevention and Health Promotion, 2020).

2. Materials & methods

2.1. Participant recruitment

We recruited participants from January 2021 to August 2021. We placed advertisements with local newspapers (print and online) in the following state markets: Alabama (Birmingham), Florida (Miami, Orlando), Illinois (Chicago and statewide), Colorado (Denver and statewide) New Jersey (statewide), and Washington (Seattle and statewide) as well as social media advertisements on Facebook and Instagram. Participants were eligible if they were age 18 years or older, spoke English, resided in the U.S. or its territories, and could use a computer with Internet access and videoconferencing capabilities. A screening web form was used to collect participant demographic information before the interview. We aimed for a mix of SGM and non-SGM people, representatives from all adult age brackets and all census regions, and at least 50% who identified their race and/or ethnicity as not exclusively white. All prospective interview participants were then individually invited to a 1:1 60-to-90-min online interview. An incentive of a \$40 gift card was provided.

We employed purposive sampling to invite non-SGM and SGM participants, especially non-SGM people (age 40 or older), SGM people who identified as transgender or gender diverse (e.g., nonbinary, gender-queer), and participants who identified as being from a minoritized race and/or ethnicity. Informed consent to participate in the study was obtained over email with verbal reconfirmation during the cognitive interview. The Stanford University Institutional Review Board (Protocol IRB-58506) approved this study.

2.2. Development of conduct of cognitive interviews

Study team members (JOM, ATP, NB, RL) iteratively developed a semi-structured cognitive interview guide (Appendix A). ATP, NB, and RL pilot-tested the cognitive interviews with non-SGM and SGM peers before interviewing enrolled participants. The online cognitive interviews were recorded using HIPAA-compliant Zoom videoconferencing software (Zoom Video Communications, Inc.; San Jose, CA) and back-up audio-recording equipment. During the interview, participants were provided a link to a Qualtrics (Qualtrics; Provo, UT) web-based survey (Appendix B). Participants were instructed to share their screen and then proceed through the survey using a cognitive interviewing read-aloud/think-aloud approach (Willis, 2005) to describe their thoughts and reactions. Interviewers used probes after each survey item to encourage participant dialogue. The survey included multiple versions of SOGI items adapted from previous national surveys such as the NHIS (Dahlhamer et al., 2014). The web survey prompted participants to respond to items about their age, race, ethnicity, primary home language, whether they had a primary care provider, past hospitalizations, and medical insurance. SOGI items were organized by question format: combined sexual orientation and gender identity (four versions); sexual orientation-only (two versions); gender identity-only (two versions); sex assigned at birth (one version); and intersex identity (one version). Participants were presented items for each version, and the survey software randomized the order of the version displayed for each question format. Participants were presented alternative versions for each question format after their initial responses were recorded and discussed. All participants saw all versions of the questions.

2.3. Analysis: Development of codebook and coding approach

Audio recordings were professionally transcribed. Dedoose software version 9.0.17 (SocioCultural Research Consultants, LLC; Los Angeles, CA) was used to code transcripts using a team of four coders (JOM, ATP, AS, AZ). We iteratively developed a codebook using template analysis as well as inductive and deductive approaches to the analysis (Brooks et al., 2015). Two members (JOM, ATP) of the coding team developed the initial codebook; each coder individually reviewed half of the completed interviews and then met to develop an initial coding schema. The initial codebook also included *a priori* categories that reflected interviewer probes from the cognitive interview guide (Appendix A). The primary coding team (ATP, AS, AZ) then pilot-tested the codebook with three interviews and reviewed each coded interview as a group. The team had weekly meetings to discuss ongoing coding processes, agree to codebook changes, and resolve disagreements. A tracking system was employed so that when new codes were added or changed in the codebook, all previously coded interviews were revisited to ensure the integration of emergent concepts. Our approach addressed four key tenets of trustworthiness – credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). We employed investigator triangulation to improve the credibility of data whereby the coding team watched recordings and read full transcripts of one another's interviews. However, member checking was not performed. We addressed transferability by including SOGI items that appeared on past federal health surveys. Each coding team member kept memos to improve data dependability. Individual observations and reflexive bracketing were discussed as a group (Tufford & Newman, 2012). A codebook was continuously reviewed and a tracking system using a change log tracked procedural and coding changes. The code book was reviewed and updated by every member of the coding team to ensure data confirmability.

2.4. Research team identities

The cognitive interview and coding team included individuals aged 23–59 years with multiple sexual orientations (gay, lesbian, straight, and queer); multiple gender identities (cisgender woman, cisgender

female, man, nonbinary, woman, and queer); multiple races and ethnicities (Asian American, Black American/African American, Caucasian, Chinese, Jewish, Vietnamese, and white); and multiple academic and professional roles (clinician investigator, medical student, clinical post-doctoral fellow, public health research consultant, senior survey methods research consultant, and undergraduate student). The team shared identities with some of the participants and held the privilege of academic training and professional experience. The team had regular discussions about acknowledging and bracketing personal identities to reduce bias and ensure the confirmability of research findings (Tufford & Newman, 2012).

3. Results

3.1. Participant characteristics

From February 2021 to August 2021, we conducted 44 cognitive interviews that met eligibility requirements. Participants ranged from 18 to 82 years old. Based on their responses to a recruitment screener, 14 participants were categorized as cisgender heterosexual (non-SGM), 19 participants as cisgender sexual minority (SGM), and 11 as transgender or gender diverse of any sexual orientation (SGM). Nine participants reported two or more gender identities, and seven participants reported two or more sexual orientations. The majority (61%) were assigned female sex at birth. The majority (64%) were from racial and/or ethnic minoritized groups, including: Black, African American, or African, Asian, Hispanic, Latino or Spanish, or some combination thereof. Participants resided in all primary U.S. census regions with 48% residing in suburban communities, 9% in rural communities, and the remaining in urban centers (Table 1).

3.2. Themes

Four major themes arose from the cognitive interviews that reflected participants' responses and their anticipation of how they would answer SOGI questions on surveys:

- 1) Purpose for asking SOGI identifiers: this included why information was being collected and how it would be used;
- 2) Context of information collection: this included the type of survey or physical setting where SOGI questions are posed, honesty in responses, and the context of incentives and benefits to responding;
- 3) Distrust of the government: this included vigilance with the government and the potential for harm with disclosure;
- 4) Fear: this included fear of disclosure of SOGI information and fear of decreased safety.

3.2.1. Purpose for asking for SOGI identifiers: why information was being collected and how it would be used

This theme encompassed concerns and questions about why SOGI information was being collected; a related consideration was how those entities and individuals collecting the data would use this information. In the absence of an explanation, non-SGM and SGM participants had difficulty coming up with a plausible explanation for interrogators to ask for SOGI information and for participants to feel comfortable answering. Even non-SGM participants questioned the purpose of the federal government asking about SOGI information.

But it, it makes me think, why would the federal government need to know if I'm a member of the LGBTQ community? So, it, it would make me question it.

- Non-SGM, 36y, Black, straight/heterosexual, woman, female sex assigned at birth

Table 1
Participant characteristics.

Age	N	%
18-29	15	34.1
30-49	7	15.9
50-69	14	31.8
70-82	8	18.2
median (interquartile range [IQR])	44	[23–65]
Gender identity^a		
Cisgender man	2	4.6
Cisgender woman	6	13.6
Man	10	22.7
Non-binary	1	2.3
Transgender man	1	2.3
Transgender woman	2	4.6
Woman	12	27.3
Another	1	2.3
2 or more	9	20.5
Sexual orientation^a		
Asexual	3	6.8
Bisexual	7	15.9
Gay	7	15.9
Lesbian	1	2.3
Pansexual	1	2.3
Queer	1	2.3
Questioning	1	2.3
Straight/Heterosexual	14	31.8
Another	2	4.6
2 or more	7	15.9
Sex assigned at birth		
Female	27	61.4
Male	17	38.6
Race and ethnicity		
American Indian or Alaska Native	0	0
Asian	5	11.4
Black, African American, or African	9	20.5
Hispanic, Latino or Spanish	4	9.1
White	16	36.4
2 or more	10	22.7
Community type		
Rural	4	9.1
Suburban	21	47.8
Urban	19	43.2
Employment status		
Employed	15	34.1
Not employed, looking for work	4	9.1
Homemaker	1	2.3
Student (Full time)	6	13.6
Disabled, not able to work	2	4.6
Retired	11	25
2 or more	5	11.4
U.S. Census region		
Northeast	11	25
Midwest	10	22.7
South	12	27.3
West	11	25

^a Percentages in these categories may add up to >100% as multiple responses were allowed.

I guess I would start – sometimes maybe if I've started a survey, and I say I'm gonna do this, and I'm getting all these questions, then I might say, like, why do you wanna know that, or what's the purpose of that ... and if somebody said ... they had a purpose.

- Non-SGM, 71y, white, straight/heterosexual, man, male sex assigned at birth

SGM participants shared similar concerns as non-SGM participants regarding the purpose of asking SOGI questions. When probed if they found SOGI questions confusing or awkward, an SGM participant questioned instead the purpose of knowing such information.

I don't think it's confusing. I think it's awkward because I don't know why the government would need to know this. If it were you know, at a doctor's office, and my doctor was gonna see it, I would feel

comfortable answering that. But for the government, I don't see why they would need to know that.

- SGM, 70y, white, bisexual, woman, female sex assigned at birth

This same SGM participant tried to contextualize the purpose of a survey asking about SOGI information.

I think I would find it invasive. Because I don't think they need to know this much detail. It depends on what the survey was about. And if it was the Census, for example, I would find this invasive. I just wouldn't be able to come up with an answer why does the government want to know this?

- SGM, 70y, white, bisexual, woman, female sex assigned at birth

3.2.2. Context of information collection: the type of survey or physical setting where SOGI questions are posed, honesty in responses, and the incentives and benefits to responding

Context influenced how participants would answer SOGI questions. Context was discussed in terms of the setting in which a SOGI question appeared and was often offered spontaneously by participants as a key component of willingness to answer or ways individuals would answer. Interviewers also probed participants specifically about how their answers might differ based on context, specific whether a SOGI question appeared in a health survey sponsored by the federal government, a community survey, or a form at a health care provider office.

Well, I would like to know the context in which it was being asked. On Census I believe they asked sexuality this time and I was happy they did ... Well, because then the numbers show that people who are not straight are a considerable part of the population and may influence resources, legislation, protections because there's so many.

- SGM, 72y, white, gay, man, male sex assigned at birth

I think it's context dependent. I think if I thought that the survey itself was important, I would. If it contributed to improving LGBTQ healthcare, I probably would. But if it is – and I might for as far as demographics information, like Census demographics kinda information. But I don't know if I would in other contexts.

- SGM, 22y, white, bisexual/pansexual/queer, transgender woman, male sex assigned at birth

The context of a health care setting was universally endorsed as a legitimate setting to obtain and share SOGI information. Participants provided specific examples where it might be helpful to share SOGI information to maximize personal health outcomes.

I like the idea of a person who's free to be who they are. And so especially when it's in ... the federal government, I start to think, well, how are they using this and how is it going to be interpreted - maybe if it was, like a public group or a community group I would have a different opinion ... I would definitely answer it if it was from my doctor or a health care agency. Let's say this was a question before I got the COVID vaccine, for sure I'd answer it.

- Non-SGM, 39y, Hispanic, straight/heterosexual, man, male sex assigned at birth

Non-SGM and SGM participants recognized the value of collecting SOGI information in the context of health equity regardless of their background.

I thought there was that earlier question about have you ever been hospitalized or if you have lost your health insurance or something, maybe they would kinda see if, like, 100 people lost their health insurance, and then, further in, they said, they were Caucasian, or they were transgender or something, they could see a pattern ... like some people in a certain group don't seem to have health care.

- Non-SGM, 71y, white, straight/heterosexual, man, male sex assigned at birth

Why would I answer them? Because I think it's important in terms of statistics. I think it's for representation, you know, in issues of health care. You know, they want to make sure that you're serving an entire community, so you ask demographic questions like this to better understand who your patients are.

- SGM, 55y, Hispanic, gay, man, male sex assigned at birth

A cisgender SGM participant offered a nuanced view of SOGI information disclosure, especially for gender minority people in the context of a health care setting.

I would want to know why it was being asked ... Let's say somebody who was presenting as male is brought to an emergency room after a motorcycle accident. Do you give that person a pregnancy test because they may be a trans male?

It's a 'why do you want to know the information?' I have a trans friend, she tells a story of going to an urgent care clinic because she had gotten some wood splinters in her calf and they wanted to know every surgery she had in the last 15 years. And, you know, they don't necessarily need to know her transition history to, you know, get some tweezers, and pluck out some splinters.

- SGM, 55y, Hispanic, gay, man, male sex assigned at birth

SGM participants indicated that they might choose to not answer or would change their answer depending on the perceived context for requesting SOGI information on a survey.

Like I feel like I would be uncomfortable answering yes to surveys ... that seems to be really against LGBT individuals.

- SGM, 20y, Asian, pansexual, woman, female sex assigned at birth

Assuming that the people giving the survey have good intentions, and assuming like you said before that it's maybe a government program or health care program, um, I know as an activist that sometimes those types of data are used to determine funding for programs that help people from different communities. And so [I would answer] if I felt confident that it was a good survey.

- SGM, 35y, white, lesbian/queer/questioning/same-gender loving, genderqueer/nonbinary/questioning/woman, female sex assigned at birth

A transgender and gender diverse participant further illustrated that they might vary their answer to a SOGI question depending on the context and characteristics of the entity who is asking the questions.

Depending on the context, I've put different answers. When I feel like ... I don't know if the organization I'm filling out for is inclusive, sometimes ... I just put male. And then if it's more inclusive, sometimes I put transgender. But then there's days when I'm just like well, I'm also, you know, identify as male, so that just doesn't fit me and I just put male ... It's just kind of such a weird question that it almost seems like a survey that says like do you have short or brown hair.

- SGM, 31y, white, bisexual, non-binary/transgender man, female sex assigned at birth

The same participant explained why specifically responding to gender identity questions on surveys is challenging for them and how the fluid nature of their gender identity might prompt them to answer differently.

This is actually a really hard question for me because I know that I'm not cisgender and I don't identify with my gender at birth, which was female. But I've never found a word that captures it for me. For simplicity's sake for the state that we are in America right now, I just

changed my ... legal ID to male but sometimes I wonder if I am agender or nonbinary.

- SGM, 31y, white, bisexual, non-binary/transgender man, female sex assigned at birth

Another contextual element discussed by non-SGM and SGM participants was honesty. Participants frequently reflected upon whether they could respond with integrity while being understood and without getting “in legal trouble.” One non-SGM participant stated that “because I’m not a member of that community,” they “definitely wouldn’t lie.” In contrast, SGM participants considered the ramifications of their responses, with one participant expressing worry about being “in legal trouble” if they didn’t respond honestly on “government paperwork,” while also saying, “I’m not sure if they would understand” were they to answer honestly. Participants reflected upon truthfulness, understanding the question, and the capacity to respond with clarity and integrity.

Maybe in a health facility, this is the hospital maybe that I visit when I’m sick or when I need medical ... attention. So, I said that I would answer truthfully because maybe in an emergency case, they will look at that survey that you answered, and if you lied or give incorrect information, that may not help you at that particular time.

- SGM, 24y, Black, lesbian, transgender woman, male sex assigned at birth

I don’t want to like get like any official like ... on paperwork it says do not lie on this so you could be in legal trouble, you know, especially government paperwork ... I’m not lying, but I’m not sure if they would understand if that makes sense.

- SGM, 21y, white, gay/queer/lesbian, gender non-conforming, female sex assigned at birth

Another component of context was that non-SGM and SGM participants suggested that they might be motivated to answer SOGI questions depending on the perceived benefit to themselves or their communities. Although they initially indicated that they might not respond to a SOGI question, a non-SGM participant later described how understanding the context for the question would motivate them to answer.

I mean, it would depend on the incentive for the survey ... I would prefer that they have a ‘decline to state’ like they sometimes have with political parties. It depends, I guess, on how much control over it I have. If it was - if you had to do it for some reason or other, for medical purpose, I’d be more willing to answer that than if somebody put that on a job application, which I guess might be illegal. But ... I also see these things that they say - I think the EEOC says you have to identify - they’d like to know how many people you’ve interviewed to make sure you’ve reached a good cross-section ... If maybe they said we need to ensure that we’ve reached a good cross-section, maybe I’d answer it.

- Non-SGM, 71y, white, man, straight/heterosexual, male sex assigned at birth

On the other hand, SGM participants frequently mentioned potential benefits to their community as a motivation to answer SOGI questions. One SGM participant considered the health disparities among minority populations and how collecting this SOGI information could raise awareness with the government.

I think it’s helpful because I think a lot of people who are minorities face a lot of stress. And that stress can lead to adverse outcomes in their health and also discrimination. And so, I think the government needs to be aware of this.

- SGM, 31y, white, bisexual, nonbinary/transgender man, female sex assigned at birth

Another SGM participant highlighted how transgender communities

could benefit from SOGI data collection if it was used for funding purposes.

I might want them to know I’m transgender but, also, might want them to know I’m just like a man. But if it were like a national health survey ... I think I might lean more toward putting transgender. ‘Cause like transgender people have like very specific health needs. So, if this were on a survey, they might be using that information to like go toward funding for like several like specialized programs. I want to like give the impression that there’s like a need for that kind of thing.

- SGM, 21y, Asian, gay, man, female sex assigned at birth

For participants, disclosure of SOGI information was at times regarded as an opportunity; one SGM participant connected this disclosure to the potential funding of transgender organizations.

It is not something that maybe I’m ashamed of so disclosing that would be important for, maybe for opportunities. And in terms of disclosing it may be important for future opportunities ... something like funding for maybe transgender people ... an organization that maybe the government maybe want to come up with.

- SGM, 24y, Black, lesbian, transgender woman, male sex assigned at birth

3.2.3. *Distrust of the government: vigilance with government and potential for harm with disclosure*

Non-SGM and SGM participants expressed an overall distrust of the federal government and both groups frequently questioned how SOGI data would be used. A non-SGM participant questioned whether the government could ensure any privacy protection with SOGI data and questioned the perceived motives of people in government.

I don’t know where the information would go or if there’s any protection of privacy with such a large organization as the government.

I don’t know if I completely trust the government anymore ... there are many, many people in the government that do not work for the benefit of the society ... I’m skeptical because ... they’re elected by people of like mind or maybe there’s just a lot of ... trickery; you know?..They’re elected because of misrepresentation; you know?

- Non-SGM, 75y, white, straight/heterosexual, man, male sex assigned at birth

Another SGM participant suggested increased trust with smaller organizations compared to the federal government but was not specific about their discomfort with the federal government having SOGI information.

I just don’t feel, like ... comfortable with it, in general ... the federal government having that information. I think I would feel more ... comfortable if there was ... a medical establishment or ... like, something smaller than the federal government, so like a ... trustable ... organization.

I’m not really comfortable with the government ... having all that data ... But I mean I guess it depends on, like, what they’re using it for maybe if they’re ... trying to ... develop, like, specific programs for ... health or whatever.

- SGM, 18y, Asian, bisexual, woman, female sex assigned at birth

One non-SGM participant related asking about SOGI to historical discrimination from the government and societal hate based on race/ethnicity. This was echoed by others in terms of the hesitancy to disclose and population surveillance.

In our history, we have had series of times to where we had various camps for Japanese Americans. And after 9/11 we just a lot of – it

wasn't necessarily coming from the government, but the government wasn't necessarily doing much about stopping the hate that was being expressed towards Middle Eastern Americans and such, and I guess that's what I would take this as well, are they – what are they going to do with this information? Is it going to be held against me in some way or whatever? Does that make sense? So – Yeah. I don't know I guess I would be leery of it given our past history.

- Non-SGM, 38y, Middle Eastern or North African/white, straight/heterosexual, woman, female sex assigned at birth

Multiple SGM participants perceived the collection of SOGI information as a possible tool for surveillance and identified this as a reason they would not be comfortable responding.

I would have mixed feelings about that ... On one side, I think it's important that the data exists and like the representation is there and the need for trans inclusive health care is understood. And at the other hand like it feels like a tool of surveillance, and I would not feel super comfortable personally responding.

- SGM, 21y, Middle Eastern or North African/white, queer, gender queer, non-binary, female sex assigned at birth

As someone who's currently taking this Human Rights class and having done readings on surveillance in the United States and having literally just read an article this morning about how Myanmar is using surveillance footage to track down protestors, like, there's a little part of my brain that's like, "Aagh! Giving information to the government, bad." But I think that stuff's still overwhelmed by just like contentment, contentment, contentedness? What? Happiness at being seen. There you go.

- SGM, 20y, Black, asexual/pansexual/queer, woman, female sex assigned at birth

Among non-SGM and SGM participants, there existed a common sentiment that perhaps the government has no business to ask about SOGI on surveys.

That's really none of their business. What my preferences are.

- Non-SGM, 60y, Hispanic, straight/heterosexual, woman, female sex assigned at birth

An SGM participant expressed concern that disclosure of SOGI information might have relevance to insurance entitlement programs like Medicare.

It's none of the government's business as far as I'm concerned. 'Cause I'm not asking for government coverage. I mean I have Medicare, that is government coverage. But I don't see why the government would need to know any of this.

- SGM, 70y, white, bisexual, woman, female sex assigned at birth

3.2.4. Fear: including fear of disclosure of SOGI information and fear of decreased safety

Fear was a pervasive sentiment among SGM participants but was nearly absent among non-SGM participants. A transgender participant related their fear of disclosure of their gender experience to their fear of being pulled over while driving.

I think just like legally for me knowing – the government knowing that I'm queer and trans scares me a little bit ... what are the ramifications going to be for this? Like, I just don't like to disclose that information. Again, because of where I live, like in a very conservative area, I get nervous, like, about getting pulled over as a trans person.

- SGM, 19y, Asian/white, queer/dyke/non-binary, transmasculine, female sex assigned at birth

Transgender and gender diverse participants expressed concerns about safety when disclosing SOGI information and suggested that fear of decreased safety could be a motivator to change their answers or not answer depending on the context, including whether they were physically observed.

I mean, if it wasn't safe to answer it correctly, I would answer it differently. If I didn't trust the people asking the question, or if there were people observing me who I didn't want to have know the answer to the question.

- SGM, 35y, white, lesbian/queer/questioning/same-gender loving, genderqueer/nonbinary/questioning/woman, female sex assigned at birth

Another SGM participant reiterated that their perception of their safety would be influenced by the safety of the immediate physical setting, their larger community, and safety of their information as tied to who would know this information and how the individual (and perhaps family) would be treated:

If I was answering the survey in a way that was maybe tied with my like legal identity and would be accessible by my family, or at least my extended family. I would probably be hesitant to do so, or if I was in a place kinda like I am now. Or like I guess in two senses. Like if I was in a very unwelcoming place like physically. Like if I was in like a clinic or something and I didn't feel particularly safe presenting in the way I'd like to. And being completely honest about who I am, then I would absolutely be hesitant to. Or if I felt like it would impact how people in my immediate community, like since I'm in like a rural small town for a year would treat me.

- SGM, 22y, white, bisexual/pansexual/queer, transgender woman, male sex assigned at birth

An SGM participant described safety in the context of outing someone as transgender on paper who may not have been otherwise public about their SGM identity in an unsafe environment. They mentioned the concept of "passing," mentioning that some transgender people may not be perceived as transgender and surveys that include SOGI information may not feel safe.

I think it would depend on context. I guess it would depend on if like I am in an environment that is not safe or welcoming and I'm not that I, you know, pass. But if I can imagine that people who do pass would feel uncomfortable potentially like being outed if they were ... I guess if someone was asking them these questions, I don't know if it's just a piece of paper, it depends on what form the survey's taking. But I can imagine that people who do pass would feel maybe more uncomfortable than I do answering that ... I'm not, you know, publicly out.

- SGM, 22y, white, bisexual/pansexual/queer, transgender woman, male sex assigned at birth

Another transgender and gender diverse participant noted how a single question may lead to follow-up questions that might feel intrusive or unsafe. Fear of ensuing questions might therefore influence answers to initial SOGI questions.

... Folks, like, when they find out that someone is trans, they then will go on to ask really intrusive questions about transition or about what body parts you have or whatever. And so, I don't like, openly disclose my transness freely to whoever.

- SGM, 19y, Asian/white, queer/dyke/non-binary, transmasculine, female sex assigned at birth

4. Discussion

In this qualitative study, we used in-depth cognitive interviews with

non-SGM and SGM participants to assess preferences for being asked about SOGI on U.S.-based health surveys. While many participants were open to disclosing SOGI information on a federal health survey (especially for the benefit of some communities and visibility), both groups questioned the purpose of the survey and expressed a distrust of the government. Unlike non-SGM participants, SGM participants expressed fear for their personal safety when disclosing SOGI information, and further SGM participants indicated that they might change their answer depending on the survey context. SGM participants also indicated that they would be more willing to disclose SOGI information in a personal medical contact or for a local community survey rather than on a federal health survey.

4.1. Context matters

Non-SGM and SGM participants wanted to know the purpose of obtaining SOGI information on a national health survey and how this information would be used. Many participants initially had difficulty coming up with a valid purpose for requesting SOGI information, but when probed, they identified that SOGI information could be useful for community visibility and resource allocation. This finding aligns with studies that specifically examined preferences regarding the collection of gender identity in U.S.-based population surveys (Holzberg et al., 2019). Therein transgender participants identified various reasons and potential uses for gender identity information; the need for population statistics, increased visibility, improved health care, and positive policy change. For non-SGM and SGM respondents, we corroborated the importance of communicating the perceived purpose of asking SOGI questions with prior research but also found that survey intent and context mattered significantly in reflections on SOGI questions and willingness to disclose.

SGM participants were more willing to disclose SOGI information in a personal medical context rather than in a survey context. They were more willing to disclose SOGI information on a local community survey rather than on a federal health survey. Previous qualitative research with SGM people similarly found that the medical context is distinct from the health study context and that the perceived relevance of SOGI information influenced disclosure (Suen et al., 2020, 2022). Contextual factors were further modified by the type of information queried, such that even though a medical context was often a favorable site for disclosure, the type of medical setting may influence whether SOGI information is considered relevant and necessary. Studies of SGM people have shown variations in SOGI disclosure in the medical context: transgender patients perceived that disclosing gender identity to primary care providers was more important than disclosing sexual orientation and they viewed SOGI disclosure as more relevant in a primary care setting compared to an emergency department setting (Maragh-Bass et al., 2017). SGM people may consider their reason for seeking medical care in their decision to disclose SOGI information (Friley & Venetis, 2022; Maragh-Bass et al., 2017). Our findings align with prior research indicating that medical relevance constitutes an important consideration when asking for SOGI information in clinical contexts. Our findings differ from prior studies that suggested that SGM people, especially those who are transgender or gender diverse, are often not comfortable disclosing their SOGI information to health care providers because of fear of discrimination (Macapagal et al., 2016; Whitehead et al., 2016). In contrast, we found that SGM people, including transgender and gender diverse people, expressed willingness to disclose SOGI information in a health care setting, provided that the setting was perceived as safe, and they understood the purpose of disclosure. This may signal shifting attitudes among SGM people towards a greater comfort with SOGI information disclosure, at least in a medical context.

4.2. Intent and perceived use of SOGI information matter in disclosure regardless of identity

In considering a justification for collecting SOGI information outside of the medical context, participants found it, at least initially, challenging to come up with reasons that a survey would need to collect SOGI information, which led them to feel uncomfortable answering SOGI questions. However, if participants felt that disclosing SOGI information would provide useful demographic information, they reported more willingness to do so. Non-SGM participants described understanding the demographics of a sample or ensuring that survey responses were representative of the population as compelling reasons for SOGI information collection. SGM participants offered more concrete uses for SOGI information, including using the collected data to influence the allocation of resources to the SGM community and/or to directly improve SGM health. These findings align with previous research about gender identity disclosure in a government survey context, which found that transgender and gender diverse participants thought that government surveys ought to collect gender identity information to better understand the discrimination faced by the transgender and gender diverse community and allocate funding, but expressed skepticism about whether the information would truly be used for those beneficial purposes (Holzberg et al., 2019). In prior research, although non-LGBT people did not explicitly identify benefits to SOGI information collection, they were less likely to consider SOGI information as private compared to LGBT people in the government survey context (Ellis et al., 2018). In addition, research has shown that racially and geographically diverse samples of heterosexual people have high levels of acceptability for routine collection of SOGI information in the healthcare context (Cahill et al., 2014).

4.3. Governmental knowledge and the role of SOGI information in Facilitating support versus harm

The sentiment that someone's SOGI information is "none of the government's business" was frequently expressed by non-SGM and SGM participants. SGM participants were ambivalent about SOGI data collection as a tool for surveillance *versus* an avenue to improve representation. On the one hand, SGM participants perceived the government as having few legitimate reasons to ask about SOGI considering the personal and community potential negative impact as described elsewhere in this manuscript. On the other hand, participants acknowledged that more robust SOGI data could raise awareness, improve health equity, and yield funding and resource allocation for SGM people. These seemingly conflicting participant viewpoints pose a considerable challenge to making concrete recommendations for SOGI data collection. The solution may lie in improving how SOGI questions are introduced and asked to reassure respondents that SOGI data will be used for equitable purposes, such that non-SGM and SGM people are confident that identity information collected by the government will benefit their communities. This ambivalence regarding the government's role in collecting SOGI information is, in some ways, analogous to the collection of racial and ethnic identity information. If national health surveys did not collect participants' racial and ethnic identities, considerable population health disparities might be missed and ameliorating interventions would not be pursued (Pérez-Stable & Collins, 2019). However, there is a long and pervasive history of discriminatory actions by government agencies on the basis of race and ethnicity that leave individuals wary of providing information lest it make them subject to discrimination (Katz et al., 2008). Our findings highlight the tension that SGM people experience between the desire to offer information to improve the conditions of SGM people (e.g., representation and increased funding for health care) and the knowledge that they must protect SGM people from further mistreatment and harm (e.g., discrimination from the government and others). Our findings suggest that SGM people want their communities to be supported and

understand that visibility is necessary for this and would be willing to provide this information if it would result in a benefit and not harm to the community. And yet, we also found that for many there is an honest appraisal and fear that for SGM people, and other minoritized groups, more information does not always result in benefits and a fear that disclosure in the interest of community visibility comes with risk and vulnerability that may be an untenable burden. In contrast, compared to SGM participants, non-SGM participants did not react to SOGI questions as strongly in either a positive or negative direction.

4.4. Fear and consequences of disclosure influence willingness to disclose SOGI information for SGM people

Fear of disclosing SOGI information was frequently expressed by SGM participants, particularly transgender and gender diverse people and was not a major concern for non-SGM participants. Research on fear as a response to SOGI disclosure focused on the personal medical setting found fear of poor treatment or a negative reaction is a potent barrier to disclosure (Brooks et al., 2018). Transgender people report delaying health care due gender-based discrimination and studies have shown that a common reason was fear of being treated badly (Burgwal & Motmans, 2021). Consistent with our findings, focus groups by the U.S. Census Bureau noted that transgender participants voiced fears of government knowledge promoting discriminatory action or information leaks leading to malicious use (Holzberg et al., 2019). Moreover, our study found that the scope of fear extended beyond concerns about government knowledge and action. SGM participants expressed concern about the prospect of their immediate communities and family members having access to their SOGI information. There was concern for immediate threat in the moment of disclosure such as unwanted observation in the physical space where they might be completing their survey responses and the longer-term impact of disclosure from family or community members knowledge of SGM status. Transgender and gender diverse participants' fears were most specific, and they described that these fears were mediated by multiple factors, including the perceived safety of the immediate environment (e.g., the clinic where they are responding to the survey) and broader environment (e.g., the perceived acceptance of transgender and gender diverse people in the town where they live).

4.5. Implications for research, practice, and policy

Our findings have significant implications for research, practice, and policy. Our findings suggest that the quality and quantity of SOGI data would be improved if health surveys communicated a clear purpose for the collection of SOGI information. While non-SGM and SGM participants demonstrated reservations about disclosing SOGI information and identified a distrust for government, SGM participants specifically expressed fear for their safety related to SOGI disclosure that may drive non-response or answer changes depending on the context of the data collection. The safety of the survey setting was a factor that influences SOGI disclosure among SGM people. Evidence has shown that non-in-person modes of disclosure as well as settings that include other SGM people increased willingness to disclose SOGI information due to lower perceived risk of stigma and discrimination (Suen et al., 2022).

A number of anti-LGBTQ+ measures were enacted into state law during the time we conducted our cognitive interviews; this may have increased distrust of government among SGM participants (Ronan, 2021). Since the time of data collection over 490 anti-LGBTQ+ bills have been introduced by U.S. state legislatures, representing a record number of bills that attack LGBTQ+ rights, especially in the area of healthcare (ACLU, 2023). This policy landscape combined with our research points to a need for sensitive, informed, well-intentioned, and well-communicated SOGI data collection as lawmakers debate the rights and privileges of SGM people and their civil rights, health, and access to healthcare. In this vein, federal surveys offer a standardized model for

state-level SOGI information collection and could help mitigate the consequences of state policies that would seek to remove SOGI data collection and disregard entire populations of SGM people.

Additional research is warranted to explore SOGI disclosure among SGM people, especially the factors that may drive them to change their answers in different survey contexts or to not answer at all. This research calls for more investigation into these contextual factors as they influence SOGI question performance among non-SGM and SGM populations, and additionally makes problematic the idea that single SOGI question sets will yield stable data across contexts. Our findings suggest that the policies for SOGI data collection and practice implementation may need to be tailored for local, community, and national settings. Thus, it seems the answer is not whether to collect SOGI information, but rather to ensure that how it is done is real, relevant, respectful, and used to support SGM people.

5. Conclusion

U.S.-based national health surveys do not consistently collect SOGI information but are increasingly striving to do so (Office of the Chief Statistician of the United States, 2023; The National Academies of Sciences, 2022). The findings in this qualitative study revealed that non-SGM and SGM people may share common concerns about disclosing SOGI information but that SGM people may change their answers depending on context and have different basis for fearing disclosure and/or government involvement compared to non-SGM people. These findings suggest taking an omnibus approach to asking about SOGI information on surveys may not be prudent, given the importance of survey intent, the physical and social contexts of questions, concerns about the originator of the survey (whether hosted by the government, a local community organization, or a personal health care provider), and the volatile landscape of public acceptance and legislature that may contribute to fears related to SOGI disclosure.

Author contributions

ATP: Conceptualization, Methodology, Software, Formal analysis, Investigation, Data curation, Writing – Original Draft, Review & Editing. NB: Conceptualization, Methodology, Investigation, Writing – Review & Editing, Funding acquisition. AS: Formal analysis, Data Curation, Writing – Original Draft, Review & Editing. AZ: Formal analysis, Data Curation, Writing – Review & Editing. RL: Methodology, Investigation, Writing – Review & Editing. ZD: Project administration, Writing – Review & Editing. MEL: Methodology, Writing – Review & Editing. AF: Writing – Review & Editing, Funding acquisition. MRL: Writing – Review & Editing, Funding acquisition. JOM: Conceptualization, Methodology, Software, Data Curation, Writing – Review & Editing, Supervision, Project administration, Funding acquisition.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: MRL has consulted for Hims, Inc. (2019 - present) and Folx, Inc. (2020). AF consulted with Hopelab, a not-for-profit research group. JOM has consulted for Sage Therapeutics (5/2017), Ibis Reproductive Health (a non-for-profit research group; 3/2017–5/2018, 2020 - present), Folx, Inc (2020 - present), and Hims, Inc. (2019 - present). None of these roles present a conflict of interest with this work as described here. The other authors have no conflicts of interest to report.

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Appendix A and B. Supplementary data

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