

Development and Evaluation of a Single, Non-Binary Gender Question for Population-Based Federal Health Surveys

Kristen Miller PhD and Stephanie Willson PhD

Collaborating Center for Question Design and Evaluation Research
National Center for Health Statistics

Interviewing Team: Kristen Cibelli Hibben PhD, Lauren Creamer MPH, Ann MacFadyen PhD, Meredith Massey PhD, Kristen Miller PhD, Paul Scanlon PhD, Amanda Titus BS

This cognitive interviewing study conducted by the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at the National Center for Health Statistics (NCHS) examines the performance of a single non-binary gender item for Federal population-based health surveys. The study is part of a larger research agenda, involving both quantitative and qualitative methodologies, to develop a non-binary gender measure for a range of Federal data collection systems. This report first describes the larger research initiative as background and then presents the methodology and findings for this specific study. Consistent with previous work, this study finds that a single item can be used to collect non-binary gender information in population-based health surveys. Additionally, the study supports earlier findings that context, including the purpose for collecting the information and perceptions of privacy and confidentiality, impact the ways in which respondents make sense of and formulate answers. Thus, along with the actual wording of the item, to collect high quality gender data, it is necessary to consider how respondents understand the reason for the question and how their answers will be protected.

Background

A series of qualitative and quantitative question design and evaluation studies were conducted by CCQDER to develop a single non-binary gender question for Federal data collection. Two applied cognitive interviewing studies were conducted for the US Department of State to develop an X gender marker for US passports and to develop a non-binary gender element for its employee management system. A third cognitive interviewing study was conducted to examine the performance of a two-question design for collecting non-binary gender data, where sex-assigned-at-birth along with current gender identity are asked concurrently.¹ The fourth study was a quantitative split-sample experiment conducted using NCHS' Research and Development

¹ A two-question approach for capturing non-binary gender first asks sex assigned at birth followed by current gender identity. While there is variation involving specific wording, ordering of the two questions, and category labels, an example is: 1) What sex were you assigned at birth, on your original birth certificate, Male or Female, and 2) How do you describe yourself, Male, Female, Transgender or Something Else? In this approach, gender minority respondents are identified as those having discordant responses to the two questions (answering 'male' and 'female,' or 'female' and 'male') as well as those selecting 'transgender.'

Survey (RANDS)² to assess error rates and impact of that error on key health estimates among different versions of the two-question design. Finally, a fifth project, the main study described in this report for the Centers for Disease Control and Prevention, specifically for NCHS surveys, was conducted to collect non-binary gender data to better understand disparities among the gender minority population. Collectively, the studies provide a broad understanding of the ways in which non-binary gender questions perform in different contexts and for various purposes.

For this study, set within the context of population-based health surveys, a single-item gender measure was developed from this broader understanding. Appendix A describes the four previous studies in more detail. For specific details pertaining to wording variations, testing iterations and rationale for the ultimate design, see the final report for each particular item. Reports are publicly available on Q-Bank, NCHS's on-line repository of question evaluation studies, at www.cdc.gov/qbank/sogi.

Across the settings of the applied studies (whether requesting a US passport or providing employee demographic information), gender minority respondents were enthusiastic about their inclusion but, at the same time, were concerned about the implications of being 'out.' These conflicting interests—wanting inclusion and requiring privacy—framed the question response process and was particularly problematic for gender minority respondents. This difficulty was mediated, however, by the ways in which respondents understood the purpose for giving the information and whether that information would be protected. Understanding this dynamic was key to determining the optimal question wording for each specific application. Given the centrality of this dynamic to question design and performance, it is worth describing these themes here as background for understanding how they play out within the context of federal population-based health surveys.

Conflicting Interests of Inclusion and Privacy

For each of the studies, the theme of inclusion was evident and profound among gender minority respondents. For these respondents, marking the non-binary X on their US passport application, as opposed to the conventional, binary categories of M (male) or F (female) held promise of an accurate representation. Since they did not identify strictly as 'male' or 'female,' the fact that they could mark X allowed for their inclusion when, in so many other places, it is not the case. One respondent, for example, explained, "I prefer to have X because I'm not in the other boxes." The fact that the passport serves as legal documentation made the option of selecting X even more poignant. Another respondent explained, "I would say that [including an X] means that the US is finally recognizing that my gender identity is valid... to have an official identifier for my gender identity."

While the document was seen as a legal form of identification, it was also seen as a requirement for international travel. Thus, while the passport could serve as documentation to identify and affirm oneself, it would also need to be publicly presented in such places as airport security and customs, not only in the United States, but in countries with different laws and norms. Within this context, selecting X could be perceived as dangerous and unwise. One respondent explained:

² <https://www.cdc.gov/nchs/rands>

I actually probably would choose X. And then I would stop. I would think, is someone going to see this? ...Like customs somewhere. ...Would they go, 'oh we don't accept X here, so you have to go home'... It's a little scary. I'd be concerned. 'We don't accept that, GO HOME! Sorry, NO ITALIAN FOOD FOR YOU! Go Home!' [Or] if they see X, they will KILL me? Or just not let you have Italian food. That's scary.

As legal identification required for travel, the full context represents a paradox of opposing interests where, on one hand, applicants are able to make themselves known in an affirming way while, at the same time, that self-attestation potentially puts them at risk. Many respondents recognized and lamented the irony. One non-binary respondent fully summed up the situation:

I guess it confirmed to me that having an X on my United States passport is only validating to me, and only a hazard if I were to leave the country. So, if TSA is going to question me... if I go to another country, and I'm victimized or harassed or questioned or judged, I'm thinking 'what's the benefit?'

As with the respondent above, multiple gender minority respondents opted to forgo the X category specifically because of the travel context. For other contexts, different factors would be considered. For example, one respondent explains why she chose F in this context but might choose X in another situation:

Yeah, especially thinking about international travel... I'm thinking about the best way to mitigate any sort of issues that could come up.... I think I would [select X] at a doctor's office. Just because I think as medical professionals, instead of assuming, it's kind of your job to, like, ask questions and build rapport with your patients.... I think I would choose it on a driver's license. Because nobody's really looking at your gender on the driver's license. But on a passport, I feel like it's a little bit different. Because everything on a passport is under heavy scrutiny.

Although somewhat different given the context, this dynamic also appeared as respondents, who were State Department employees, weighed whether or not to report their non-binary gender status in the agency's Global Employee Management System (GEMS).³ On one hand, there was sincere appreciation of being recognized and, perhaps more importantly, that the agency was abiding by Executive Order 14035 requiring federal agencies to recruit, hire, retain, and promote employees in an equitable manner regardless of gender.⁴ However, respondents also recognized the potential peril of "outing" themselves to their employer, in this case which also happened to be the Federal government. This fear was compounded by a privacy statement appearing above the race/ethnicity questions that undermined a sense of discretion or safety in disclosing. The line that was particularly troubling to respondents stated:

³ The Global Employee Management System is used for all State Department employees. Therefore, this study included a diverse sample. See Appendix A for a more detailed description of the GEMS system.

⁴ Biden, J. R. (2021, June 25). *Executive order on diversity, equity, inclusion, and accessibility in the federal workforce*. The White House. <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/06/25/executive-order-on-diversity-equity-inclusion-and-accessibility-in-the-federal-workforce/>

Providing this information is voluntary and has no impact on your employment status, but in the instance of missing information, your employing agency will attempt to identify your race and ethnicity by visual observation.

As some respondents relayed, the statement raised concern that, indeed, it might not be safe to report their true gender status. For example, one respondent, inferring that only racial and ethnic minorities would be protected, took the statement as a warning to not disclose her gender information:

Having been in the Federal government since 1984, this raises the question of, they can assume all they want. But don't forget, look at the very first line: ethnicity and race are protected. Nothing else.

Similarly, another respondent explained:

I felt uncomfortable putting trans-ness or trans or transgender on any kind of legal form because there is something in the back of my head that says, 'they're going to come for you for this.' Because it's happened before. Because there have been past administrations that have been openly hostile, and when we put ourselves on a form in any way, we are opening ourselves up, ultimately, to having someone say, 'Alright, you're fired for this.'

Context and Question Design

As described above, both applied studies illustrate how perceptions of privacy and purpose influence the paradoxical dynamic framing the question response process. Ensuring respondents' sense of security by reinforcing the legal requirement for privacy protection as well as clearly articulating the reason for collecting the data can offset this dynamic. The GEMS study, for example, made clear that the disconcerting line in the privacy statement should be removed. Both studies also revealed that the specific wording of the gender item can also help to mediate the problem.

The final chosen wording for the US passport definition of X is: "Unspecified or another gender identity." Use of the term 'unspecified' at the beginning of the definition increased the sense of privacy and safety by allowing applicants to provide a more anonymous, non-committal response. At the same time, use of the phrase 'another gender identity' is not limiting and can include a range of identities. Moreover, the word 'another' as opposed to 'different' minimizes the potential of othering those gender identities that do not align with the conventional male/female categories.

With an amended privacy statement, the final chosen wording appearing in GEMS is:

Are you:

Mark all that apply.

- Female
- Male
- Transgender, non-binary, or another gender

Because its sole purpose is to serve gender equity goals, the question need only identify whether an employee was gender minority; there is no need to capture the nuances of individual gender category labels (e.g., a separate option for transgender vs. non-binary). This allows for a simple three response option design—a design that provides less specificity and an improved sense of discretion. Because some gender minority employees also identify as male or female, the mark-all-that-apply format promotes inclusivity. As with the passport wording, inclusivity is improved by the terminology ‘another gender’ because it allows for a range of identities. Finally, limiting the category wording to the most common identity labels allows for the fact that personal experiences and terminology continue to evolve, and this provides flexibility for inclusion of future identities.

In terms of the two-question approach for collecting non-binary gender data, it is worth noting that the sex-assigned-at-birth question is also viewed through the inclusion/privacy lens. As was discovered in the GEMS study, this was particularly problematic for gender minority respondents. Foremost, the question was seen as an invasion of personal privacy. For example, one respondent explained:

That was me when I was a little baby and now, I'm an adult.... Kind of like trying to figure out what genitalia you have. Which doesn't really seem work-appropriate to me.

Similarly, another respondent remarked:

Do you need to understand what their genitals are to work with them? [The transgender community is] one of the few communities where it's acceptable to ask about our genitals.

Additionally, as another respondent explained, the question is an invasion of privacy as it seeks to spotlight personal information that respondents, themselves, seek to keep in the past:

It is triggering language.... It's a little bit like dead-naming a transgender person... even though I openly admit I'm transgender, I would not answer that question.

Yet another respondent explains the same sentiment:

Ugh. I hate it.... The journey of a transgender person is extraordinarily difficult. There is a period of great difficulty in understanding their gender. And it runs in contrast and contrary to the assigned gender at birth. You're doing everything in your power to get away from this. And undergoing some rather painful procedures in order to get away from who you were.

Importantly, the sex-assigned-at-birth question appears to undermine the sense of inclusivity and enthusiasm (as it was with the addition of the X gender marker or the simple three category

gender item for GEMS) that should go along with the collection of non-binary gender data. For example:

That, to me, is a hard do-not-do-that! I think that's especially problematic for an employer to phrase a question like that... because it's not how I define myself. In fact, [it's] the opposite of how I define myself.... So that's a problem. And also, this is my legal identity—my passport, my driver's license—all do not have that sex on them. So how is it relevant to my employer what my history was?

Finally, as was seen in previous studies, context (that is, purpose and perceptions of privacy) can offset this problematic dynamic. One respondent, for example, explains how the sex-assigned-at-birth question might be acceptable if asked in another context:

I would definitely be more comfortable saying it to a doctor because I would assume the doctor is examining me and trying to keep me healthy.... So, they would have a good reason of asking that question.... How can we best treat this person's health? So, I wouldn't have an issue answering that question in that context.

Evaluation of a Single, Non-Binary Gender Question for Federal Population-Based Health Surveys

The purpose of this study was to develop a non-binary gender item for NCHS population-based health surveys. Unlike GEMS and the US Passport, NCHS surveys are interviewer-administered. With the presence of an interviewer, it is less likely for respondents to skip over questions. Additionally, the interviewer is able to follow-up with clarifications or address potential misunderstandings. With the presence of an interviewer, it might appear that the sense of privacy is undermined, however, respondents are explicitly told their rights as a respondent, including how data will be used and the specific privacy protection laws.

For this study, the GEMS item was chosen as a starting place, based on the results of that study. Although with health data there may be an analytic reason to provide more response options (for example, transgender respondents may be more likely than non-binary respondents to experience health disparities), the expanded, more specific categories would very likely be collapsed for final data dissemination and analysis given the small numbers within each group. Therefore, so as to not compromise the now-defined principle of maximizing discretion and privacy (particularly when infringement of this principle does not improve analytic power), it was deemed that this simple three-category question was the most efficient and practical choice.

Adapted for interviewer administration, the item in the questionnaire appears as:

You may select more than one answer. Are you:

1. Female
2. Male
3. Transgender, non-binary, or another gender

Although the actual number of response categories is three, it is important to note that respondents might easily perceive it as having five when verbally presented by an interviewer. When administered, the question reads as: “You may select more than one answer. Are you female, male, transgender, non-binary or another gender?”

The difference in administration mode, along with the clearly articulated purpose and privacy protection afforded to respondents, are important differences between the GEMS and the NCHS surveys. Although the items are technically identical, the circumstances in which they are administered may be so different that they do not function in the same intended manner. It is the purpose of this study, therefore, to examine how this question operates in this context: an interviewer administered, population-based health survey.

Methodology

This qualitative study is consistent with the socio-cultural approach to question evaluation as described by Miller and Willis (2016)⁵ and adheres to each stage of the research process (including data collection, analysis, and documentation) fully detailed by Miller et al. (2014).⁶

The methodological design for this study was developed to identify constructs captured by the question as well as cases or potential causes of response error. In-depth, personal interviews were conducted with interviewers first asking the question and then asking retrospective follow-up questions to understand respondents’ interpretations and processes for formulating answers.

The study was part of a larger study to examine questions for NCHS’ National Health Interview Survey.⁷ (See Appendix B for the full questionnaire.) The protocol for the study was approved by the NCHS Ethics Review Board and CDC Human Subjects Review. Interviews were conducted in-person and took place in Los Angeles, CA with many being held in the courtyard of the Los Angeles LGBT Center.⁸ Interviews were a maximum of 60 minutes in length and were video-recorded to ensure accuracy of the subsequent analysis.

Sampling and Respondent Demographics: As a qualitative study, cognitive interviewing methodology employs a purposive non-random sample. Rather than aiming for statistical representation, individuals are chosen for characteristics relevant to the questions and topics under investigation. Along with achieving a diverse sample in terms of age, race, education and sexual identity, a primary goal for this study was to have a relatively equal number of gender minority and non-minority respondents. A total of 50 English-speaking adults over the age of 18 were interviewed. Twenty-four were gender minority respondents; twenty-six were non-minority respondents. Table 1 summarizes the sample composition.

⁵ Miller, K., and G.B. Willis. (2016) “Cognitive Models of Answering Processes”. In *The Sage Handbook of Survey Methodology*. C. Wolf, D. Joye, T.E.C. Smith, T.W. Smith, Y. Fu (Eds.). Sage.

⁶ Miller, K., Willson, S., Chepp, V., and Padilla, J. (Eds.). (2014). *Cognitive Interviewing Methodology: An Interpretive Approach for Survey Question Evaluation*. Wiley and Sons.

⁷ <https://www.cdc.gov/nchs/nhis/index.htm>

⁸ <https://lalgbtcenter.org>

| Table 1: Sample Composition | |
|---|--------------------------------|
| | Total Number (n=50) |
| Age | |
| Under 25 | 24 |
| 26 – 39 | 12 |
| 40 and over | 14 |
| Education | |
| Less than High School | 10 |
| High School or less | 20 |
| 2-year college degree | 14 |
| 4-year college degree | 4 |
| Graduate degree | 2 |
| Ethnicity | |
| Non-Hispanic | 43 |
| Hispanic | 7 |
| Race | |
| White | 16 |
| Black | 21 |
| Asian | 1 |
| Native Hawaiian/Pacific Islander | 1 |
| American Indian | 3 |
| Multiracial | 8 |
| Gender Identity | |
| Non-minority | 26 |
| Female | 8 |
| Male | 18 |
| Minority | 24 |

Analysis: Analysis of interview data included a multi-stage process similar to the constant comparative method first developed by Glaser and Strauss (1967)⁹ and adapted to cognitive interviewing studies by Miller et al. (2014).¹⁰ Data analysis was assisted by the use of Q-Notes, a CCQDER-developed software application specifically designed for cognitive interviewing studies.¹¹

Analysis first occurred within each interview as respondents were asked to explain their answers, revealing how they made sense of and went about answering the questions. Careful attention

⁹ Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine de Gruyter.

¹⁰ Miller, K., Willson, S., Chepp, V., & Padilla, J.-L. (2014) *Cognitive Interviewing Methodology: A Sociological Approach for Survey Question Evaluation*. Hoboken, NJ: Wiley.

¹¹ For information, see: <https://www.cdc.gov/nchs/ccqder/products/qnotes.htm>

was paid to ensure that respondents' explanations pertained to the interpretive processes within their own experience—not hypothetical or speculative notions as to how others might interpret the question. Transcripts and detailed notes were then produced from the recorded interviews.

After interviews were conducted and transcripts compiled, comparisons across interviews were made to identify interpretive themes and patterns of potential error—the basis for investigating construct validity. Finally, comparisons were made across subgroups, particularly, across gender minority and non-minority respondents, to examine comparability and issues of measurement equity.

Findings

For the vast majority of respondents, the question was straightforward and required little thought. Almost all respondents readily and easily provided an answer. No respondent asked for clarification or for the question to be repeated. In most cases, respondents provided immediate responses. For example:

Um, female, transgender.

I am currently non-binary.

Just male.

I'm transgender.

Female.

One respondent, who visually saw the questionnaire was able to see that there were three (not five) response options and answered “Number 3.” In a couple cases, respondents provided an answer even as the question was being read. For example, one respondent first answered ‘male’ as the interviewer read the response option (‘male’) but as the interviewer continued reading the words ‘transgender, non-binary, or another gender,’ they changed their answer to ‘non-binary.’ To explain the change in answer, the respondent stated that they assumed ‘non-binary’ would not be an option until it was read: “Usually they don't have that on a survey or applications. It's either male or female, you don't get the choice.” Table 2 shows the specific identity labels that respondents chose.

| | Total Number (n=50) |
|--------------------|--------------------------------|
| Female | 8 |
| Male | 18 |
| Non-Binary | 7 |
| Transgender | 3 |

| | |
|-------------------------------|---|
| Female Transgender | 6 |
| Male Transgender | 4 |
| Transgender Non-Binary | 1 |
| Another Gender | 1 |
| Refused | 2 |

The ‘mark all that apply’ format was also straightforward for respondents. As shown in Table 2, eleven respondents provided two categories in their response. As interviewers read the options, respondents simply provided the answer that (as they saw it) most appropriately fit their life experience and self-understanding. For example, as the response categories were being read, one respondent stated: “Female. Transgender. I’m a transgender female.”

Despite being informed of purpose and privacy protections, two respondents outright refused to provide an answer. When asked the question, one respondent exclaimed, “Skip!” and then followed up by saying, “I just don’t want to discuss the matter with you.” When the interviewer asked in what situations she¹² would feel comfortable, she stated, “It would just depend on the situation... cause each situation is different, I have to take it case by case... It depends on the person, place, and how I’m feeling.” When asked if, for other forms or questionnaires, she fills it out or leaves it blank, she responded, “If I feel like it.” The other respondent who would not provide an answer merely stated, “It doesn't seem like it’s who you are that matters, but who you're not.”

In terms of performance, the simplicity of the question, specifically, that the construct is embedded within the response categories as opposed to the stem, did not create problems. No respondent required clarification in order to provide a response. In fact, it was only when interviewers used the terms ‘sex’ and ‘gender’ to discuss respondents’ thought processes that conversations became convoluted. Some respondents, for example, were confused by what ‘sex’ and ‘gender’ actually meant, saying that they were not entirely sure about the difference. As one respondent explained, “I’m familiar with the terms but I’m not sure what they mean. I’m too old to try and get it—to get new definitions.” Others, particularly, gender non-minorities conflated the concepts, with some even confusing sexual identity and being straight with sex and gender. For example, one respondent explained his version of transgender as a concept: “It’s kind of like, they need love. Like that’s my take on it, like they can’t get love from the opposite sex.” Finally, with reference to the terms ‘gender’ and ‘sex’ in the follow-up discussion, some respondents (particularly those with simplistic or conflated understandings of the terms) began to perceive the question as becoming complicated and taking on more meaning than what it should.

To be sure, there was no unanimity in the ways respondents understood the identity categories. To the extent that some respondents had invested much thought into the meaning of the

¹² While the respondent refused to answer the survey question as it was administered in the cognitive interview, she presented herself as female and used the pronoun ‘she.’

categories, they became invested in the “correctness” of their own understanding—in some cases outright arguing against others’ definitions. For example, one respondent relayed:

To me personally, even though I’m open minded, I don’t accept the fact that a lot of gays, they dress up in female clothes, and they call themselves transgender. And to me it’s ridiculous. I don’t think they’re prepared mentally as transgender in society. They think they are, or they want to be included as a transgender.

In the end, all respondents (but the two who refused) provided an answer that best reflects themselves as it made sense within their own personal understanding of the category. The section below relates respondents’ understandings of the category with which they identified, and why they chose the answer that they did. In no way does this analysis claim to account for all the ways in which people might understand themselves within their particular identity category. Given the sample size, it seems likely that other patterns would exist. It does, however, reflect the understandings of the fifty people in this sample. As will be shown, within each category, respondents held nuanced, if not sometimes striking, differences in understandings.

Male: Many respondents who identified solely as ‘male’ had spent little time considering what it means to be ‘male,’ and therefore had simplistic understandings. For example:

I’m a boy. I feel like a boy! It is such a straightforward question that I don’t know how to answer it in any other way other than ‘male.’

I have been born and lived all my life as a male. I don’t know what it means to be male. I never delved deep into it. I’m just a guy.

Others had clear and entirely biological understandings of being ‘male,’ tying it to their anatomy and being able to reproduce—understanding that ‘who they are’ is static, essential, even ordained. For example:

It means I have a penis.

I know that I am not female because I don’t have female parts. I’m male because I got male parts.

[I can] mate with females and have children.

God made me a guy. And I feel like if God made me a male, I should stay a male so I can find a wife and have kids.

Interestingly, one respondent who reported being ‘male’ despite the fact that they have begun to transition to ‘female’ explained that she was really ‘male’ because “I haven’t had any surgeries done to my body yet.”

Given the close connection to anatomy and reproduction, it is understandable that some respondents understood their ‘male-ness’ as a component of their sexuality. For example, one

respondent, just after answering ‘male’ stated, “If your gonna ask me about my sexual orientation, I’m also straight.”

For others, being straight and able to reproduce had little to do with being ‘male.’ Rather, as one respondent explained, being ‘male’ involved multiple dimensions: “Biologically I’m male. [But also] spiritually and mentally I perceive myself as a male.” Like the respondent above who took issue with gay men (as he perceives them) who call themselves ‘transgender,’ ‘being male’ could even involve feminine gender expression. For example:

[I’m] just male. I just have never thought of myself differently. I like to do drag. I’m a little drag queen.... I know myself, and I know I just, like, have the masculine energy. But I also have the feminine energy. And I just channel it in a different way instead of identifying like that.... Yeah, I’m just a super flamboyant man.

Female: Conceptualizations of ‘being female’ were very similar to those of ‘being male.’ Like many of those answering ‘male,’ many respondents who solely answered ‘female’ had either not considered this identity or understood it as being fully biological. For example, when asked to describe what ‘being female’ means to her, one respondent explained, “Um, uh [pause] I don’t know. I never really thought about it I guess.” Another respondent stated, “Because I was born a female, I’m a biological [female].” Similar to those answering ‘male,’ some women also conflated the concepts of sex, gender and sexuality. For example, when explaining why she chose ‘female,’ one respondent answered, “I’m not bisexual. I go out with girls if they want to go out but there’s no having sex or anything.”

Finally, as with those answering ‘male,’ some respondents who identified as ‘female’ had much broader, multi-dimensional conceptualizations of being female—conceptualizations that went beyond biological, reproductive or heterosexual understandings. For example, when asked what ‘being female’ to her means, one respondent explained:

I feel like I have a female body and then being out here in this very strong environment, the LGBTQ center... I’ve been a lesbian my whole life... and I feel stronger... and I’m a woman and like my feminine side. I like to be in touch with that. Yeah, I believe that I am a woman.

Non-Binary: Unlike respondents identifying as ‘male’ and ‘female,’ all respondents identifying as ‘non-binary’ had spent a great deal of effort reflecting on their feelings and experiences, developing a full personal understanding of what it means to be ‘non-binary.’ One respondent went so far as to draw a diagram for the interviewer. (See Appendix C.) The diversity of understandings among respondents was also much broader. Some, for example, described themselves as being on a continuum, between the polar categories of ‘male’ and ‘female.’ Some saw the middle point of the continuum as constituting what it means to be ‘androgenous.’ Even more detailed, some who understood ‘non-binary’ as being within a continuum also described their position on that continuum as fluctuating. For example:

I don’t really identify with man or woman, it’s more like somewhere in between, it fluctuates from time to time.

Uh, so basically, I consider myself a person that's neither male nor female but embody the energies of both. Like I'm androgenous, but can kind of like definitely lean, fluctuate between the spectrum as far as expression.

Not surprisingly, given their polar conceptualizations of 'male' and 'female,' some non-binary respondents saw the category of 'transgender' as being binary because (as they saw it) those who are transgender typify either end of the continuum. One respondent, for example, who had their breasts surgically removed within the past year explained that they do not identify as transgender because "they don't feel completely male or completely female," but rather "something different or what I choose to be that day." Identifying themselves as 'non-binary' affords them the freedom to express their gender as it changes, as frequently as day-to-day.

Of note, some respondents did not conceptualize 'non-binary' as being on a spectrum, but rather on a place fully outside of a continuum. For example, the respondent who drew a picture to illustrate the meaning of 'non-binary,' explained that:

It just means to me that I don't identify as anything within the binary of male or female. My mind aligns with that view, like I see myself—if there a spectrum of male to female—I kind of see myself right smack dab in the middle of that, and also outside of that.

Elaborating on what is meant by 'outside of that,' they explained that they truly do not feel themselves to be anywhere on the male/female continuum. In the end, they stated that they actually identify as 'agender' or 'two-spirit,' but will report 'non-binary' "to keep it simple."

Finally, some respondents who identified as 'non-binary' explained that this identification was primarily a phase or a steppingstone within a broader transition to becoming 'transgender.' One respondent, for example, explained "I am currently non-binary. I recently switched from male to non-binary. I am starting my transition. This is one step." Another respondent explained that they were identifying as 'non-binary' as a "holding place" while they worked out some confused feelings. Over the past decade they had identified as a "transman," but because of a traumatic experience decided to stop identifying as such; being 'non-binary' afforded them the ability to appear more feminine, which feels safer.

Transgender: Only three respondents answered 'transgender' as the sole category in their response; the other eleven transgender respondents utilized the 'mark all that apply' format and included another response option. As such, there is not a full picture as to the reasoning for this type of response; more research is needed to fully understand the composition of this group. However, one respondent did relay a clear reason for the single answer. Although they had been on hormone therapy for a year, they continue to see themselves in transition and do not fully consider themselves to be 'male.' Like the transitioning non-binary respondent above, they fully see themselves as becoming 'male.' The non-binary respondent, however, uses the category 'non-binary' to signify a place or a steppingstone within the transition. This respondent uses the category 'transgender' as a verb to signify the passage: "I say transitioning. I don't say transgender. I say I'm transitioning. But other than that [reporting 'male'], no."

Transgender, Female/Male: The majority of respondents who selected transgender also selected another identity label. For the majority of these respondents, selection of the two categories was straightforward and matter of fact. For example, one respondent explained:

I'm transgender female. When I say I'm transgender female, I know that I was born male, officially male, but I truly live as a woman.

Similarly, another respondent explained:

I just identify as a female, like a trans female... female first because people seem to want to forget that or 'other' it because I'm trans or because we didn't come about our womanhood in the same way. But yeah, that's it. I just picked that because that's me.

Others did not convey such an absolute, factual justification for their answer. Rather, their explanations reflected not only a personal journey, but one that exists in this historical context. One respondent, for example, explained:

That's really still a new thing, cause I'm 50 and it wasn't until about 10 years ago that I heard that term. Up until that point nobody said anything about gender—you were just gay. But this (transgender) is more of a mental thing, so it's good that [it can be] separated now.

Another Gender: Only one respondent provided the answer 'another gender.' When asked what that other gender would be, they said "gender queer." To them, the use of the terminology 'gender queer' was a recognition of the intersectionality of their gender and sexuality. This is different from conflating the two constructs as was seen earlier among 'male' and 'female' respondents. Rather this was the recognition that their personal sexuality and gender intersect, and this intersection affords them a sense of freedom:

Well, it means that I have relations with other men, and I have relations with women. So that's bisexual. But it's more than that, as I'm moving towards transgender sometime in the future. I'm not restricted, I'm free to be me while I explore my life. And it's more than just sexuality, it's my whole identity.

Finally, one respondent described themselves as being both 'non-binary' and 'transgender,' though this response would have been recorded as one answer (that is, the third response category) as opposed to two responses. Like the respondent above, they also conceptualized the intersectionality of sex and gender, explaining that they were transgender to the extent that they were "just not aligned with what someone was at birth." At the same time, they were 'non-binary' to the extent that they did not occupy either the male or female positions. In the end, the respondent stated that they truly saw themselves as being 'gender queer' or 'gender fluid.'

Discussion

These findings are consistent with previous studies, particularly as they underscore the existence of the inclusion/privacy paradox framing the question response process for gender minority

respondents. Respondents were enthusiastic and sometimes even surprised to be offered a non-binary gender option. The inclusion provided affirmation as well as appreciation of the fact that government seeks to better understand health disparities among the gender minority population. As in the US passport and GEMS applied studies, the specific wording of the question was chosen to account for this dynamic. However, as was suggested by the two respondents who refused to answer, elements of wariness still exist, at least to a certain extent. Therefore, additional messaging as to the purpose and privacy protections for respondents who may be reluctant to answer would be critical for administration of these questions in a health survey. For example, additional language for interviewers can further clarify how this item, in particular, will be used, laying out the risks as well as the benefits for the respondent. In the end, however, it is the individual respondent who will determine whether the information will be provided.

Consistent with the previously discussed CCQDER studies, this analysis also illustrates that respondents' answers (that is, the actual data captured by the question) reflect self-understanding coupled with personal conceptualizations of the particular identity categories. As such, the understandings are multiple, varied and sometimes conflicting. Importantly, the question's simple design accounts for this diversity, allowing respondents the autonomy to define the categories based on their own understandings. In particular, the terms 'sex,' 'gender' and 'gender identity' do not appear in the question's wording. While making distinctions between the theoretical concepts of 'sex' and 'gender' might be appropriate or useful in academic discussions, they are not comparably or consistently understood across respondents and, consequently, would not be practical within the context of general population surveys. Thus, in this design, the response categories convey the intent of the question. In fact, previous work on both the passport and GEMS studies suggests that respondents do not read stems of demographic questions and instead simply use the response options to determine what the question is asking and how to answer. Thus, it is even more important that interviewers articulate each of the categories, even if a respondent answers before the full list has been read.

This set of studies represents an expansive body of research into non-binary gender identity measurement for the federal government. By all indications, the collection finds that a single item can be used to collect non-binary gender information in diverse population-based surveys. Additional research, however, intends to expand upon these findings. Specifically, translation and Spanish language testing is planned for 2023. Also in 2023, a large scale RANDS split-sample experiment is planned that will quantitatively assess potential error, causes and impact of that error. Finally, another large-scale cognitive interviewing study is planned in less urban regions of the United States.

Conclusion

Consistent with previous work, this study found that a single item can be used to collect non-binary gender information in diverse population-based surveys. With the 'mark all that apply' format and the simple design, specifically, conveying the construct through the response categories as opposed to the question stem, allows for the collection of non-binary gender data. Additionally, the study supports earlier findings that context, including the purpose for collecting the information and perceptions of privacy and confidentiality, impact the ways in which

respondents make sense of and formulate answers. Thus, along with the actual wording of the item, to collect high quality gender data, it is necessary to consider how respondents understand the reason for the question and how their answers will be protected.

Appendix A: CCQDER Non-Binary Gender Question Evaluation Studies

Reports are publicly available on Q-Bank, NCHS's on-line repository of question evaluation studies, at www.cdc.gov/qbank/sogi.

An Initial Cognitive Evaluation of a 2-Step Gender Identity Measure (2021)

This study, conducted by the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at the National Center for Health Statistics, investigated construct validity of a gender identity measure for federal surveys. Specifically, the study examined a 2-step measure, whereby respondents were first asked sex assigned at birth followed by a question on current gender identity. The primary focus of the study was two-fold: 1) to determine whether respondents perceived the two questions as asking about distinct constructs, as opposed to seeing them as repetitive, and 2) to identify the ways in which respondents defined or conceptualized those constructs when formulating answers. As such, the study sought to investigate construct validity as well as to provide insight into potential response error. A total of 31 cognitive interviews were conducted.

Cognitive Interview Evaluation of X Gender Marker Definitions for the U.S. Passport Application Form (2022)

The U.S. Department of State is updating passport forms DS-11, DS-82, and DS-5504 to better support all passport holders by adding an X gender marker. Several countries offer the option on passports, and 21 states and the District of Columbia currently offer the category on driver's licenses and birth certificates. However, varying definitions of the X marker are used, and it is not known how the marker is interpreted and utilized by the general population. In partnership with The U.S. Department of State, the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at the National Center for Health Statistics conducted a cognitive interviewing study to assess how potential passport applicants would interpret different versions of the definition as well as how various options would inform response choices.

A total of 100 one-on-one cognitive interviews were conducted of a diverse sample, both gender minorities and gender non-minorities. Respondents were first shown a mockup version of the passport application form, asked to independently complete it, and then asked follow-up questions to explore respondents' experiences and thought processes, with a focus on the gender marker fields and instructions.

Cognitive Interview Evaluation of Demographic Questions for the US Department of State Global Employee Management System (2022)

Staff of the National Center for Health Statistics' (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) conducted a cognitive interviewing study to evaluate demographic and identity questions for use in the Global Employee Management System (GEMS) for the Department of State. Executive Order 14035 on Diversity, Equity, Inclusion, and Accessibility (DEIA) in the Federal Workforce requires that federal agencies recruit, hire, retain, and promote employees in an equitable manner and with a focus on

fostering a diverse workforce.¹³ To this end, government agencies are interested in adding questions to their personnel systems that would allow employees to voluntarily share demographic and identity information. This information would be anonymized and aggregated to track objectives for equal employment opportunity and DEIA efforts within agencies to identify strengths, areas for improvement, and potential barriers. The questions evaluated for this study included a range of demographic and identity information, including ethnicity and race, gender and sexual identity, national origin, and educational attainment.

A total of 44 one-on-one cognitive interviews were conducted. Respondents were first shown a mockup of the GEMS form. In order to simulate a realistic employee experience, respondents were asked to complete the fillable PDF form as though they were supplying information directly to their employer; the interviewer did not interrupt the respondent until the form was complete. The interviewer then asked follow-up probes to explore the respondent's experience and thought processes in answering the questions.

RANDS¹⁴ 2-Step Gender Identity Experiment (2022)

This study evaluated a two-question approach for capturing gender identity, where one item asked for sex assigned at birth (SAAB) and another asked for current gender identity (GI). Specifically, the study used a split-sample experimental design with follow-up confirmation and error probes to examine data quality, including non-response and classification error. Importantly, the study examined the impact of identified error on key health estimates. The study was conducted using the Research and Development Survey (RANDS), specifically RANDS 5. RANDS is an ongoing series of surveys conducted by the Division of Research and Methodology at the National Center for Health Statistics (NCHS) that uses quantitative and mixed methodologies to assess measurement error, validity, and bias. The sample for RANDS 5 was drawn from NORC's AmeriSpeak® Panel, a probability-based sample.

Of the 6,896 respondents, 6,806 (98.69%) were identified as 'true' cisgender respondents using the basic two-question approach. Nineteen (0.28%) of the 6,896 respondents, however, were initially misclassified as gender minority, but then identified (and ultimately corrected) as 'true' cisgender respondents with use of the confirmation question and review of write-in responses. Of the 6,896, 66 (0.96%) were identified as 'true' gender minority respondents using the basic two-question approach; 2 (0.03%) of the 6,896 were initially misclassified as cisgender and then ultimately corrected as gender minority respondents. Because of missing data (respondents either refused or answered 'don't know' to either of the two questions), 24 (.35%) respondents were unclassifiable.

Findings indicate significant differences in key health estimates when erroneous cases are not corrected and illustrate the importance of a follow-up confirmation. Further research is also needed to understand the accuracy of the confirmation question itself, since it may not be accurately identifying all erroneous cases.

¹³ Biden, J. R. (2021, June 25). *Executive order on diversity, equity, inclusion, and accessibility in the federal workforce*. The White House. <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/06/25/executive-order-on-diversity-equity-inclusion-and-accessibility-in-the-federal-workforce/>

¹⁴<https://www.cdc.gov/nchs/rands/index.htm>

Appendix B: Cognitive Interview Guide

CCQDER Field Test Sept 2022

Respondent ID: _____

SECTION: Demographics and General Health

ETHNICITY.

Are you Hispanic or Latino?

RESPONSE OPTIONS:

1. Yes
 2. No
-

RACE.

You may select more than one answer in this question. What is your race?

RESPONSE OPTIONS:

1. White
 2. Black or African American
 3. Asian
 4. Native Hawaiian or Other Pacific Islander
 5. American Indian or Alaskan Native
 6. Other (please specify: _____)
-

GENDER.

You may select more than one answer. Are you...

RESPONSE OPTIONS:

1. Male
 2. Female
 3. Transgender, non-binary, or another gender
-

SEXID.

Do you think of yourself as...

RESPONSE OPTIONS:

1. Lesbian or Gay
 2. Straight, that is not Lesbian or Gay
 3. Bisexual
 4. Something else: _____
-

PHSTAT.

Would you say your health in general is excellent, very good, good, fair, or poor?

RESPONSE OPTIONS:

1. Excellent
 2. Very good
 3. Good
 4. Fair
 5. Poor
-

HITLOOK.

During the past 12 months, have you used the Internet for any of the following reasons? To look for health or medical information.

RESPONSE OPTIONS:

1. Yes
 2. No
-

HITCOMM.

During the past 12 months, have you used the Internet for any of the following reasons? To communicate with a doctor or doctor's office.

RESPONSE OPTIONS:

1. Yes
 2. No
-

HITTEST.

During the past 12 months, have you used the Internet for any of the following reasons? To look up medical test results.

RESPONSE OPTIONS:

1. Yes
 2. No
-

SECTION: Traumatic Brain Injury

The next questions are about head injuries that may have occurred in the past 12 months. Please think about all head injuries, for example, from playing sports, car accidents, falls, or being hit by something or someone that may have occurred in the past 12 months.

TBILOCMEMDAZ.

During the past 12 months, as a result of a blow or jolt to the head, have you been knocked out or lost consciousness, been dazed or confused, or had a gap in your memory?

READ IF NEEDED: PLEASE THINK ABOUT ALL HEAD INJURIES, FOR EXAMPLE, FROM PLAYING SPORTS, CAR ACCIDENTS, FALLS, OR BEING HIT BY SOMETHING OR SOMEONE THAT MAY HAVE OCCURRED IN THE PAST 12 MONTHS

RESPONSE OPTIONS:

1. Yes
 2. No
-

TBIHEADSYM.

During the past 12 months, as a result of a blow or jolt to the head, have you had headaches, sensitivity to light or noise, balance problems, or changes in mood or behavior?

READ IF NEEDED: PLEASE THINK ABOUT ALL HEAD INJURIES, FOR EXAMPLE, FROM PLAYING SPORTS, CAR ACCIDENTS, FALLS, OR BEING HIT BY SOMETHING OR SOMEONE THAT MAY HAVE OCCURRED IN THE PAST 12 MONTHS

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF TBILOCMEMDAZ= YES or TBIHEADSYM= YES]

TBICOUNT.

During the past 12 months, how many head injuries did you have that caused you to experience these symptoms?
For this question, it is okay to give your best guess.

Number of times:

[SHOW IF TBICOUNT >=1]

TBISPORT.

[SHOW IF TBILOCMEMDAZ= YES] Think about the blows or jolts to the head that caused you to lose consciousness, become dazed or confused, or have a gap in your memory. Were you playing a sport or participating in a physical or recreational activity, such as jogging, biking, or pick-up games, when you experienced any of these blows or jolts to the head?

[ELSE] Were you playing a sport or participating in a physical or recreational activity, such as jogging, biking, or pick-up games, when you experienced any of these blows or jolts to the head?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF TBISPORT=YES]

TBILEAGUE.

Were you participating in an organized team or league sports competition or practice when you experienced any of these blows or jolts to the head?

RESPONSE OPTIONS:

1. Yes
 2. No
-

TBCHKCONC.

During the past 12 months, as a result of a blow or jolt to the head, were you evaluated for a concussion or brain injury by a doctor, nurse, paramedic, athletic trainer, or other health care professional?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF TBCHKCONC=YES]

TBCHKRECENT.

For your most recent head injury, were you evaluated for a concussion or brain injury by a doctor, nurse, paramedic, athletic trainer, or other health care professional?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF TBICKRECENT = YES]

TBIWHRCHK.

Where did the first evaluation for your most recent head injury by this health care professional take place?

RESPONSE OPTIONS:

1. Your regular doctor or primary care physician's office
 2. A hospital or emergency department
 3. An urgent care clinic
 4. On the sideline, for example, at a sporting event
 5. Somewhere else, please specify _____
-

[SHOW IF TBICKCONC = YES]

TBIDX.

Following your most recent head injury, did a medical professional diagnose you with a concussion or traumatic brain injury?

RESPONSE OPTIONS:

1. Yes
 2. No
 3. Don't Know
-

[SHOW IF TBILOCMEMDAZ= YES or TBIHEADSYM= YES]

TBIMOI.

When you got your most recent head injury, which best describes how you got hurt? Please select one

RESPONSE OPTIONS:

1. I fell and hit my head
 2. A car or motorcycle crash
 3. Bumped my head on something
 4. An object fell on me
 5. Bicycle crash
 6. I got hit in the head during a fight or an argument
 7. Collided with another person
 8. Felt dizzy or sick and fell, or passed out
 9. Other, please specify _____
-

[SHOW IF TBILOCMEMDAZ= YES or TBIHEADSYM= YES]

WORKMISS.

Did you miss any work or school due to your most recent head injury?

RESPONSE OPTIONS:

1. Yes

2. No
 3. Don't Know
-

[SHOW IF WORKMISS = YES]

WORKMISSA.

How many days? For this question, it is okay to give your best guess.

Number of days: _____

[SHOW IF TBILOCMEMDAZ= YES or TBIHEADSYM= YES]

SYMSTILL.

Are you still experiencing any head injury-related symptoms after your most recent head injury?

RESPONSE OPTIONS:

1. Yes
 2. No
 3. Don't Know
-

[SHOW IF SYMSTILL = NO]

SYMRECA.

How long did it take for all of your head injury-related symptoms to go away after your most recent head injury?

RESPONSE OPTIONS:

1. Less than 1 day
 2. 1 – 2 days
 3. 3 – 7 days
 4. More than 7 days
-

SECTION: Firearms Safety

The next questions are about safety and firearms. Some people keep guns for recreational purposes such as hunting or sport shooting. People also keep guns in the home for protection. Please include firearms such as pistols, revolvers, shotguns, and rifles; but not BB guns or guns that cannot fire. Include those kept in a garage, outdoor storage area, or motor vehicle.

BRFSS_FA1.

Are any firearms now kept in or around your home?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF BRFSS_FA1 = YES]

FA1A.

Are any of the firearms handguns, such as pistols or revolvers?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF BRFSS_FA1 = YES]

FA1B.

Are any of the firearms long guns, such as rifles or shotguns?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF BRFSS_FA1 = YES]

BRFSS_FA2.

Are any of these firearms now loaded?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF BRFSS_FA2 = YES]

BRFSS_FA3.

Are any of these loaded firearms also unlocked?

READ IF NECESSARY: BY UNLOCKED, WE MEAN YOU DO NOT NEED A KEY OR A COMBINATION OR A HAND/FINGERPRINT TO GET THE GUN OR TO FIRE IT. DON'T COUNT THE SAFETY AS A LOCK.

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF BRFSS_FA1 = YES]

FA4.

How often were any loaded firearms stored unlocked when not in use?

READ IF NECESSARY: BY UNLOCKED, WE MEAN YOU DO NOT NEED A KEY OR A COMBINATION OR A HAND/FINGERPRINT TO GET THE GUN OR TO FIRE IT. DON'T COUNT THE SAFETY AS A LOCK.

RESPONSE OPTIONS:

1. Never
 2. Rarely, or less than 3 times
 3. Occasionally, or 4 to 10 times
 4. Often, or more than 10 times
 5. Always
-

[SHOW IF BRFSS_FA1 = YES]

FA5.

What is the main reason that there are firearms in or around your home? Please select all that apply.

RESPONSE OPTIONS:

1. Hunting or sport
2. Protection
3. Work
4. Some other reason, please specify _____

SECTION: COVID and Long COVID

COVIDDEV.

Have you ever had or likely had Coronavirus or COVID-19?

RESPONSE OPTIONS:

1. Yes [SKIP TO SYMPTOMS]
2. No

[SHOW IF COVIDDEV = NO]

NHIS_TEST.

Have you ever been tested for Coronavirus or COVID-19?

RESPONSE OPTIONS:

1. Yes
2. No

[SHOW IF NHIS_TEST = YES]

TEST_POSITIVE.

Has a test found that {you/SP} had coronavirus or COVID-19?

RESPONSE OPTIONS:

1. Yes
2. No

[SHOW IF COVIDDEV=YES OR TEST_POST=YES]

SYMPTOMS.

How would you describe your coronavirus symptoms when they were at their worst?

Would you say no symptoms, mild symptoms, moderate symptoms, or severe symptoms...

RESPONSE OPTIONS:

1. No symptoms
2. Mild symptoms
3. Moderate symptoms
4. Severe symptoms

[SHOW IF P_LONGCOVID = 1 AND COVIDDEV=YES OR TEST_POSITIVE=YES]

NHIS_SYMP3MO.

Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19?

READ IF NECESSARY: Long term symptoms may include: Tiredness or fatigue, difficulty thinking, concentrating, forgetfulness, or memory problems (sometimes referred to as "brain fog"), difficulty breathing or shortness of

breath, joint or muscle pain, fast-beating or pounding heart (also known as heart palpitations), chest pain, dizziness on standing, menstrual changes, changes to taste/smell, or inability to exercise.

RESPONSE OPTIONS:

1. Yes
2. No

[SHOW IF P_LONGCOVID = 1 AND COVIDEV=YES OR TEST_POSITIVE=YES]

NHIS_SYMPNOW

Do you have symptoms now?

RESPONSE OPTIONS:

1. Yes
2. No

[SHOW IF P_LONGCOVID = 2 AND COVIDEV=YES OR TEST_POSITIVE=YES]

ONS_LONG

Would you describe yourself as having “long COVID,” that is, you are still experiencing symptoms more than 3 months after you first had COVID-19, that are not explained by something else?

RESPONSE OPTIONS:

1. Yes
2. No
3. Don't Know

[SHOW IF ONS_LONG=YES]

IMPACT

Does this reduce your ability to carry-out day-to-day activities compared with the time before you had COVID-19?

RESPONSE OPTIONS:

1. Yes, a lot
2. Yes, a little
3. Not at all
4. Don't Know

[SHOW IF P_LONGCOVID = 3 AND COVIDEV=YES OR TEST_POSITIVE=YES]

NHANES_LONG

Did {you/SP} experience any new, recurring, or ongoing symptoms four weeks or later after being infected with COVID-19 or suspecting to have been infected with COVID-19? These symptoms can sometimes appear after recovering from the initial infection. Please look at this sheet for some examples of commonly reported post-COVID symptoms.

RESPONSE OPTIONS:

1. Yes
2. No
3. Don't Know

[SHOW IF NHANES_LONG=YES]

NHANES_SYMPTOMS

Among all of the post-COVID symptoms that you experienced, which ones bothered you the most? List up to three different symptoms. You can refer again to this sheet for some examples of commonly reported post-COVID symptoms.

What are the {first/second/third} symptoms that bothered you the most?

RESPONSE OPTIONS:

1. First: _____
2. Second: _____
3. Third: _____

[SHOW IF NHANES_LONG =YES]

IMPACT

Does this reduce your ability to carry-out day-to-day activities compared with the time before you had COVID-19?

RESPONSE OPTIONS:

1. Yes, a lot
2. Yes, a little
3. Not at all
4. Don't Know

[SHOW IF NHANES_LONG =YES]

NHANES_SYMPNOW

Do you still experience any of these symptoms now?

RESPONSE OPTIONS:

1. Yes
2. No
3. Don't Know

[SHOW IF NHANES_LONG =YES]

NHANES_DURATION

How long {did/have} these symptoms {last/lasted}?

RESPONSE OPTIONS:

1. 1 month to less than 2 months
2. 2 months to less than 3 months
3. 3 months to less than 6 months
4. 6 months to less than 9 months
5. 9 months to less than 12 months
6. 12 months or more?

SECTION: Well Being and Discrimination

Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)

I'm now going to read some statements about feelings and thoughts. Please let me know what best describes your experience of each over the last two weeks: None of the time, Rarely, Some of the time, Often, All of the time.

- SWEMWBS1. I've been feeling optimistic about the future
- SWEMWBS 2. I've been feeling useful
- SWEMWBS 3. I've been feeling relaxed
- SWEMWBS 4. I've been dealing with problems well
- SWEMWBS 5. I've been thinking clearly

- SWEMWBS 6. I've been feeling close to other people
SWEMWBS 7. I've been able to make up my mind about things
-

Brief Resilience Scale (BRS)

READ IF NECESSARY: Just a few more questions like this. Again, please let me know what best describes your experience of each over the last two weeks: None of the time, Rarely, Some of the time, Often, All of the time.

- BRS1. I tend to bounce back quickly after hard times
BRS4. It is hard for me to snap back when something bad happens.
BRS6. I tend to take a long time to get over set-backs in my life.
-

Everyday Discrimination Scale Short Version (EDS) and Heightened Vigilance Scale (HVS)

In your day-to-day life how often have any of the following things happened to you? Would you say: Almost every day, At least once a week, A few times a month, A few times a year, Less than once a year, or Never...

- EDS1. You are treated with less courtesy or respect than other people.
EDS2. You receive poorer service than other people at restaurants or stores.
EDS3. People act as if they think you are not smart.
EDS4. People act as if they are afraid of you.
DS5. You are threatened or harassed.

In your day-to-day life, how often do you do the following things:

- HVS1. You try to prepare for possible insults from other people before leaving home.
HVS2. Feel that you always have to be very careful about your appearance to get good service or avoid being harassed.

- HVS3. Carefully watch what you say and how you say it.
HVS4. Try to avoid certain social situations and places.

SECTION: Immunization

SHTCVD191

The next questions are about coronavirus or COVID-19 vaccination. Have you had at least one dose of a COVID-19 vaccination?

RESPONSE OPTIONS:

1. Yes
 2. No
-

[SHOW IF SHTCVD191=YES]

SHTCVD19NM

How many COVID-19 vaccinations have you received?

Count each individual dose you have received. For instance, a two-shot series of an mRNA vaccine like Pfizer or Moderna, would count as two vaccinations.

RESPONSE OPTIONS:

1. 1 vaccination
 2. 2 vaccinations
 3. 3 vaccinations
 4. 4 or more vaccinations
-

VAX_HES.

Overall, how hesitant about vaccines in general would you consider yourself to be?

Please think about all vaccines, and not just the COVID-19 vaccines.

RESPONSE OPTIONS:

1. Not at all hesitant
2. Not that hesitant
3. Somewhat hesitant
4. Very hesitant

[SP]

VAX_SIDE.

Have concerns about serious, long-term side effects impacted your decision to get vaccinated in the past?

RESPONSE OPTIONS:

1. Yes
2. No

VAX_KNOW.

Do you personally know anyone who has had a serious, long-term side effect from a vaccine?

RESPONSE OPTIONS:

1. Yes
2. No

VAX_MD.

Is your doctor or health provider your most trusted source of information about vaccines?

RESPONSE OPTIONS:

1. Yes
2. No

VAX_RISK.

How confident are you that the benefits of vaccines outweigh their risks?

RESPONSE OPTIONS:

1. Very confident
2. Somewhat confident
3. Not at all confident

VAX_HERD.

Do you believe that getting vaccinated helps protect others from getting disease?

RESPONSE OPTIONS:

1. Yes
2. No

CVD19_HES.

Thinking specifically about the COVID-19 vaccines, how hesitant would you consider yourself to be?

RESPONSE OPTIONS:

1. Not at all hesitant
2. Not that hesitant
3. Somewhat hesitant
4. Very hesitant
77. Don't know

PROBE_VAX.

When answering the previous question about your hesitance towards the COVID-19 vaccines, which of the following, if any, were you thinking about? Select all that apply...

RESPONSE OPTIONS:

1. Overall social benefit of vaccine
2. Long-term health impacts
3. Speed of development
4. Government approval process
5. Personal risk of getting vaccinated
6. Risk of contracting COVID-19
7. Information you received from a medical provider
8. Information you received from friends or social media
9. Previous experiences with vaccines
10. Something else, please specify _____

Appendix C: Picture Drawn by Respondent to Illustrate 'Non-binary' as Being Outside the Female/Male Continuum

