

**Cognitive Testing of the NHANES Sexual Orientation Questions
Interviews Conducted October 18 - December 8
in the Questionnaire Design Research Lab, NCHS
Sponsored by: Office of Research on Women's Health, Office of the Director, National
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Changes made: Unknown

Overview

This report describes research designed to evaluate sexual behavior and orientation questions for the National Health and Nutrition Examination Survey (NHANES). The evaluation is based on 30 in-depth, semi-structured cognitive interviews conducted in the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS).

The tested questions appear in the audio-CASI portion of the NHANES. Cognitive evaluation of the questions consisted of participant response using the audio-CASI equipment (i.e. the touch screen lap-top computer and head phones) followed by a question by question debriefing in a face-to-face interview. In addition to the sexual orientation items, other questions in the audio-CASI portion (as specified by NHANES staff) were tested in this series of interviews. Those additional items include questions on prostate health and illegal drug use.

This report will first outline the QDRL research objectives and methods used for collecting and analyzing interview data. It will then present an overview of each question, outlining patterns of interpretation, observed problems, potential difficulties and recommendations for change.

QDRL Research Objectives

A primary objective of this project was to examine questions regarding sexuality (specifically, sexual behavior, identity and attraction) in an effort to produce valid and reliable measures of sexual orientation for national surveys. Because of administrative concerns inherent in large-scale national surveys as well as analytic considerations necessary for producing valid and reliable measurement, the following criteria were emphasized in the evaluation:

- Questions possess a clear analytic intent and establish a consistent frame of reference across participants.
- Words and concepts are understandable and accessible to a broad range of education levels, age cohorts, and diverse cultural groups.

- Questions reflect appreciation of individuals' personal understandings and are circumspect to the potential sensitivity of the subject matter.

As in all QDRL projects, another central objective was to identify any underlying problems or difficulties in the response process that could potentially lead to measurement error. Examples of these potential problems include unclear terms, inadequate response options, overly-complex question structures, respondents' inability to accurately recall information, and difficulties in the audio-CASI mode of administration.

Method

General Comments Regarding the Methods of Cognitive Testing

It is important to note that the purpose of cognitive interviewing is not to obtain survey data generalizable to a larger population, but rather to examine question response processes and to characterize potential response problems. Data collection procedures for cognitive interviewing, therefore, differ significantly from those of survey interviewing. While survey interviewers strictly adhere to a scripted questionnaire, cognitive interviewers use survey questions as starting points and rely on immediate follow-up probing in order to conduct extensive examinations of response processes.

While survey research employs a deductive, quantitative methodology and relies on a relatively large random sample to achieve statistical inference, cognitive testing employs an inductive, qualitative methodology and, consequently, draws upon a relatively small sample. Due to its small sample, it is impossible for any cognitive testing study to achieve complete inclusivity, that is, not all social and demographic groups are represented in each sample. As a general rule, sample definitions are based upon the content of the survey and the purpose and objectives of the particular study.

Again, unlike survey research, the primary objective of cognitive testing is *not* to generate statistical data that is generalizable to an entire population. Rather, the objective is to provide an in-depth exploration of particular concepts, processes and/or patterns of interpretation. With this type of method, cognitive research is able to 1) illustrate themes or patterns as well as inconsistencies in participants' interpretations, 2) characterize response problems or difficulties, and 3) indicate potential sources of response error— information that is beneficial to improving the overall quality of survey questions. It should also be noted that, because our sample is not representative of the survey's larger population of potential respondents, we do not purport to have identified *all* sources of error or *all* patterns of interpretation that may incur in the fielded survey.

Sample for This Project

The QDRL staff conducted and analyzed data from 30 in-depth, semi-structured cognitive interviews with participants of diverse sexual orientations. Participants were recruited from an advertisement in the Washington Blade and through the distribution of flyers. Because

we were especially interested in recruiting low income, low education participants (and typically have difficulty recruiting these participants through newspaper advertisements), participants from previous QDRL projects with these characteristics were phoned and asked to participate.

We received over 200 phone calls responding to the newspaper advertisement and flier and, consequently, were able to select a relatively diverse sample. The chosen sample consisted of 30 participants between the ages of 23 and 56 (NHANES sexual behavior questions are asked only to those 18-59 years of age), half of whom were women and the other half of whom were men. Of the fifteen women, 5 defined themselves as heterosexual, 7 as either lesbian or gay, 2 as bisexual, and 1 reported that she was unsure of her identity. Of the fifteen men, 5 defined themselves as heterosexual, 7 as gay, 2 as bisexual and 1 reported a transgendered identity. Of the 30 participants, 12 identified as White, 13 as African American, 2 as Multi-racial, 2 as Hispanic, and 1 as Asian-American. Fourteen participants reported an annual household income of less than \$20K, 5 reported an income between \$20K and \$30K, and 11 reported an annual household income of \$30K or above. (See Appendix A for more detailed demographic profile).

Interviewing Protocol

The interviewing protocol consisted of two sections. First, participants used a touch screen lap-top computer and head phones to answer the audio-CASI questions. Having participants respond to questions with the audio-CASI equipment was essential because it allowed us to identify problems specific to the audio-CASI format mode. Additionally, by first answering questions in the privacy afforded by this format, participants were sensitized to the types of questions that would eventually be discussed in the interview.

The second section consisted of a question by question debriefing in a face-to-face interview. In the debriefing, participants were reminded of each question, were asked to explain how they got their answer and how they interpreted key words such as “sex,” “vaginal, anal or oral sex,” “main sexual partner,” and “sexual attraction.” The debriefing was semi-structured, that is, the interview schedule was framed by pre-established questions, but follow-up questions were also asked to clarify relevant issues or emergent difficulties. Because of various skip patterns, not all participants received every question in the audio-CASI portion of the interview. For example, in the sexual behavior component, only seven of the 30 participants were asked three particular questions. Those questions included: “The last time you had sex was it with your main sexual partner?” “In the past 30 days, with how many partners have you had sex?” and “In the past 30 days, how many times did you have sex without using a condom?” In order to make a reasonable assessment of these questions all participants (regardless of whether they were skipped in the audio-CASI segment) were asked the questions in the debriefing.

All interviews were audio-taped and then transcribed.

Analysis of Interviews

Analysis was conducted from transcribed interviews. The text of the interviews was collated by question so that comparisons could be made systematically across all participants. Two levels of analysis were then performed. First, distinct occurrences in which participants

specifically expressed difficulty or confusion while answering were noted. Second, participants' interpretations of each question were examined. To analyze the interpretive aspects of question response, the constant comparative method, a standard method for analyzing qualitative data (Lincoln and Guba, 1985; Strauss and Corbin, 1990; Creswell, 1998), was employed. By comparing across all cases, individual responses were categorized according to a participant's particular interpretation of a question. From these categories, interpretive aspects (e.g. the consistency and degree of variation among participants) of each question were examined. Our concurrent recommendations derive from both levels of analysis.

Question Overview

SXQ.020. The next set of questions are about your sexual behavior. By sex, we mean vaginal, oral, or anal sex.... Have you ever had sex?

Problem Overview:

- Question works in most cases.
- Potential false negatives in rare situations: 1) those who are put off by the words “vaginal, oral, or anal” and rebuff the entire question; 2) those who have only had oral sex and do not consider oral sex as “having sex.”
- The question's definition of sex (“By sex, we mean vaginal, oral or anal”) does not establish a consistent frame of reference among participants for the remaining sexual behavior questions.

Discussion:

We see this question as serving two important functions. First, the question, as a screener question, should determine which respondents have not had sex and route those respondents to the end of the section. Second, the question should establish a coherent and consistent frame of reference, outlining the types of behaviors that respondents should include when responding to the subsequent sexual behavior questions.

As for the first objective (screening out participants who have not had sex), the question was relatively straight-forward for our participants. No participants expressed difficulty understanding the question, and no one was inappropriately routed out of the questionnaire. Through the course of the interviews, however, we identified two issues that may lead to future false negative responses. First, a few participants, primarily heterosexual women, expressed that they were uncomfortable with the topic of sexual behavior and noted a specific uneasiness with unconventional sexual intercourse. Although these participants did not respond incorrectly, their comments lead us to believe that it is possible that some respondents may rebuff the entire question, answering “no” because they are uncomfortable with the words “vaginal, oral, and

anal.” Second, throughout the course of the interviews, we found that, despite the survey’s instruction to include oral sex, some participants did not include oral sex as a “having sex.” Given this, we believe it is entirely possible that some respondents may answer “no, have not had sex” even though they have engaged in oral sex. Because these circumstances did not apply to any of our participants, however, it is difficult to assess the potential problem that these circumstances may actually pose.

As for the question’s second objective (defining the parameters of what constitutes “sex”), the question appears to work for this question, but does not establish a frame of reference that endures throughout later questions. Despite the question’s wording “by sex, we mean vaginal, oral, or anal sex,” we found that there was enormous grey area as to what participants considered would qualify as “sex.” This grey area was primarily shaped by people’s experiences, not the survey’s definition. Furthermore, individuals’ own definitions shifted from question to question, indicating that how people interpret key words in questions is also shaped by the context of the question itself.

Many participants saw the terms as establishing broad parameters for what would constitute sex, including oral sex as well as manual stimulation in some cases. These participants who held broad conceptualizations of “vaginal, anal or oral sex” did not limit their responses to penile intercourse, but incorporated a wide range of sexual activity, including “any time someone had an orgasm,” “everything that requires you to be private with someone,” and “anything that’s sexually arousing.”

Some participants, on the other hand, held much narrower understandings and interpreted the terms “vaginal, oral or anal” as inquiring about incidents of penetrative penile intercourse only. Heterosexual participants who held this narrow interpretation reported that they would not count broader definitions as incidents of sex and dismissed other forms of sexual activity as foreplay:

Heterosexual woman: They call that— people use that as foreplay. But I don’t consider it sex. It’s just foreplay....

Heterosexual man: I don’t think that really is because — mmm— boy, you’re really playing in an interesting arena there. That’s still kind of like I almost think of the old term, what was it, foreplay.

A few lesbian and gay participants, on the other hand, also interpreted the terms “vaginal, anal or oral” as penetrative-specific and, consequently, viewed the parameters as too restrictive and lacking inclusivity— lesbians because penile intercourse is irrelevant and gay men because the AIDS epidemic has caused some gay men to participate in non-penetrative sex only:

Lesbian: I would be tempted to say yeah [the survey’s definition is limiting]. Because pretty much that just says it has to do with either penetration or with oral stimulation, and you can go a long way without any of that. My partner and I have a lot of fun without any penetration or anything.... And a lot of times that’s

even more satisfying.

Gay man (describing the problem in the erectile dysfunction question): You need to define that better I think. Because under the strict definition of it, I haven't had intercourse in years. But, I've had sex..... I mean I think one of the questions later on says you define intercourse as oral, anal or vaginal? Okay. Under those terms, I have not -- as I just said, I have not had sex in years.... I mean like maybe 15. Okay. Well, I probably have. Probably have. But, I certainly have not been celibate for 15 years. Okay. You know, I think you need to add other -- other forms of sexual release in there.

While these differing interpretations may seem (at least for this question) inconsequential, the lack of an established consistent frame of reference among participants leads to more significant problems in the subsequent questions. Some of our participants, for example, reported much younger ages of their "first sex" because they used a much broader definition of what constituted "sex." Similarly, some participants reported not using a condom more often than other participants because, while others counted only penetrative intercourse, they also included oral and manual stimulation.

Additionally, as the interview continued on to the subsequent questions, we found that participants' definitions of sex were also inconsistent, often varying from question to question. Not only would participants diverge from the survey's definition (that is, their particular understanding of this definition), but they would also diverge from their own previously articulated understanding of what constituted "sex." Most participants, for example, stated up front that they considered oral sex as a form of sex. Some participants even mentioned the Clinton scandal, musing that oral sex was touted as *not* having sex. One heterosexual man, for example, stated:

I would say that our President is highly confused if he doesn't think that oral sex is sex. That's sex..... I don't know how you can actually look at that as not being sex. I mean, maybe I'm getting old, I don't know. It kind of floored me when he didn't think that was sex.

Still, many participants, including this man, excluded oral sex in some of the following questions, including "How old were you when you first had sex?" "With how many men/women have you had sex?" and "In the past 30 days, how many times have you had sex without using a condom?"

It is also important to note that interpretations of what constitutes sex may differ depending on the gender of the partner. This observation was especially prominent in the interviews of bisexual men and women. This bisexual woman, for example, explains how she defined the parameters:

I guess anything involving. I mean, anything involving the vagina. It would not

have to include a penis.... I sort of ignored the definition a little bit when I answered that question.... I have a different way of defining it.[later on she explains] I have a much more sort of like fluid and open idea of sex with women than I do with men..... If I kissed a woman or if she just touched like my breast or something, I wouldn't count that sex. I mean, I would count that as like a sexual activity, but not like sex. So I mean with a woman, it would either have to be that I did oral sex to her or she did it to me or I penetrated her or she penetrated me. Whereas, if a man did oral sex to me and that was it or I just did oral sex to him, I wouldn't really consider that sex.

Recommendation: Because all participants were appropriately routed, we believe that this question itself is adequate (i.e. it most likely excludes respondents inappropriately on rare occasions only). However, we see the inconsistent interpretations among participants (even among heterosexual participants) as a noteworthy problem— not so much because the question elicits inaccurate responses, but because it does not establish a coherent and consistent frame of reference for the subsequent questions.

Depending on the intention of the question, several changes may alleviate this problem. First, the question could be broken down into multiple parts with more fully explained definitions. Dividing the question will probably also improve both types of conditions contributing to the potential false negative problem.

If the question is to remain as it stands, we suggest developing a more thorough clarification in several audio-CASI screens to instruct respondents what they should count as “having sex.” In addition, we recommend providing help screens throughout the section, reminding respondents of the survey's parameters and discouraging respondents from using their own personal definitions.

SXQ.030 How old were you when you had sex for the first time?

Problem Overview:

- Participants used differing definitions of what constitutes “having sex,” thereby reducing the accuracy of the measurement.

Discussion:

Only a few participants considered the survey's parameters, “vaginal, anal or oral sex,” when forming their response to this question. Most participants had preconceived narratives detailing their first sex, and they simply recalled this age when forming a response. As in the first question, however, the types of activities that participants considered as “first sex” varied. Some men, for example, including those who adamantly stated earlier that oral sex should indeed count as “having sex,” did not include oral sex in their response to this question about their first

sex:

(Heterosexual man discounted oral sex and included only vaginal sex)
[Interviewer pointed out discrepancy: So you were kind of going with President Clinton] I guess I was there.... Well, I guess when you think of your first time, it's more than just your first all the way home run, I guess. And I guess when you think back to high school a home run is not oral sex.

(Gay man discounted oral sex and included only anal intercourse)
When I was thinking of sex [for this question], I was thinking of anal sex.
[Participant now remembers that the survey instructed him to include oral sex in his response] I didn't incorporate the oral sex in there, so then my response would be different then.... [My answer is] probably wrong then. I know it's wrong because I remember having oral sex before I had anal sex, and I didn't remember that, but that's how it was defined in that question.

Because participants would simply recall a preconceived narrative of “the first time they had sex” to provide a response, participants, like these men, were inclined to abandon the survey's definition of sex. A man who identified himself as transsexual, for example, and who defined sex as “any type of penetrative intercourse involving a penis,” reported that he was 16 when he first had sex with a man—the experience that he had always considered to be his “first sex.” He was astonished later in the interview, however, when he remembered that he had sexual intercourse with a woman a few years prior to that experience.

Another participant had always considered his first sex as occurring when he was 11 years old; he was sexually abused as a child and considered giving oral sex to older men as his “first sex.” Still another man had always considered his first sex, occurring when he was 9 years old, when he had non-penetrative sexual contact with a woman:

When I first had sex, I thought sex was you rubbing your penis near in the vagina area. I didn't know that sex meant penetration. I didn't know that it meant that... I thought it was, you know, you rubbing yourself up against your female partner... I was answering it [the question] based on my first experience. [That it, the non-penetrative activity.]

As the cases above suggest, it was particularly striking how many participants, as they used preconceived narratives to base their answers, found themselves using definitions that were contradictory to their earlier statements about what constituted sex. One lesbian, for example, was surprised when she realized that she counted vaginal intercourse with a man, not manual stimulation, in her response to the question:

Well, the way the question was— yes, I mean, before when you asked me if I only consider penetration the only kind of sex, obviously I said no. There's lots of other things that I consider sex. But the way the question was— despite that, the

way the question was worded, "How old were you when you first had sex," I immediately in my mind went to that intercourse thing.

Furthermore, in the course of the interview, this same woman was shocked when she became aware of another contradiction in her response:

You know, before you go on, sorry, I just have to say here's another contradiction. Actually, that experience was a rape. It was somebody I knew, and I've always had a lot of that guilt stuff that goes along with that— I should have known better, I shouldn't have let it happen kind of thing. Now, when you asked me before if I considered rape sex, I said no. But in my own case— it was rape, but I still think of it as a sexual thing rather than -- you know, there's a contradiction there.

While most participants abandoned specific definitions of what constituted sex in favor of a preconceived narrative, a few attempted to use the survey's definition, even if that definition (as they interpreted it) countered their own personal definition. One heterosexual man, for example, interpreted the survey's term "vaginal, anal or oral" very broadly, though his own definition of "having sex" included only penetrative sex. Although, he confessed that he later reverted to his more narrow definition for the remaining questions, he attempted to use the survey's definition for this question:

Well, see, that's the one that I was sitting here trying to debate on what you meant. And I used short of intercourse just anything involving some kind of climax is what I counted basically, but then see I was entirely inconsistent in answering the question now that you mention it.

Another man also attempted to answer according to the survey's definition. However, opposite of the previous participant, his own personal understanding of sex was relatively broad ("anything that you couldn't do in public"), yet he interpreted the survey's parameters, "vaginal, anal or oral," much more narrowly ("complete penetrative sex"). As a result, like the previous participant, he expressed some difficulty (specifically stating that the question was "tricky") discerning the appropriate response to the question:

I will call sex like whenever there was a contact with anyone.... something that we wouldn't do in public. That would be my first sexual experience. Now if you ask for a sexual complete intercourse, that's different. That's different. When you say have sex for the first time, I went back to your definition.... [I answered] thinking about complete intercourse. But my first reaction was thinking well, when I could have this foreplay thing and then I came back and then I came back and changed my answer.

Recommendations: Again, the problems with this question are related to the inconsistent frame of reference among participants. Providing more explicit definitions as indicated in the prior question as well as reminding participants of the types of behaviors that they should include will

most likely improve the consistency and accuracy of the data.

SXQ.100/200. In your lifetime, with how many men have you had sex?

Problem Overview:

- Often poses estimation challenges for participants.
- Prompting from the Audio-CASI voice makes people feel self-conscious and rushed.
- Participants' definitions of "what counts as sex" differed, producing possible false positive and false negative responses.
- Sensitivity of the question content probably generates substantial under-count.

Discussion:

In comparing this and the previous question, we observed a marked difference in the processes participants used to construct a response. Unlike the previous question in which participants used preconceived narratives detailing their "first sex," almost all participants had no previously conceptualized response. One gay man, for example, explains:

That's kind of difficult. I mean, because... you never keep track. You never think to count, and it was just a question to— it's just never been asked of me before. So, I had to really sit and think....

Because they had no preconceived response as in the previous question, most participants more likely returned to a preconceived definition of sex and attempted to count each incident that fit their particular definition. Those who interpreted "having sex" as penetrative intercourse, then, attempted to count the number of men with whom they had this type of intercourse. Those who had a relatively broad understanding of "having sex," returned to a much more inclusive frame of reference. Consequently, many gay men who did not include oral sex in the question about first sex were now more likely to include oral sex.

(Gay man realizing that he included oral sex in this question, but not in the previous question about age of first sex)

See, that's the funny thing, because in that one, I did think of oral sex.... I did incorporate that in that answer. Because I thought of everyone I had anal sex with first, and then I thought okay, well, there's anal sex and there's oral sex, throw that in there. So, I did remember in that question, but I didn't in the previous.

The primary problem with this question, however, was that many participants, especially those who had a significant number of sexual encounters, were unable to provide an accurate response. While participants were now attempting to use an established criteria for what constituted sex, many simply could not recall all of those incidents. These participants stated

that their answer was only an estimate; several acknowledged that their answer was a “wild guess.”

Because these participants were unable to clearly remember all encounters, their definition of what constituted sex was often compromised. To form a response, many participants focused only on one dimension or pieced various definitions together, counting some types of experiences and estimating others.

(Heterosexual woman focusing on long-term relationships)

The way I defined it was people that I had long term sexual relationships— like to me, I wouldn't consider a one night stand... as a man I had [sex with] — I guess when I look at that question, I look at that more in terms of making love. I'm not even going to say that. I would say— I mean, you can't really count them because like I started when I was 15. I'm 32 now. I can't remember— well, I'm not going to say I can't remember everyone. I remember the people that were important and I felt something about. But not all of them were accounted for. Let's put it that way.

(Lesbian piecing definitions together)

I had to estimate that number. [*She reported having sex with 16 men in her lifetime*] And most of my sexual experiences with men were intercourse type of experiences. And because it was an estimate, there might have been two or three where it was only heavy petting and the other stuff. So I guess because I had to estimate anyway, it didn't really matter. If I had only sex with three men and then there were two others that had been just heavy petting or manual stimulation or whatever, then I would have said five. But since it was a much higher number than that anyway, and I had to estimate it, it kind of all got estimated in together.

Adding to the problem of recall difficulty, several participants complained that they felt hurried when the voice in the audio-CASI recording repeated the question before they could calculate an accurate response. For example, one participant, who ultimately provided an answer of 30, later reported that the accuracy of his answer was reduced because of the repeated prompts:

I didn't take a lot of time to think about it. ...this lady was asking me questions... over the earphones and I kept thinking she's in a hurry.... It's like, oh my God, this thing is going to crash if I don't answer it now!

Although inconsistent definitions and inability to recall may be the greatest source of response error in this question, it is important to note that the social desirability inherent in this question may also cause some degree of response error. To be sure, many participants stated up front that this was the most sensitive question in the entire series. The shame and stigma associated with both numerous sexual partners as well as the implication of homosexuality appeared as common themes in participants' perceptions of this question:

(Heterosexual woman/stigma of numerous partners)

Now, that question— that was the troubling one. I can't answer that..... I said I'd rather, oh yeah, I said I'd rather not answer it..... I skipped it. Matter of fact is I didn't put no answer.... Because I think it was kind of personal.

(Gay man/stigma of multiple partners)

...believe me, it [the number that I came up with] had me thinking that numbers were really high. It kind of even startled me to even answer it because I never even looked at it like that.... Because I was just being so honest with, you know, with the question, and I feel comfortable [as in feeling like the answer was accurate] with this answer. It made me look at it... I looked at the number, I really didn't feel good.

(Gay man/stigma of homosexual behavior)

I was always told I was going to hell and all this other stuff. So, it's not easy to put the number there -- out there and because it's not proud -- I'm not proud of any of it. Best relationship I had in my life is the one I got now and now, I just kind of wonder if I'm doing the right thing.

Recommendation: Because respondents may infer from the repetitions that they have an unusually high number of sexual partners, the short time (as it is perceived by some participants) between question repeats may actually increase the sensitivity of the question and decrease its accuracy. We, therefore, recommend lengthening the amount of time before the question is repeated by the audio-CASI voice.

Although we have relatively little information pertaining to the types of behaviors that heterosexual men would consider same-sex behaviors, it is important to note that the ambiguous definitions of “having sex” may be a serious problem if the intent of this question is to measure sexual orientation. If respondents interpret “sex” as only anal intercourse or only oral and anal intercourse, the question may not be discriminating enough to accurately portray same-sex behavior among men. Men who identify as heterosexual, for example, may engage in oral sex with other men, but may not consider oral sex as “having sex” and respond negatively. The ambiguous terminology coupled with the social stigma associated with homosexual behavior will most likely produce a substantial under-report to this question

SXQ.120/220. In the past 12 months, with how many men have you had sex?

Problem Overview:

- The same problems mentioned above, however, problems with estimation were somewhat reduced.

Discussion:

For the most part, participants reported using essentially the same definitions in this question as they did in the previous question. The major difference between the two questions, however, was that participants' ability to recall each incident dramatically improved. Consequently, for this question, participants' definitions were not as readily compromised by an inability to remember various experiences; those participants who were inclined to use broader definitions were now able to incorporate their more liberal understanding into their response. For example, the heterosexual woman who in the previous question stated that she focused primarily on her long term relationships, reported that while she was still "geared more towards the serious relationships," she also included one incident that was "just kind of like a fly by night." Similarly, a bisexual man stated that by this point he had completely forgotten about the terms "vaginal, anal or oral" and "just went by my definition," which was "anything that couldn't have been done in public."

While participants expressed that it was much easier to recall incidents of sex in this more limited time frame, it is important to note that, in our probing, we still found some response error. In two cases participants mis-reported and were consequently routed out of the next set of potentially relevant questions. In the first case, a gay man did not remember until the debriefing that he inadvertently omitted a specific encounter and wrongly answered 1 instead of 2. In the other case, a gay man's narrow interpretation of the survey's definition, "vaginal, oral or anal," forced him out of the same subsequent questions:

I changed that answer because I found it a little bit confusing, okay. It was confusing because I had not had oral, anal or vaginal intercourse that led to ejaculation with anybody. Okay. Ejaculation's key there. I have, however, had what I consider to be sex with people. But, I have not come inside anybody and nobody's come inside me.

As in the previous question, this question also tended to be one of the more sensitive questions. The heterosexual woman who stated in the previous question that she preferred not to answer also stated in her interview that she did not want to answer this question. When reviewing the computer responses, however, she did not report "prefer not to answer," but answered "0."

Recommendation: Clarifying "have sex" in previous questions and re-stating the definition will create a more consistent frame of reference among participants. Because respondents may use the reference period beginning in January (which one participant stated that she did) we recommend inserting, "that is, since [month] of [year]."

SXQ130/170. In your lifetime, with how many women have you had sex?

Problem Overview:

- This question also poses major estimation problems.
- Participants' definitions of "what counts as sex" differed, producing possible false

positive and false negative responses.

Discussion:

Like the question, “In your lifetime, with how many men have you had sex?,” participants primarily referred to some type of definition of “having sex” and attempted to count each incident that fit the particular definition. In this question, however, (perhaps even more so than the last), it was particularly striking how individuals’ personal experiences shaped the way in which they would define “sex,” specifically “sex with women.” Heterosexual men, for example, tended to abandon the survey’s definition, “vaginal, oral or anal,” as well as any broader interpretation, and focused almost exclusively on penetrative vaginal intercourse. Most notably, heterosexual men were not likely to include oral sex as “having sex,” though they had noted earlier that oral sex would count.

(Heterosexual man now excluding oral sex)

That’s funny— now I’m reassessing because of your question. Should I be saying now that I had sex with 15 women or 14 women simply because I got lucky in one particular part of sex. But I probably should. Although I don’t even think women would consider that they’ve given it up if they didn’t have complete sex. That’d be interesting. I’d like to get a woman’s perspective on that. And I wouldn’t think that a lot of women would probably be the same as guys thinking, ah, we really didn’t have any intercourse, so we didn’t really have complete sex.

In the extreme opposite, lesbians’ definitions of “having sex” tended to be especially broad with little specific clarification as to what would and would not count. While heterosexual men tended to focus on only penetrative intercourse, lesbians were more likely to mention sexual arousal as well as emotional closeness. Specific statements included, “not necessarily penetration, but the arousal, the emotional involvement would have to be there,” “pleasure, sharing pleasure, pleasurable touch,” and “lovemaking to orgasm, if not orgasm, some kind of arousal.” One woman stated that she would even be inclined to include passionate kissing as a form of “having sex.”

Definitions used by non-heterosexual men, on the other hand, appeared to span the continuum. Some included only penetrative intercourse, while others used much broader definitions:

Bisexual man: Here again it could be vaginally. I mean anything from touching any intimate area to intercourse. Anything beyond kissing.

Gay man: [*He included oral sex earlier when counting the number of men with whom he had sex, but did not include oral sex when counting the number of women.*] I didn’t count that. I guess that’s not fair. That’s a little double standard isn’t it?

The problem of inability to recall did not surface in this question nearly to the extent that it did in question about number of male partners. This, however, is probably an artifact of this

particular sample which, overall, reported much higher incidence of sex with men than sex with women. (The average number of men was 28.8 while the average number of women was 9). Several participants did, however, report that their response was an estimate and not necessarily accurate:

Heterosexual man: I couldn't pinpoint that at all so I just took an estimate.... In a way it was because right off hand I started counting and lost count.... I guess from my lifestyle I was just thinking, you know, approximately, maybe around, and you know, you don't want to overblow it and try to under-blow it so I just took a wild guess and around that number. It might be off some, it might be off less.

Lesbian: I guessed, yes. Absolutely. Because there's no way you can sit and like count. Seriously, when it gets to a number beyond 20 or something, you can't. It would take some time. It would probably take me a good half hour to really seriously come up with a really good estimate. And it would still be an estimate.

Recommendation: As an interesting side note, unlike the male counterpart question, this question was never indicated as being a sensitive question. Still, there may be a potential problem of participants feeling hurried by the computer to form an answer, and we recommend extending the length of time before repeating the question here as well.

As we noted in the earlier question, this question is probably not discriminating enough to be used as an adequate sexual orientation measure. Like the question about number of men, the ambiguous terminology coupled with the stigma associated with homosexual behavior will most likely result in a significant undercount.

SXQ.150/190. In the past 12 months, with how many women have you had sex?

Problem Overview:

- Same problems as above, but with fewer estimation problems.

Discussion:

As in the previous question, participants' interpretations were primarily based on personal experience. Lesbians tended to include a broad range of sexual activity, while men (primarily heterosexual men) reported basing their answer on incidents of penile intercourse only. (We should also note, however, that we are uncertain as to whether or not men actually excluded a specific experience, such as experience with a woman in which only oral sex occurred, because it did not fit this definition.)

Not surprisingly, participants had a much easier time answering this as opposed to the previous question because of the shorter time frame. Although the reference period is much shorter, however, we still found some participant response error. One participant reported only

one woman in the past year, but after probing it was discovered that there had actually been two women within the last 12 month period. Because he deemed his current relationship as being a year old, it was likely that he would conceptualize the other incident as “earlier than a year ago.”

Recommendation: To deter this type of response error, we recommend inserting, “that is, since [month] of [year].”

New 002. For this survey, we use the term “main sexual partner” to describe someone who is your spouse, lover, or anyone else you feel committed to or have a special relationship with. The last time you had sexual intercourse, was it with your main sexual partner?

Problem Overview:

- The term “sexual intercourse” is not defined and has not been used previously in this questionnaire. It is interpreted by many as only heterosexual sex.
- Question assumes people have one main sexual partner, when in reality they may have none, one, or more than one.

Discussion:

The switch in terminology from “sex” to “sexual intercourse” did not go unnoticed by participants, especially those who were using broader definitions to answer the sexual behavior questions. Most participants understood the term sexual intercourse as implying specifically penile intercourse. For non-heterosexual women, the implicit assumption of heterosexuality posed a problem:

I was wondering why it said sexual intercourse because that’s assuming that my main sexual partner is somebody I have intercourse with. And I don’t like that.... It tends to slot women into a heterosexual form of lovemaking which is not fair in the question.

It is important to note, however, that not all non-heterosexual women were offended by the switch in terminology. Rather than viewing the word “sexual intercourse” as an exclusive term, some simply re-interpreted the word so that it was suitable to their own experience:

[Interviewer: In this question, what does the term “sexual intercourse” mean to you?] Well, it could, just like I said, oral sex, anal or vaginal sex. So that’s how I interpreted it... as being sexual.

Additionally, as several participants indicated, a fundamental problem with this question is that it implicitly assumes that each respondent indeed has a “main sexual partner.” Respondents who did not have a main sexual partner, but who were routed into this question, found it to be somewhat presumptuous as well as awkward to answer. Respondents, therefore, might answer “no,” not because they were non-monogamous, but because the question simply

did not apply:

I had a problem with that because I don't have a main— I don't have a committed relationship right now. I answered no because I didn't have any closer accurate option.

Furthermore, a few participants mentioned having difficulty discerning whether or not their current partner should qualify as a “main sexual partner,” particularly as it was defined in the question. For example one heterosexual man reported that he was unsure whether or not the woman who he was seeing would actually qualify as a “special” or “committed relationship.” The relationship, he stated, was not that serious (they would go weeks without seeing each other), but he is not currently seeing anyone else.

A few participants also noted that the question, while it assumes that respondents have a main sexual partner, it also assumes that respondents have only one main sexual partner. A heterosexual man, for example, stated that, as he understood the term “main sexual partner,” there was a time in his life when he had more than one main sexual partner:

There was a time in my life I did have about two, three or four. [Interviewer: What would it take for someone to qualify as being a main sexual partner?] Well, someone that I [spend] most of the time and we enjoy being with each other when we're together and we spend a lot of time together.

Bisexual participants, particularly, noted this assumption in the question and expressed that the question lacked inclusivity:

Bisexual woman: Right now I have a woman and a male partner, and we sometimes make love together. And we're creating a family together. So, it was also not an accurate question for me in terms of... I mean, I definitely have a different relationship with each of them and I've been with one of them much longer. But for it to say one sexual partner and assume there is only one main sexual partner, in my case was not accurate.

Bisexual man: I have two partners, and I care a lot about them.... you know, one is not my spouse. So I don't know, is that— do you see what I mean?

Finally, we should also point out that this question holds the potential of being extremely sensitive. One heterosexual woman, for example, who admitted in the debriefing that she answered “no,” stated that privacy was necessary for her to give a truthful answer:

I mean, if this was sent to my home... I don't think I would have filled it out. Because it is very personal. I mean, it's a lot different asking these questions at the place that it's going to be, you know, at the place that this is going to stay.

But for me to answer it at home, my son could get it, you know, there. I'm not sure how many people would go through with this. Just because it's pretty risky.

Recommendation: Because this question wrongly assumes that every respondent has one (and only one) main sexual partner, at the very least we recommend adding a screener question asking if respondents have one main sexual partner before this question.

Additionally, because the term “sexual intercourse” is not defined and has not been used previously in this questionnaire, we recommend using the term “have sex” to maintain consistency.

As noted in our initial report, the utility of asking this question merely in reference to the most recent sexual episode is questionable. Expanding the reference period may provide more comprehensive information.

Finally, because many respondents are screened out of this and the next few potentially relevant questions, we recommend re-evaluating the skip patterns in this section. We specifically note that the fact that women who have had multiple sexual partners, but none with men, are skipped out of this question.

SXQ.240. In the past 30 days, with how many partners have you had sex?

Problem Overview:

- “Partner” is another new term that may also have connotations of commitment. Respondents may omit incidents of causal sex in their answers.

Discussion:

While most understood the word “partner” in generic terms, that is, as anyone (both male and female) with whom they had sexual relations, a few participants viewed the word as pertaining to a long-term committed relationship. This confusion may, in part, occur because the previous question stipulates that a “main sexual partner” is a long term, steady relationship. However, most of the participants that recognized the word “partner” as a steady relationship, were non-heterosexual participants (only one heterosexual woman understood “partner” as a long term relationship, not “just somebody you kicked on the side with.”), indicating that a compounding factor may be the cultural use of the word “partner” to signify the long term, committed partner of lesbians, gays and bisexuals.

(Lesbian, when asked how she was interpreting the word)

Your lover, that's what it means. [Interviewer: Does it mean a steady long term relationship?] It does to me. Yeah, it does to me. [Interviewer: would you think that it would mean a one time episode? Or could it mean a one time episode?] No, not your partner. I wouldn't consider that as a one— you know, a night stand.

(Woman unresolved sexual identity)

When you use the word partner, I immediately think of lesbians and homosexuals, so I don't know if you really want to use the term partner or say partner or significant other, or something like that. Because otherwise I think people are going to think that you are asking a question designed only for lesbians or homosexuals.

(Bisexual man)

Someone that you was very close and comfortable with. You know, someone that you know, I mean, ... that's just not new to the situation.

(Bisexual woman)

I would have just read that to mean people you had sex with.... But it might be confusing to somebody just because ... it could mean "partner" like significant other, you know?

(Lesbian)

[I defined it as] people. But I can see where it might be construed otherwise. Well, especially in the— when you're talking about lesbians, you're talking about partners; you're talking about committed relationships. Lovers— I mean those words are all interchangeable— partner, wife, spouse, lover. I didn't take it that way, but it could be taken that way.

Recommendation: Because of the potential misunderstanding, we recommend changing the word "partner" to "people."

Again, we recommend re-evaluating the skip patterns for this section. Some women, even though they have had multiple sexual partners with other women, are skipped out of this question because they have never had sex with men.

SXQ.250. In the past 30 days, how many times have you had sex without using a condom?

Problem Overview:

- Many participants tended to only count "sex incidents" that they deemed as being unsafe. Some counted only anal or vaginal sex; others counted all forms. Therefore, the accuracy of the measurement may be reduced.

Discussion:

For this question, we observed another shift in the way participants defined the term "sex." Significantly, for this question, participants' interpretation of "having sex" appeared to be based on their condom-use practices. Those who reported using condoms for all forms of sexual encounters were inclined to include a broad range of sexual behaviors in their definition. Those,

however, who used condoms for only penetrative sex, tended not to include incidents of oral sex or manual stimulation.

(Broad definition)

[*Bisexual man uses condoms for any type of sexual encounter*] I gave it the same broad interpretation, and I interpreted that as I get excited and I'm with a sex partner, then I'll put on a condom and regardless of what we do, hoping to reduce the passing of body fluids from one person to another. So, unless I come before I can get that far, it's always my goal just to be protected.

(Broad definition)

[*Man defining himself as transsexual, who for all other questions excluded oral sex and defined "having sex" as only "penetrative intercourse with a penis," now includes oral sex*] Always. There are flavors now. Yes, grape, banana. They have all kinds.... And I insist because there's a couple who wanted to start and then wanted to take it off and I say "no, no."

(Narrow definition)

[*Gay man who, for previous questions had included oral sex, now excludes it for this question*] No, I mean, because like I said [we] really ain't... I don't consider what we do as having sex.

Participants (especially male participants) tended to view this question as inquiring about their susceptibility to STDs. Those that believed it was unnecessary to use a condom for oral sex, then, could easily interpret "having sex" (in this question specifically) as only penetrative sex:

That I took to as meaning penetration.... I didn't consider [oral sex].... You hear people waffling back and forth, still the general consensus is that oral sex is not as unsafe without condoms as anal sex. You tend to read things saying you should be careful both ways. You see studies go, well we have never proved anything that anybody's ever contracted HIV from oral sex. But I still think that's up in the air. You hear people saying different things, well that doesn't mean that's completely safe.

[*This bisexual man was uncertain how to define "having sex" for this question. Until this question he has used a broad definition*] I have had sex without a condom tons of times, but I never did anything risky, not anything kind of vaginal or anal penetration or anything like that. But, yes, but I was how do you say— I didn't give oral sex. I received oral sex.... Since this is a health institute I think you care about the public health issues and definitely there is a different risk of receiving oral sex and giving oral sex. There is almost no risk at least for HIV when you receive oral sex, but it is kind of a high risk when you give oral sex. Now, for the other sexually transmitted diseases I don't know how the risk levels are, but for at least HIV it works like that.

It is interesting to note that heterosexual women participants were not as inclined to view this question as an STD question, but rather as a contraception question. This is probably due to the fact that these participants tended not to have many sexual partners. The one heterosexual women who did have many partners, indeed, saw this as an STD question. On the other hand, those who did not, saw the question as a contraception question and, consequently, did not believe it was an appropriate question for women:

I'd probably say N/A, not applicable. Because I don't put condoms on. It's a male question. I mean, I did hear years ago that they have female condoms, but I've never seen one and I'm not sure I want to see one.

Finally, we also should mention that we found this question to have specific problems for both gay men and lesbian participants. For gay men, the question does not account for the fact that two men are involved. How should an incident be counted if one partner, but not the other uses a condom? For lesbians, the question is somewhat irrelevant if respondents are only having sexual relations with other women. For women that are not having sexual relations with men, the question's heterosexual implication can cause participants to re-think the terms of previous sexual behavior questions. That is, lesbians who considered the terms "vaginal, anal, or oral" as being inclusive of their experience, may now realize that the survey only really intended to count more conservative definitions that are exclusive of their experience.

Recommendation: In order to get an accurate assessment of condom-use, it is important to specify the type of sexual activity that is in question. It may also be helpful to have a different question for men ("did you wear a condom?") and women ("did the man wear a condom?").

Again, we recommend re-evaluating the skip patterns for this section. Women who have reported not having sex with a man in the past 12 months may still be asked this question.

SXQ.292/294. Do you think of yourself as heterosexual or straight (that is, sexually attracted only to women/men); homosexual or gay/lesbian (that is, sexually attracted only to men/women); bisexual (that is, sexually attracted to men and women); something else; or you're not sure?

Problem Overview:

- The question does not seem to pose problems for most heterosexuals. There were a couple, however, who needed the parenthetical definitions because they were unable to distinguish between the terms "heterosexual," "homosexual," and "bisexual."
- Response categories may be too limiting.
- Parenthetical definition conflates two analytically distinct concepts of sexuality, creating

a double-barreled question.

- The parenthetical statement may bias the question toward the response category “bisexual.”

Discussion:

Unlike the previous sexual behavior questions which seek an (ideally) objective measure, the conceptual interest of this question is respondents’ personal understanding of self— an inherently subjective concept. It is important to note that sexual identity, like racial identity, is a complex phenomenon. Research has shown that sexual identity is not necessarily concurrent with sexual behavior or desire, and that individuals’ sexual identities are not static or discrete conceptions of self (Institute of Medicine, 1999; Plummer 1995; 1981). Instead, sexual identity (as an understanding of self) is multi-dimensional, rooted in social and political contexts, and changes (sometimes multiple times) over the course of individuals’ lives (Stein and Plummer, 1994). Furthermore, as a subjective phenomenon, what actually constitutes “sexual identity” varies immensely among individuals. Community ties, cultural and political values, friendship relations as well as sexual behavior and desire have all been identified as central components of sexual identity (Esterberg, 1997; Stein, 1997). Consequently, individuals’ sexual identities do not necessarily conform to discrete, objective, and uniformly-defined categories. Given this, we would be remiss if we did not acknowledge that it is somewhat problematic to quantify the concept of sexual identity. Our goal, then, is to construct a question that most accurately reflects the concept, produces little response error and is relevant and accessible to respondents.

One problem that we found (related to the subjective and fluid character of sexual identity) is that the question’s response categories were potentially limiting. In a couple of cases, the categories did not entirely reflect the participants’ particular self-understanding. One woman, for example, reported that the question was difficult to answer because she was “in the process of coming out”— a process that began in the mid ‘70s:

Well, I mean, I’m in the coming out process. Well, I’m in a coming out process. I’ve made many, many attempts to get involved with lesbian groups or women. But you know back in the mid ‘70s— see, when I was 21 after a year I knew that I didn’t want to be involved with men. So then I started going to lesbian groups, but they were so damn militant back then, full of so much hatred and anger. And I thought, oh my God, this is going to destroy me... That was around, say, ‘72 to ‘74. And then about 10 years later, ‘82 to ‘84, I started corresponding with lesbians through [a lesbian group] in Washington... I don’t know if [the group] exists anymore, but I was writing to women from all across the country. And then I met my husband....

Even though she currently belongs to several lesbian organizations and has told many people (including her husband) that she is a “lesbian,” the question was not straight-forward. Many gay and lesbian participants also corroborated this type of problem, noting that their answer would have differed at another point in their life and that they (like this woman) endured a long

transition period before they actually identified as “gay” or “lesbian.” Recognizing that the question may pose a problem for those in “the coming out process,” several gay and lesbian participants recommended adding the response category “Questioning.”

Similarly, another participant who defined his sexual identity as “transgendered,” expressed concern that this particular category was also overlooked by survey designers. He ultimately answered “Other,” a response that he deemed inadequate, and recommended adding a “Transgendered” category. While the suggestions for adding these two response categories may improve this question, we are unable to make this recommendation without further investigation.

Another particular problem involving the response categories was first discovered by NHANES when the question was fielded. Not all respondents, they found, could distinguish between the terms “heterosexual,” “homosexual,” and “bisexual.” Originally (as we understand), the question was modeled after Laumann’s (1990) national sexuality survey, in which the question simply asked, “Do you think of yourself as heterosexual or straight; homosexual or gay/lesbian; bisexual; something else; or you’re not sure?” When this question was fielded, however, a handful of respondents (typically lower income/lower education) emerged from the audio-CASI booth and indicated that they could not answer appropriately because of unfamiliarity with the terms. According to field representatives, respondents asked, “Which one is normal?” Therefore, the parenthetical definition (as seen presently in the question) was added for those participants.

In this round of cognitive testing, we also found evidence to suggest that there may be comprehension difficulty among some respondents. In the interviews, two participants stated that they were confused by the terms “heterosexual,” “homosexual,” and “bisexual” and indicated that the parentheses were indeed helpful. One heterosexual woman, for example, reported:

I know what gay is, but there are a couple of terms that I don’t understand. Bi and [*participant did not know how to pronounce the word heterosexual*] heteral... are the two [words] that confuse me. That kind of thing, so you need to put the parentheses in there.

Another woman confirmed that, until recently, she did not know the meaning of the word “heterosexual:”

Because, see, back when I was in high school I’d never heard of heterosexual. Now the word straight, I had heard the word straight.... But I think like in the ‘90s, the mid-90s, yeah. I started hearing the word because I was watching a show, something about heterosexual and I looked it up [in the dictionary].

Because all of our participants are from a larger metropolitan area, we are somewhat concerned that this comprehension problem may be greater among survey respondents, especially those from more rural, poorer areas. We agree with NHANES staff that the question, in its previous

form, is not ideal.

However, adding this particular definitional statement (with an emphasis on sexual attraction) dramatically changes the parameters of the question and creates another type of response problem. First, we should note that many participants (both heterosexual and non-heterosexual) indicated that they did not even notice the statement. In their response process, they simply saw the category with which they strongly identified and, ignoring all other information, responded accordingly. For these participants, the parenthetical statement did not pose a problem. However, for some non-heterosexual participants the parenthetical definition actually generated difficulty in the response process, even causing error in one case.

Most critically, the parenthetical definition interjects another distinctly separate dimension of sexuality, creating a double-barreled question. Participants (particularly lesbian and bisexual women) repeatedly stated that attraction should not be the definition of being lesbian; this definition simply contradicted their own personal experience. One bisexual woman, for example, reported:

I had problems with it because I don't know that attracted should be the definer for the identity because I was just with a lesbian friend of mine last night who was telling me about having sex with a man. And this is about the 20 hundredth time that has happened to me. And she is a lesbian. And she will adamantly tell you she has "lesbian sex" with a man. So attraction is not the definer.

One gay man even stated that he thought the parenthetical definition was "dangerous" and that federal surveys are doing a disservice by promoting uninformed conceptions of sexuality:

I personally have an issue of how that definition is phrased because I don't think being heterosexual, homosexual, or bisexual is limited just to sexual attraction. I think there is an emotional... part of your homosexual or bisexual or heterosexual identity. Asking a question like that really I think is dangerous, especially for people who are homophobic because it just perpetuates the notion that being homosexual or bisexual is just about sex, and it's not.

Because of the double-barreled components, those participants who identified as gay or lesbian and who also felt sexual attraction for both genders, could only respond to either the sexual identity component of the question or the sexual attraction component. If participants responded to the identity component, answering the question meant breaching the provided definition. For example, after reporting in her interview that she answered "lesbian" in her response, one woman stated:

So you're thinking, "but she just said she slept with men— one in the last year." See, to me, sexuality is more than just who you sleep with. In fact, it's more about emotion or it's equally about emotion, not just sex. So, I could never imagine myself in a relationship with a man, but I do occasionally sleep with

one.... [As far as answering the question], I thought I can't answer this any other way aside from "lesbian" because of what I said before about the emotional part of it, because I could never imagine being in a relationship with a man. [Interviewer: So, basically, you had to discount the parentheses?] Kind of, yes, because I do... in reality, I am occasionally attracted to a man. [Interviewer: Were you at all inclined to put bisexual?] For like a quarter of a second I looked at that, but that was it. I can't define myself that way. [Interviewer: And you say you've been defining yourself that way for 20 years now?] That's right. As a lesbian.

Similarly, a bisexual woman explains that she also had to disregard the statement:

[My bisexual identity] is something that I like have an affinity for. I like the idea of it, and... it's connected to other parts of my identity, but just feeling like I'm in the middle and feeling like I'm not quite one or the other. I'm also bi-racial, so it's like the same kind of thing to me to like embrace both of the things and neither at the same time. So, I mean I feel very strongly connected to that identity. So, even though the definition was not clearly how I define myself, like I don't really feel equally attracted. I mean I definitely wanted to write that I was bisexual.

These two participants, while recognizing the incongruence, dismissed the sexual attraction component of the question and, with little hesitation, responded to the identity component. Conversely, two men (both identifying as "gay") attempted to base their answer on the question's sexual attraction component. Because they had been sexually involved with both genders in the past or because they had felt some attraction to both genders, the question was not as straight-forward:

Well, actually, the more I think about it, it's kind of hard because [in the beginning of my life], well, when I was younger and beginning my sexual life, I guess, it was with mostly women. And then the later part of my life, it's been entirely with men.

I actually had to think about that because I can be... sexually attracted to a person of the opposite sex. I could be attracted to them because, you know, they have beautiful features or something. That doesn't mean I'm sexually attracted to them. So I had to think about that.

Because many people do not exclusively experience attraction toward one gender, the parenthetical statement may actually bias the question, directing respondents toward the "bisexual" category— even though their self-identity is gay or lesbian. Similarly, we might also suggest that some heterosexually-identified respondents may also be erroneously directed toward the "bisexual" category because of the added sexual attraction component.

Finally, we should acknowledge that this question may be potentially sensitive for two

reasons. First, because of stereotyping and discrimination, some respondents may not want to reveal their sexual identity to unfamiliar or unknown sources. We, however, are unable to determine whether or not this is really an issue and whether the question itself would elicit a substantial under-report of lesbian, gay, and bisexual (LGB) respondents. While all of our participants stated that they did not have a problem answering the question, a few also indicated that other LGB respondents might regard the question as being sensitive and noted that it is probably beneficial to ask the question in the audio-CASI format.

Perhaps more importantly, this question is potentially sensitive because the content of the question is about personal understandings; people have strong opinions about how they want to be seen and what they want to be called. As discovered in questions regarding racial identity, using inappropriate, irrelevant or out-dated categories or terms can be interpreted as offensive or presumptuous. A number of gay and lesbian participants, for example, stated that they did not use the term “homosexual.” Similarly, the transgendered participant did not appreciate having to answer “Other” for his sexual identity. Just as race categories need to reflect the historical time period, sexual identity questions also need to be relevant and current.

Recommendation: We recommend eliminating the parenthetical definition and switching the response category labels to “straight or heterosexual,” “lesbian, gay or homosexual” (for women), and “gay or homosexual” (for men). We also recommend providing supplemental material, either with the FR or in help screens on the computer, that more thoroughly clarifies the problematic terms. Finally, we recommend considering further testing that investigates the addition of the categories “Questioning” and “Transgendered.”

KN-1. People are different in their sexual attraction to other people. Which best describes your feelings? Are you...Only attracted to females, Mostly attracted to females, Equally attracted to females and males, Mostly attracted to males, Only attracted to males, or Not sure

Problem Overview:

- Participants’ were not always able to articulate a clear conceptualization of the term “sexual attraction.” Additionally, interpretations seemed to vary among participants. Therefore, the accuracy of this measure may be reduced.

Discussion:

Although we probed extensively in the interviews, it is unclear how participants actually interpreted the term “sexual attraction” and what sort of information they actually considered when forming their answer. Some participants were simply unable to fully articulate a conceptualization of sexual attraction, and their descriptions tended to be relatively ambiguous. For example, one woman attempted to explain:

If you like... when you’re around him, you know, ... if you liked somebody when

you're around them. It's just something that you... I forgot what they call it... something that you get inside you. I forgot what they call it though.

Others with less ambiguous interpretations described attraction in a variety of ways: “who you have sex with,” “who you want to have sex with,” “who you are aesthetically drawn to,” “who you are emotionally drawn to,” and “who you want to be in a relationship with.” Lesbian participants, in particular, tended to focus their description of “sexual attraction” on “emotion,” “intimacy,” “being drawn to,” and “desiring a relationship” with another person. One lesbian explained:

It's easier for me to relate on an emotional level with a woman than a man. I don't see all those things with men, I just don't, which is why I won't be in a relationship with a man. I guess it's easier to see the intelligence in a man than it is to see the sensitivity or even the sensuality.

Some participants (both heterosexual and non-heterosexual) stated that, in forming their answer, they needed to make a distinction between “attraction” and “sexual attraction.” For example:

Gay man: I can see a female and think she's attractive.... So, I had to think about the purpose of the question to just finally, you know, [answer].

Gay man: There's a bunch of beautiful women in the world, but I don't think of them as a sexual object. I just think of beauty.

Because the previous question also asked about sexual attraction, several participants stated that they did not see any difference between this and the last question. Other participants noted that they appreciated this question more because the response categories were scaled. Notably, some participants, who were forced in the previous question to answer “only attracted to...,” were now able to indicate that they were “mostly attracted to...”

Finally, it is important to note that because of the ambiguity around the term “sexual attraction” and because of prevailing negative attitudes surrounding same-gender attraction, respondents who do not already have a well-defined LGB identity may not be inclined to report having same-gender attraction.

Recommendation: Although we are not entirely certain what respondents considered as they responded to the question, we recommend keeping the question because it is considered one of the three dimensions of sexual orientation in current sexuality literature. It may, however, be advisable to continue a more thorough investigation into the meanings associated with this word as well as the cognitive processes respondents use to answer the question. Finally, because the terms “male” and “female” appear overly clinical and biological we recommend changing the word “females” to the word “women,” the word “males” to “men.”

General comments about prostate section: Some of the medical terms in the prostate questions are potentially unfamiliar terms to respondents. Several participants expressed frustration because they were unfamiliar with some of the more technical terms, such as “benign enlargement” or “prostate specific antigen.” Additionally, the concepts of “disease,” “infection,” “inflammation,” and “enlargement” were not necessarily understood by participants as distinct concepts. Most particularly, some did not know the difference between “inflammation” and “enlargement.” Because they may need clarification, it may make better sense to have these questions in the face-to-face interview, or at a minimum it may be helpful to provide a simple definition of prostate gland prior to this set of questions or in help screens for those who are not familiar with the prostate.

Finally, a few participants expressed that the prostate questions seemed inappropriately placed next to the more sensitive questions about sexual behavior:

Isn't there at least some tiny little risk of fetishizing that issue in ways that it doesn't need to be fetishized like suggesting that there's something more sort of secretive about prostate cancer as opposed to colorectal cancer, you know.

KIQ.105. Have you ever been told by a doctor or health professional that you have any disease of the prostate?

Problem Overview:

- Several participants did not know whether an enlarged prostate should be included as “disease of the prostate.”

Discussion:

Participants primarily interpreted the term “disease of the prostate” as having cancer. When asked what other conditions would qualify, some mentioned symptoms or conditions ranging in degree of seriousness: “prostatitis,” “inflammation,” “an enlarged prostate,” “a urinary tract infection,” “some type of irregularity,” and “bacterial or viral disease.” At the same time, however, other participants stated that they were uncertain as to what would actually qualify as a disease:

“Prostate cancer is pretty much the only— I mean I know there’s more, but that’s the only one I know as far as a general.”

“Well, when it says disease of the prostate, would that include an enlarged prostate gland as opposed to prostate cancer or a disease?”

Most notably, like the participant above, some wondered if having an enlarged prostate should be counted as having a disease. For one of our participants diagnosed with an enlarged prostate, answering the question involved the added step of figuring whether or not to include this

condition:

I had to pause and think because I had been told I have an enlarged prostate and I didn't know if that is considered to be a disease or not or a condition, but as far as ever being told was it infected or something like that. So, I had to think about that just slightly. But, I decided that, you know, disease of the prostate's much more involved than just having a digital and telling you that it's enlarged and having -- and knowing the other tests came back, you know, indicating that it's -- it's not diseased. So, I sort of, you know, had to do a logic.

Recommendation: While no one to our knowledge answered this question incorrectly, if possible, we suggest using more specific words to avoid confusion and to make a more simplified response process. Listing the specific type(s) of disease(s) instead of using the more generic term “disease” may be more clear-cut to respondents. For example, if the question is intended to elicit cancer (the way in which it is primarily being interpreted), the word “cancer” may be a better substitute.

We also recommend specifying whether an enlarged prostate is to be included at the end of the question.

KIQ.115. Do you have an infection or inflammation of the prostate gland at the present time?

Problem Overview:

- Several participants did not know whether an enlarged prostate should be included as “infection or inflammation of the prostate gland.”

Discussion:

While no one indicated that cancer should be included as “an infection or inflammation,” many of the secondary symptoms that were included in the first question were also included in this question. A few participants, themselves, commented that they did not see any difference between the first and second prostate questions. As in the previous question, symptoms included “problems with urination,” “prostatitis,” “an irritation,” and “a condition causing it to not operate correctly.”

Again, the problem of whether or not an enlarged prostate would qualify surfaced; those participants with an enlarged prostate were impelled to define “an infection or inflammation” before forming an answer.

Recommendation: Again, to ease the response process, we recommend specifying at the end of the question whether an enlarged prostate should be included.

Have you ever been told by a doctor or health professional that you had an enlarged prostate gland?

Problem Overview: None.

Discussion:

While there were some participants who were unfamiliar with the term “enlarged prostate,” the lack of understanding did not cause difficulty for participants. To the best of our knowledge, those who were told by their doctor that they had the condition were aware of the terminology and could easily answer this question.

Recommendation: We recommend leaving the question as it appears.

KIQ.140. Was it a benign enlargement, also called benign prostatic hypertrophy?

Problem Overview:

- Respondents may not know the definition of “benign.” One participant believed that “benign” meant cancerous.

Discussion:

The vast majority of participants were unfamiliar with the terms “benign enlargement” and “benign prostatic hypertrophy.” Most admitted up front that they had never heard of the terms (including one of the three participants who were diagnosed with enlarged prostates) and had to construct an interpretation based on their knowledge of the word “benign.” For example:

Participant: See, I don't understand. I don't understand that.

Interviewer: Okay. What does the benign part mean? You said you did know what that means.

Participant: As far as I mean my understanding is that it's okay.... I ain't sure that's [benign prostatic hypertrophy] even English.

While most participants understood the word “benign” as being non-malignant, one participant with an enlarged prostate believed the word actually meant cancerous and responded incorrectly:

Interviewer: What does the term benign mean to you?

Participant: Well, benign means that it could be cancerous, you know, and I could be wrong on that, but benign to me means that you had cancer.

Additionally, several participants expressed frustration because the question used words that were not easily understandable. While they sincerely wanted to provide accurate and truthful information, their unfamiliarity with particular concepts undermined their ability to do so:

My gut feeling is that question there, unless I knew what it was, then I'm either not going to answer it, or the answer is not going to be truthful, or either I'm just not going to know, you know. I'm either not going to know or I can't answer the question truthfully.

Recommendation: Because unfamiliarity of terminology may not only frustrate respondents but may also lead to inaccurate responses, we highly recommend providing a simple definition of “benign enlargement.”

KIQ.320 Have you ever had a blood test that your doctor told you was being used to check for prostate cancer, called PSA, or Prostate Specific Antigen?

Problem Overview: None.

Discussion:

While younger participants tended to be unfamiliar with the terms “PSA” and “Prostate Specific Antigen,” participants over the age of 40 years were typically aware of the test and were able to easily answer the question. We did, however, identify one potential source of error: one participant said that he has had many blood tests but answered no because he was not certain of the tests’ purpose.

Recommendation: We recommend leaving the question as it appears.

KIQ.340. Have you ever had a rectal examination?

Problem Overview:

- Question does not clarify type of exam.

Discussion:

All participants were familiar with the word “rectal.” Additionally, all participants conceptualized the term “rectal examination” as a digital rectal exam. One participant, however, noted that there were several types of rectal exams (digital and colonoscopy) and that the question did not clarify the type of exam.

Recommendation: Although all participants in this series of interviews were familiar with the term “rectal,” we suspect that some respondents may be unfamiliar with the term. Therefore, we recommend a brief description to clarify both the word “rectal” and the type of exam. For example: “A digital rectal exam is when a finger is inserted in the rectum or butt to check for problems. Have you ever had a digital rectal exam?”

KIQ.400. Many men experience problems with sexual intercourse. How would you describe your ability to get and keep an erection adequate for satisfactory intercourse. Would you say that you are... Always able or almost always able to get and keep an erection, usually able to get and keep an erection, sometimes able to get and keep an erection, never able to get and keep an erection?

Problem Overview:

- Participants held differing conceptions of the term “satisfactory intercourse,” thereby possibly reducing the accuracy of the measure.

Discussion:

All participants reported that the question was clear and easy to answer. There was, however, little variation in participants’ responses (only two participants reported “usually able” while all others reported “always able),” and we wonder how carefully or accurately our participants actually considered the question. In the interviews, we obtained relatively little information that allows us to judge whether or not the question can adequately measure this phenomenon.

We were, however, able to discern the ways in which participants made sense of the question by asking how they were interpreting the term “satisfactory intercourse.” In keeping with the focus of the question, participants primarily mentioned the ability to penetrate, incorporating the “ease of the erection” as well as the “length of time able to sustain.” Others also referred to ejaculation as an important aspect of “satisfactory intercourse.”

For a relatively reasonable length of time as opposed to having a premature ejaculation and being able to achieve an erection.

Well, is it an erection that is satisfying to a person? I mean, are you comfortable with having that erection, you know, if you're in fact being stimulated. Is that an erection that, you know, you would have to fight for or is it an erection that you're comfortable with, an erection that would come between you and your partner.

That to me meant experiencing prolonged sensation and coming to a climax and where you ejaculated semen.

We also found that because of the use of the word “satisfactory,” some participants were inclined to perceive a more subjective component in the question:

I would interpret that as meaning you're satisfied with it so it's a floating definition based on each person....

I think satisfactory would mean that at minimum, you were able to engage in some sort of insertive behavior, but I can see there's some ambiguity, and I would

adjust that question, what satisfactory might mean for some.

Recommendation: It may be advisable to omit the word “satisfactory” because it adds a subjective dimension which may vary among respondents.

DUQ.100. Have you ever used cocaine, including crack or freebase, or other street drugs? Do not include marijuana.

Problem Overview:

- Participants’ definitions of “street drugs” were relatively ambiguous and varied (e.g. some included illegally obtained prescription drugs while others did not).

Discussion:

Notably, participants did not have entirely clear or consistent interpretations as to what constituted a street drug. While many participants held particularly broad conceptions of a “street drug” (e.g. “anything that’s illegal,” “if it causes harm”), others definitions were relatively restrictive. One participant with an especially narrow conception, for example, stated that he did not identify illegally obtained prescription drugs as a street drug. He continues:

I wouldn't think of sleeping pills— I mean I'm thinking more of the upper-type, speed— or those kinds of drugs people do to bring them up, rather than bring them down.

Still others held extremely broad interpretations:

I sort of interpret [it] broadly. As I get more information about something [I try] trying to place it in a category. So, you know, party drugs and all sort of fall in that umbrella -- big umbrella called street drugs. It's something that somebody would buy to get a response. So, even if it's glue.

One participant noted that, by using the generic term “street drug” in the question, some respondents may not include some drugs that he believes really should be included:

I think the way it's worded someone could with all intentions of answering your questions honestly, would say— who may have, you know, guzzled Robitussin could say no because that's— Robitussin is not a street drug. So if you wanted to know that, you'd have to ask a different question I think.

Recommendation: Because participants’ conceptions of “street drugs” are relatively ambiguous, relying heavily on the term can cause potential inconsistencies in responses. Some participants may include specific types of drugs that others may omit. Providing clearer definitions or specifying the particular drugs in mind can help to alleviate this problem. For example, additional examples can be provided to help set the parameters of what may constitute a street

drug: “Have you ever used cocaine, including crack or freebase, LSD, heroin, illegally obtained prescription drugs... , or any other street drugs?”

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Appendix A Participant Demographic Tables

Women

Sexual Identity	Age	Hispanic	Race	Education (in years)	Employed	HH Income
Lesbian	35	No	White	13	Yes	>30 K
Questioning	50	No	White	18	Yes	<30 K
Lesbian	28	No	Black	14	Yes	<30 K
Heterosexual	31	No	Black	12	Yes	<20 K
Bisexual	52	No	White	19	No	<20 K
Gay	38	No	Black	9	No	<20 K
Bisexual	37	No	Black and White	19	Yes	>30 K
Heterosexual	32	No	Black	13	No	<20 K
Lesbian	45	No	White	13	No	<20 K
Lesbian	29	No	Black	16	Yes	>30 K
Heterosexual	40	No	White	16	Yes	>30 K
Lesbian	39	No	Black	16	No	<20 K
Heterosexual	41	No	White	13	Yes	<30 K
Heterosexual	48	No	Black	12	No	<20 K
Lesbian	35	No	White	16	Yes	>30 K

Men

Sexual Identity	Age	Hispanic	Race	Education	Employed	HH Income
Gay	39	No	White	14	No	< 20K
Gay	52	No	White	16	No	> 30K
Heterosexual	35	No	Black	16	Yes	> 30K
Bisexual	30	Yes	White	18	Yes	< 20K
Heterosexual	40	No	Black	13	Yes	< 20K
Bisexual	38	No	Black	13	Yes	< 30K
Heterosexual	53	No	Black	16	Yes	< 20K
Heterosexual	36	No	White	18	Yes	> 30K
Gay	40	No	Black	12	Yes	< 20K
Gay	41	No	Black	13	Yes	< 20K
Gay	30	Yes	White	16	Yes	> 30K
Gay	56	No	Black, White, American Indian	16	Yes	< 30K
Gay	23	No	Asian	16	Yes	< 20K
Heterosexual	47	No	White	13	Yes	> 30K
Gay	40	No	White	16	Yes	> 30K