

Testing of Sexual Identity and Health Related Questions Results of Interviews Conducted May-July 2005

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Introduction

This report summarizes findings from the evaluation of common demographic questions, as well as questions regarding sexual identity. The data used in this analysis came from a larger project conducted by the Questionnaire Research Design Laboratory (QDRL) at the National Center for Health Statistics (NCHS). This project was commissioned to develop questions regarding sexual identity for future NCHS health surveys.¹ A copy of the questionnaires used during testing can be found in the appendix. The main goals of the project were to 1) assess respondents' interpretations of the survey questions and gain a better understanding of the processes respondents engaged in when responding to the questions and 2) identify any potential problems in the question response process that could lead to error in the survey data. The project was funded, in part, by the Ford Foundation, the CDC Division of Smoking and Health, and the National Center for Health Statistics (NCHS). The following section outlines cognitive testing methodology and describes how analysis of the data was conducted. The final section of the report provides a general summary of the research findings followed by a question-by-question summary of the findings.

Methods

Sample

For this project a purposive sample of respondents was recruited, ensuring a diverse sample of sexual orientations and genders. Two rounds of cognitive interviews were conducted. In the first round of interviews, 17 respondents were recruited from an LGBT community center; all interviews were conducted off-site at this location. The majority of respondents in the first round of testing self-identified as gay, lesbian or bisexual and 4 of the 17 respondents identified as transgendered. Recruitment in the second round of testing respondents was done by contacting participants from past QDRL

¹ Questions regarding general health, access to healthcare, cancer screening and health insurance were also tested during this project, however results are not presented here.

projects All interviews in this round were conducted at NCHS (n=20). The majority of these respondents self-identified as heterosexual; no respondents in this round reported being transgender. See Table 1 for sample characteristics.

Table 1: Demographic summary of respondents in total and for each round of testing

	Round 1 n=17	Round 2 n=20	Total(%) N=37
Sexual Identity			
Heterosexual	2	19	21 (57%)
Gay/Lesbian	11	0	11 (30%)
Bisexual	1	1	2 (5%)
Other	3	0	3 (8%)
Age			
Under 35	7	2	9 (24%)
35 & Over	9	18	27 (73%)
DK	1	0	1 (3%)
Gender			
Female	4	14	18 (49%)
Male	8	6	14 (38%)
Transgendered FTM	3	0	3 (8%)
Transgendered MTF	2	0	2 (5%)
Race/Ethnicity			
Hispanic	6	0	6 (16%)
NH-White	9	9	18 (49%)
NH-Black	2	11	13 (35%)
Native American/ Alaska Native	3	0	3 (8%)
DK	3	0	3 (8%)
Education			
High school or less	5	10	15 (41%)
More than high school	11	9	20 (54%)
DK	1	1	2 (5%)
Income			
Under 20,000	8	3	11 (30%)
20,000 and over	7	14	21 (57%)
DK	2	3	5 (14%)

Interviewing Procedures

Cognitive interviewing is a qualitative question evaluation method used to uncover potential response errors that can occur during the question response process that may not be readily apparent. These include problems with comprehension, recall, decision processes, and the mapping of response onto the survey question (Willis 2005; Tourangeau, Rips, and Rasinksi 2000). Additionally the method can be used to determine the validity of survey questions. That is whether questions measures the constructs they were intended to capture (Miller, 2009).

During the interviews, retrospective, intensive verbal probing was used to collect response process data, that is, respondents were first administered the questionnaire in its entirety, and then interviewers returned to each question for retrospective probing. Probe

questions including such things as: Why did you answer the way you did? Can you tell me more about that? What do you think this question is asking? All interviews were video taped; the video and interview summaries were used to conduct the analysis.

Data Analysis

Data from the interviews were analyzed using qualitative techniques, specifically, the constant comparative method (Lincoln and Guba, 1985; Strauss and Corbin, 1990; Creswell, 1998). Patterns of question interpretation and cognitive processing problems were identified. The first step of data analysis, open coding, entailed reviewing the data and assigning codes to analytic categories found in the data. Next, we performed axial coding, which involved refining the themes/categories that emerged from open coding. In order to specify the dimensionality of the themes/categories we compared respondents, whose narratives were assigned similar themes/categories, resolving any discrepancies between the themes/categories and noting similarities. Additionally, we examined the relationship of the themes/categories to each other. Finally we performed selective coding, which involved specifying the core themes that emerged from the analysis. These core themes served as the unifying link between all the themes/categories, and denoted a working theory that depicts the phenomena captured by the survey questions.

Summary of Findings

The questions examined in this study include standard demographic questions used on population-based surveys to measure sex/gender, race, ethnicity, education, marital status, and sexual identity. Demographic questions are often perceived as straight forward questions that perform consistently as intended, and require little, if any, cognitive processing. While for many of the respondents in our study, this was indeed the case, for other respondents these questions were more complex and difficult to answer. Often this difficulty stemmed from underlying assumptions in the question.

Many of the questions assume a uniformity in experience. However, as found in this evaluation there is often variability in experiences across respondents. Specifically, many of the questions assumed conformity to traditional and discrete pre-determined categories, such as the male-female dichotomy. However, for those respondents whose experience operates outside those categories (e.g. the transgendered respondents whose gender identity have shifted), the questions were not straightforward. Whenever a respondent's personal experience did not fit into the discrete categories, they were required to spend more time thinking about the question's intent and work, to the best of their ability, to provide an answer that would satisfy that intent. Interestingly, this was also true for some of the heterosexual respondents answering the sexual identity question. Rather than having a salient sexual identity, these respondents often formed what is referred to as "not-me identities," which constructed through a process of disidentification with an often stigmatized group (McCall 2003) – in this case a gay identity. Because of this, heterosexual respondents had difficulty understanding many of the terms used in these questions, which at times prevented them from providing valid responses. Gay and lesbian respondents, on the other hand, had no difficulties with the sexual identity question.

For many of these questions, then, to accurately capture information on one group of respondents necessarily means sacrificing the validity of the information gathered on other groups. This problem is particularly difficult to address when questions work well for a large majority population group, but are problematic for small minority groups within the population. For example, while the gender question works extraordinarily well for most—and would not be prudent to change, it does not provide a response option for the transgender population. Conversely, some questions may work well for a minority of the population, but be problematic for majority groups, as is seen in the sexual identity questions. While these questions are written to accurately capture the gay and lesbian population, those respondents who are not familiar with the terms used in these questions (typically lower SES respondents, heterosexual respondents) sometimes ended up placing themselves in the other category or providing no response. Ideal questions would account for the diversity of experience, conveying both perspectives.

Question by Question Review

Are you male or female?

- 1 Male
- 2 Female

Two major findings emerged during the evaluation of this question. First, respondents interpreted this question as asking about two different constructs: biological sex and gender. Additionally, this question was found to have an underlying assumption that sex/gender is discrete and static. This was particularly problematic for respondents who were in fact transgendered. The following will discuss these findings in more detail.

As stated above respondents interpreted this question in one of two ways: 1) as asking about biological sex or 2) as asking about gender. The majority of respondents interpreted this question as asking about their biological sex. When asked why they answered the way they did these respondents often provided responses that indicated that their physical anatomy marked them as either male or female. For example a common response to probing on why they answered the way they did was:

“I mean I know what I was born as.... Because of my physical body parts and everything. I don’t have the same organs that a male has. I’ll put it that way. Such as men have different body parts than women.”

However a small minority of respondents interpreted this question as asking about gender, rather than biological sex. When asked why they answered this question the way they did these respondents often discussed gender specific roles and their enactment of those roles. For example common responses to probing on why they answered the way they did were:

“(to be female means) to be feminine, makeup, nails, manicures, being concerned with what’s going on with your body – healthwise, going to the doctor. Do that more than guys do.”

“Well, I think the general things come in first, wife, mother, cooking, cleaning, housework.”

For respondents whose biological sex and gender were congruent and consistent over time this question was very easy to answer. These respondents often gave quick, automatic responses that required little thought on their part. For example, when asked why she answered the way she did one woman replied, “Basically because I was. (laughs) Why would I think any other way? I never think about it.” In fact, some respondents thought it was strange that they would even be asked this. Furthermore, for these respondents the validity of their responses was not dependent upon whether they interpreted this question as asking about their biological sex or their gender, as these two constructs were congruent. However, for respondents who were transitioning sexes/genders this interpretation was significant in terms of how they answered the question.

In fact, this question was not so straightforward for respondents who were transitioning genders or who had already transitioned. First the ambiguity of the question intent was particularly problematic for transgendered respondents as their biological sex did not necessarily equate their gender. While some transgendered respondents had no difficulty answering this question because they simply interpreted it as asking about their gender or their sex and answered based on that, other transgendered respondents had a difficult time deciphering the question intent and formulating a valid response as their sex and gender were incongruent, or if they were congruent had shifted over time. For example, one respondent who ultimately answered “male” to this question discussed the following.

“[male] seems closer to my identity certainly than does female, on an internal gender identity perspective, in terms of my gender identity. Biologically, with the exception of hormones I take into my body and some of the surgical procedures I have had on the upper part of my body, I would still be perceived as female, chromosomally, as well as in terms of other aspects of my anatomy.”

Several respondents expressed desire to report their sex/gender as transgendered.

“[Transgender] probably would be a better way to identify myself. Because, I think it’s tricky, because my documents say female currently and yes eventually after I go through certain physical things, they will be changed to male. So it’s always whether I put what it says on my legal records or what I actually is. If it says transgender FTM...that would state exactly that legally I’m considered female and that could change.”

One respondent did initially respond “transgender” to this question, adding,

“A transgender female, I’m a pre-op transsexual female. I’ve been on hormones for 22 months. I’m getting ready to get my letter to go in for surgery. You get a letter saying they feel that you’re ready for surgery, and psychologically fit to go through surgery.”

In addition, one respondent noted the importance of being able to mark transgender on a health surveys in particular.

“I could say that I’m male and be comfortable with it but it would miss a lot about my history and my health care and why I access health care so much. If forced, I’d pick male because that’s my current sex.”

Having the ability to indicate that they are transgendered has important implications for understanding their current health status, as well as their medical histories.

Some respondents interpreted the question as asking about biological sex, while others interpreted it as asking about gender. This ambiguity did not cause response error for respondents whose sex and gender were congruent and static over time. However, this question was far more complex for respondents who have transitioned or are transitioning genders. Given the limited response options provided and the fact that respondents are only allowed to select one response option did not allow transgender individuals to fully express their sex/gender history.

2. Are you now married, widowed, divorced, separated, never married or living with a partner?

- 1 Married
- 2 Widowed
- 3 Divorced
- 4 Separated
- 5 Never married
- 6 Living with a partner

For most respondents, particularly those who identified as heterosexual or straight, this question was uncomplicated and easy to answer. Respondents often gave quick answers to this question exhibiting no difficulty and little hesitation. In fact several respondents answered this question before the interviewer had completed asking it. For respondents who were heterosexual, these response categories appeared to adequately describe their lived experiences. However, for one heterosexual respondent this question was found to be problematic. This respondent was both divorced and currently living with a partner and, therefore, she wanted to select both of these response categories, as they both were valid responses.

While this question worked well for most heterosexual respondents, it was problematic for respondents who identified as gay or lesbian. Among these respondents the majority of them reported that they were either never married or living with a partner however, some of the respondents struggled with this question because the response options did not adequately fit their experiences. For example, one respondent, who

identified as gay, initially replied to this question “never married,” however he didn’t feel that this question captured his current status.

“This question, really quick, that also could be a little limiting. Why isn’t there single on there? I mean that, I’m just wondering. Because when I answered that I actually had to think about it for a second. Only because I have a partner but we’re not, we don’t live together, so, but you know what I mean? And I wouldn’t consider myself- I would say partnered but I don’t know if that’s there.”

Because same-sex marriage was not available to this respondent, “never married” isn’t really a status that pertains to him. Therefore, while he is able to answer this question, and his answer is valid in the sense that he has never married, it is incongruent with his own lived experiences.

Similarly, another respondent, who identified as a lesbian, replied to this question “Uh with a partner but I don’t live with her. I stay with her once in awhile. I have my own, she has her own.” This respondent had difficulty selecting a response from the options given. This respondent is partnered but she does not currently live with her partner, and because it is not a possibility for her to marry her partner, she doesn’t consider “never married” a valid response for herself. Additionally, she has had long-term relationships with women, which she considers to be the equivalent of being married, despite the fact that they were not legally recognized as such.

“You know what, I’ve been in relationships but not married, but long term relationships, like 10 years, 6 year relationships, so for me I don’t think I got to go in front of somebody and sign a paper and all of that to be married, that’s just for me. Because you know what there’s uh, for instance, a straight man and woman they live together and common law, so why can’t it be like that for two women? It feels like a marriage when it’s long term like that.”

Ultimately this respondent ended up choosing “living with a partner” as it was the one response option that she felt best fit her situation.

In sum, this question worked well for heterosexual respondents, however, for respondents who identified as gay or lesbian, this question was problematic as the response options did not adequately reflected their own lived experiences.

3. Do you consider yourself to be heterosexual or straight, gay or lesbian, or bisexual?

- 1 heterosexual or straight
- 2 gay or lesbian
- 3 bisexual

This question was intended to capture sexual identity, and in fact we found respondents, particularly those who identified as gay, lesbian, and bisexual interpreted this question as such. Although respondents who identified as heterosexual also interpreted this question as asking about their sexual identity, their responses were based

on disidentification from a gay identity, and for them, this identity was based solely on their own sexual behaviors and attractions. Finally, although transgendered respondents interpreted and responded to this question in a similar way as gay, lesbian and bisexual respondents, their response also took into account where they were in the gender transition process, which at times made it difficult for them to choose a response. The following section will describe these patterns of interpretation in more detail.

Respondents who self identified as gay, lesbian, and bisexual interpreted this question as asking about their sexual identity. That is, in discussing how they chose their response, these respondents referred to aspects of their self-acceptance and self-acknowledgement, as well as having a social and cultural connection to the LGBT community. Often this connection involved a political aspect as well. Although these respondents did acknowledge that their response took into account the gender of the persons they were attracted to, engaged in sexual behavior with, and formed relationships. One respondent's discussion of this question sums up these findings very well:

“To be gay is to accept and acknowledge that homosexual attraction and consider it a major part of their identity. There are plenty of people who consider themselves to be straight but still have sex with people of the same sex and they certainly would not consider themselves gay or lesbian because gay and lesbian also have a political weight to them.”

When asked what identifying as gay meant to him personally, he responded:

“It means that I acknowledge that my sexual attraction to my own gender is as much a part of my identity as any normal completely heterosexual person's attraction to the opposite gender is. That it's not something- that it because of a variety of political and social, and cultural situations the person that- the gender of the person that I am sexually attracted to, is – puts me in a specific category that just goes beyond who you have sex with. To say that I am gay or I am lesbian is a political statement. And it's about self-acceptance and about self-acknowledgment and that there's more- it's more than just the mechanics of sexual behavior and it has more to do with a community, a cultural connection and a social connection than just who you have sex with.”

A few respondents, who identified as gay or lesbian, also raised issues with the terminology used in this question, as they preferred to use alternative terms to describe themselves. For example, one respondent, who was a black male, associated the term “gay” with white homosexual men and did not feel that it applied to him as a black male. Although this respondent chose the response option “gay or lesbian” for himself, he reported that he is currently considering the term “same-gender loving” to describe himself. Similarly, another respondent, who responded as “gay or lesbian” has been exploring using the term “queer” to describe himself, as he felt queer was more encompassing of individuals who do not fit into the male-female binary.

Respondents, who identified as heterosexual also interpreted this question as asking about an identity, however these respondents often possessed sexual identities that

were loosely defined and constructed as a reaction against a gay identity. For example, a common response to this question by respondents who identified as heterosexual was: "I'm not gay, what's that?" Furthermore, when probed on what it meant to these respondents to identify as heterosexual, their responses were largely based on previous sexual behaviors and sexual attraction. An example of a common response among this group of respondents was, "Well since I've never had an attraction to the same sex or to both sexes I thought that was pretty easy. You know I'm attracted to men."

As noted above, these respondents often had a limited understanding of the terms used in this question. Several respondents, who identified as "straight," did not know the meaning of the term "heterosexual." However, because the term straight was provided in the first response option they were able to provide a valid response. For example, upon hearing this question, one respondent responded "Heterosexual means you only deal with men right? I guess I'm hetero- say that again because I'm not gay so I want to make sure." After hearing the question a second time this respondent then repeated, "I'm straight then. Now I have to go home and figure out what heterosexual is." This respondent had a clear understanding of the word straight and had heard of the term heterosexual before but could not remember the definition of the word.

Some respondents also held misconceptions of the terms used in the response options. A couple of respondents interpreted the term heterosexual to mean bisexual. For example, when probed on the meaning of the term heterosexual one respondent provided the following definition: "You know I hear that it means male and female, a person that like a male or a female. A female like a female and male. Heterosex- is that heterosexual? That's what I think it is. I shouldn't be asking you. That's what I think heterosexual is. I think a heterosexual is a male like a male and female and vice versa, a female like a female and male." Although these respondents were able to provide a valid response to this question because of the inclusion of the word straight in the response options, had this not been provided more response error may have been found.

As with respondents who identified as gay, lesbian, or bisexual, a few respondents, who identified as "heterosexual" did not associate with terms used in the response options, in particular the term "straight." These respondents perceived the term "straight" as meaning to be "straight laced," which is not how they wished to identify. Instead, these respondents prefer to identify as heterosexual, however in order to do so they had to select the response option "heterosexual or straight."

This question also posed unique challenges for transgendered individuals. That is, individuals who were currently transitioning genders/sex or who had transitioned genders/sex. Although these respondents interpreted this question as asking about a sexual identity, in order for them to provide a response, they had to take into consideration their gender, their sexual behavior history, sexual attractions and identities, all of which may have been inconsistent over time. For example, one respondent, who was transitioning from male to female, found it difficult to choose a response given the options available. She initially responded to the question, "heterosexual woman and homosexual man" and stated that she would have circled both heterosexual and gay on this questionnaire, or she would have skipped the question if forced to choose one response option. Another respondent, who was transitioning from female to male, initially responded to this question "Um... I guess you'd put straight," however it was clear that he was not comfortable with this response. This individual reported that he ultimately chose straight because he is transgendered female to male and is sexually

attracted to females, therefore this would technically make him heterosexual, according to definition. However, he reported being uncomfortable with the terms heterosexual and homosexual because they presuppose that there are only two genders and as one of those genders, an individual is either attracted to the same or opposite sex. Instead he prefers to identify as “queer,” because he believes the queer community recognizes that gender identity encompasses more than just the dichotomy of male or female and therefore there is a broader spectrum of gender identity and sexual identities and this term best represents his social experiences.

For other transgendered respondents, choosing a response option was easier, however it was obvious that their sexual histories were not captured with this question. As these respondents’ sex/genders had evolved over time, so had their sexual identities. For example, one respondent had only in the past six months began to identify as lesbian, prior to this time period she had always identified as bisexual. Another respondent who has completed the transition from female to male also cites the progression of his sexuality over time. Prior to transitioning to male this respondent had identified as a straight woman, and then later identified as a lesbian, however since transitioning sexes he now identifies as a straight man. Although once involved in the gay community he has become more integrated into the heterosexual community since transitioning and has been in a committed relationship with a woman. To only ask about an individual’s current sexuality misses a lot of information not only about individual’s previous behaviors but also their previous sexual identities, which may have had implications for their previous access to health care.

Finally, we should note that the use of “or” in the response categories caused confusion for a some respondents as it made it sound like there were five response options. First a couple of respondents, who were unsure of the meaning of the term heterosexual, were further confused by the use of “or” in the first response option. These respondents initially perceived heterosexual and straight to mean the same thing, but upon hearing “heterosexual OR straight” they interpreted this to mean these were two separate and distinct categories. Similarly, while another respondent was able to choose a response option, “lesbian”, she felt there was redundancy in this question, as she saw gay and lesbian to mean the same thing, as do heterosexual and straight. “I think there is redundancy right there because either you are straight or gay or bisexual. So to me it is only three alternatives.” While the use of “or” in response options is likely only to be a problem if the question is interviewer administered, it is important to note that this can cause added confusion to respondents who are already unfamiliar with the terms being used.

6. What race or races do you consider yourself to be? [Mark all that apply.]

- | | | |
|---|------------------------|--------------------|
| 1 | White | 10 Chinese |
| 2 | Black/African American | 11 Filipino |
| 3 | Indian (American) | 12 Japanese |
| 4 | Alaska Native | 13 Korean |
| 5 | Native Hawaiian | 14 Vietnamese |
| 6 | Guamanian | 15 Other Asian |
| 7 | Samoan | 16 Some other race |
| 8 | Other Pacific Islander | |

Although this question seems straight-forward, some respondents had difficulty selecting from the response options provided as they did not adequately capture how they self-identified in terms of race. This problem was particularly pronounced for respondents who self-identified as Hispanic, as they perceived their race to be Hispanic. For example, one respondent initially answered “Hispanic” before hearing the response options, but even after listening to the response options provided she still stated, “I’m Hispanic.” A couple of respondents who also initially stated that their race was Hispanic did select a race when pushed to do so, however they did not truly identify with these races. Another respondent who moved to the U.S. from Colombia answered “some other race,” adding that race is conceptualized differently in Colombia than it is in the US and he never knows how to classify his race in this country.

19. What sexual orientation do you consider yourself to be? [Read Categories]

- 1 heterosexual
- 2 gay or lesbian
- 3 bisexual
- 4 other
- 5 don’t know

Respondents who identified as gay, lesbian, bisexual and transgendered interpreted this question as asking about a narrower construct than question 3. That is, they interpreted this question as only asking about the gender of the persons for whom they were sexually attracted, engaged in sexual behaviors, and formed relationships. Respondents, who identified as heterosexual, interpreted this question as asking about the *same* construct as the previous question – that is, their identity, and like in the previous question this entailed a disidentification with a gay identity. Two patterns of interpretation emerged among the transgendered respondents. For some transgendered respondents, this question was interpreted as asking about their sexual identity, and they viewed this question as similar to the previous question. However, other transgendered respondents interpreted this question in a similar manner as the gay, lesbian and bisexual respondents. That is, they interpreted this question as asking about behavior and attraction. These patterns of interpretation are discussed in more detail below.

As mentioned above, this question was found to capture a distinct construct from question 3 among some respondents who self-identified as gay, lesbian and bisexual. For these respondents the term “sexual orientation” introduced a narrower construct into the question, which caused variation in respondents’ interpretations and response formation. For example, one gay respondent who interpreted this question as asking about sexual orientation, found this construct to be limiting in providing information on his sexuality: “By limiting it to sexual orientation it seems like it is more about behavior and attraction and the acting out of that attraction.” This respondent goes on to discuss how the concept of sexual identity, which was captured in the previous question is much more than just who one is attracted to or the behaviors one engages in.

“Identity, the gay or lesbian identity is much broader. There is a, whether you want to call it a culture or a subculture or a community, I mean there is a system of shared identities, and things in common that gay men as a group, lesbians as a group, and gays, and lesbians, and bisexuals, and transgender people as a larger group have in common that distinguish themselves from heterosexual people other than just the gender of the person they want to have sex with.”

Conversely, respondents who self-identified as heterosexual viewed this question as asking about the same construct as the previous question, and in fact some found the question to be repetitive. These respondents based their responses on the gender of the persons for whom they were sexually attracted and with whom they engaged in sexual behaviors. As with the previous question respondents had difficulty comprehending the terminologies used in this question. Unlike in the previous question the term “straight” is not included in the response options for this question. Therefore, respondents who were unfamiliar with the term “heterosexual” were often unable to provide valid answers. These respondents reported that they wanted to answer straight, however this was not a response option. Consequently some of these respondents chose heterosexual, guessing that it meant straight, while others chose the response option “other.” For example, one respondent who was unfamiliar with the term heterosexual replied, “Other, okay what do you mean by other? Do you mean, um, there’s more? I’ll just say other. That will be straight.” Another respondent who asked for the definition of heterosexual in the previous question, responded to this question “[laughs], um, my mind is not working I’m just going to put other.” When offered to the option of stating “don’t know” he stuck with his response of “other,” stating that to respond “don’t know” would imply that he is unsure of his sexuality. One respondent, who was unfamiliar with the term heterosexual, could not provide any response option to this question, stating “I guess I’m going back to heterosexual I guess- [paused] other, I want to be straight, [laughs] I’m straight. You can write men only if you want.” Like the respondent above, this respondent also stated that she wasn’t comfortable choosing “other” because she knows what her sexual orientation is and choosing “other” would imply that she didn’t.

Some respondents who were transgendered interpreted this question as asking about a sexual identity, while others interpreted it as asking about a narrower construct. That is, asking about their sexual behavior and attraction. Respondents who were transitioning or who had already transitioned genders/sexes also had problems providing a response to this question. Among these respondents, two of these respondents chose “other.” However, they were not completely satisfied with this response option. One of the respondents who chose ‘other’ stated, “They should have transgender there. I think that if you are transgender you should be able to choose that and let them know that you are and they should have the option of M to F and F to M too and know what it is.” For this respondent the term transgender included not only her gender but also her sexual orientation. Because the terms heterosexual, gay or lesbian, and bisexual are contingent on biological sex and do not capture the experiences of transgendered persons. Another respondent, who was transgendered female to male, hesitated before answering then chose ‘other’ later stated,

“I picked other because honestly I feel like my gender isn't necessarily so simple. My attractions aren't really very simple and if I could pick one word I would probably pick queer, honestly, and it's because it is, I mean I think it's a term that the community is using more and more, to me it's also just about a community affiliation. Like I feel like I have a different kind of sexual orientation. I'm someone who doesn't have a completely traditional male body and I'm part of the queer community.”

This respondent goes on to state that he would have checked queer or queer and heterosexual if given the option, and if could only choose one he would have chosen queer. However, queer was not an option so he chose other. Similar to other respondents this respondent is interpreting sexual orientation in terms of both his attraction and behavior, but also in terms of his community affiliation.

“For myself and I think I can say for many trans people, but certainly speaking for myself, I came out as a lesbian at like 14 years old, so really being a part of the queer community and movement was very, very vital for me, so part of it is a community identification, there is that aspect of it, of the community I feel at home with, people identify as queer.”

Finally, one respondent who was transgendered female to male responded “I guess, uh, heterosexual.” But this respondent clearly struggled to select a response option that he felt comfortable with. “Because I'm trans I kind of consider myself, I mean I date women but I guess I might identify my orientation to be kind of heterosexual but a little queer. I mean I'm not, I don't date men but at the same time I'm biologically female, transitioned to male so. I guess heterosexual let's say heterosexual.” When probed further on how he was interpreting this question he responded,

“For me it's because of the process to get where I'm at has been so much a part of the queer community for so many years, it's hard to fully identify as heterosexual because it's more, in terms of, less about my orientation and more about I think culture and feeling still a part of that queer culture in some respects. Although I've been moving a little bit more away from that as I got through this process of living my life the way I do now.”

Although this respondent could categorize himself as “heterosexual,” given that he is biologically now a man and he only has sexual attractions with women, and only forms relationship and engages in sexual behaviors with women, this orientation conflicts with how he identifies, which is queer.

20. Do you feel like you belong to or relate to one of these groups more than the other?

Heterosexual
Gay or lesbian
Bisexual

This question was only tested in Round 1. There were no significant problems associated with this question. Most respondents interpreted this question as asking about relating to a community and/or having shared interests with a particular group, and feeling accepted by that group. For example, when probed on his interpretation of this question one respondent discussed that it meant “being different from the majority and then finding individuals who share that difference and uniting my identity with them for support and solidarity.” For him this also included volunteering at an LGBT community center, attending gay political events and/or being involved in gay religious institutions.

A few respondents did report difficulty choosing from the response options provided. When it came to the response choices, some respondents found that the choices did not represent his/her sense of belonging. For example, one woman who self identifies as lesbian, discussed how she relates to the lesbian community, rather than a larger “gay” community. When probed on her response she stated, “I feel more comfortable being with another lesbian or a group of lesbians than with a group of heterosexuals.” She also added that she believed that all lesbians have sexual preference in common, but all women share commonalities because females in general are “sensitive and loving.” Another respondent compared belonging to the lesbian community to that of a “sisterhood”. Additionally, she commented that the lesbian community helps each other out and gives support to those who are “wanting to come out.” Similarly, a male respondent also distinguished between gay and lesbian communities. He said, “we’re all a family” so from the choices shown, I would choose gay or lesbian”. But, if the options were separate, he would choose gay. He then discussed how he believes there are multiple variations of gay and this category itself can be further broken down into subcategories, such as economic status and social status.

Other respondents reported having difficulty selecting from the response options provided as they felt they belonged to more than one of the groups listed. For example, one respondent, who was transgendered, believed he belonged to all the groups equally listed except bisexual. “I see myself as a heterosexual and a gay”. He acknowledges that he knows the question says “more than the other,” but he sees these two groups as equal with one another because they both mean he’s attracted to men.

Finally one respondent wanted to select a response option that was not present. This respondent stated that he would have chosen “queer” rather than any of the other categories presented, as he believed gay, lesbian, and bisexual communities were all one group that he related to and felt he belonged.

21. Do you believe that you are identified more often by other people as belonging to one of these groups?

Heterosexual
Gay or lesbian
Bisexual

This question was only tested in Round 1 of the interviews. Respondents generally interpreted this question as asking about a reflected appraisal. That is how they perceive others to view them in terms of belonging to a sexual majority/minority group. Several themes emerged from the testing of this question. First, the term “other people” was ambiguous and was interpreted in a number of different ways. In some cases respondents could not provide an answer as they could not determine which “others” this question was asking about. Second, respondents’ response to this question was highly dependent on the context they considered when answering, as their answer could change depending on with whom they interacted. Third, while some respondents based their answer on direct appraisals they received from others, some respondents based their responses on their own self-appraisals and self-presentations. The following will describe these findings in more detail.

The term “other people” was interpreted in a variety of ways. Some respondents interpreted this question as asking about a “generalized other,” meaning an individual’s aggregate perception of how others in society view them (Mead 1934). For example, these respondents talked about “other people” in a more general sense, stating that they were thinking about “people,” “others,” “most people,” “strangers on the street” when discussing how they selected their answers, while others did mention thinking of specialized generalized others, such as “employers,” “men,” “gay and lesbian people,” and “heterosexual people.”

The ambiguity of the term “other people” made it difficult for some respondents to provide a valid response. For example, one respondent could not provide a response because he could not determine which others the question was asking about.

“I’m not entirely sure what that means. Do others, is the question do other gay or lesbian people accept me as one of them? Or something like that? Or do say heterosexual people assume that I am heterosexual or gay or? I’m confused.”

Context

As mentioned above, which “others” the respondents considered had important implications for how they answered, as they are perceived differently in different contexts. For example, one man discussed that at work and in the community in which he lives, he feels that he is perceived as gay. However, outside of this context he thinks anyone who saw him on the street would perceive him as heterosexual.

“Well it’s difficult because I work at the center and almost all of my professional work, which comprises a lot of my life is in LGBT environments. And people assume that if you’re a male in an LGBT

environment that you're gay. It's because of work environment. I'm sure if I didn't work in an environment like this I would be perceived to be heterosexual. Outside of here and outside of my work I'm perceived to be heterosexual, so it's kind of tough. But I run in LGBT circles based on history and my career...walking down the street I'm probably identified as heterosexual. I live in a very specific part and work in a very specific little niche of the world but I think practically everywhere else nobody would assume that I was necessarily anything other than a typical straight male."

He ultimately selected "gay" based on the context that he spends the majority of his time in. Another respondent, who self identified as a lesbian, stated that she feels that she is only perceived as a lesbian when she is with her partner. "Only when I'm with my partner. Then it's obvious." This woman reported that she would tell most people that she is a lesbian or people may be able to pick up on it based on her body language when she is with her partner. However, she doesn't feel that she fits the stereotypical image of a lesbian and she feel that most strangers would assume that she was straight unless they saw her with her partner.

Self appraisals

In fact, many respondents relied on their own self-appraisals when answering this question, in lieu of direct appraisals from others. Often this entailed determining if they had stereotypical characteristics that would indicate to others their sexual identity. For example one woman, who self identified as lesbian, stated, "Most of the time I am heterosexual for the rest of the people because I don't appear to be very masculine."

"The way I act, the way I carry myself, my mannerisms. I'm more feminine, more dainty. Butch, uh, someone that would know you are a lesbian would think that you're a lesbian by you have more masculine qualities more than your feminine qualities. All my qualities are 100% pure feminine and I do things a female does. You know I'm always going shopping. I'm always very picky in what I wear."

Similarly, several respondents noted that they believe 'others' assume that they are straight because they do not possess stereotypical characteristics of "gay" or "lesbian."

"I would say straight because of lot of people who are straight don't really ask me about do you have a boyfriend or do you go out to gay clubs, you know, they just don't. They just assume that I don't. I think they just assume that I have a straight girlfriend."

"Some people might think that most lesbians have short hair and more socially man-ish, you know in that sense. People might think that they're more aggressive and I don't tend to be aggressive. So I guess, you know, physical features, like I don't wear makeup so I mean, that's a stereotypical generalization but somebody might think that I'm a lesbian because of that or because I have short fingernails."

In addition, several respondents often mentioned that ‘other people’ often make assumptions that everyone is heterosexual unless given reason to believe otherwise.

“I think the majority of heterosexual people if they cared to bother to think at all would just tend to assume that I am heterosexual. I think most people just assume that other people are like themselves until proven otherwise, unless given reason to believe otherwise. And I believe that among homosexual people who are gay or lesbian they would be more quick- they would be more apt to see me as homosexual, at least that's been my experience.”

“Well my experience has been that everybody presumes heterosexuality in everyone else unless you explicitly state your sexual orientation to be different than heterosexual or if your mannerisms are different from what the society will expect for your gender. So being a male you became too feminine then they would assume that you're not heterosexual. So it's by your look and your behavior that people will judge and in my case often most of the time people assume heterosexuality until I disclose.”

Similar to the responses above, one man who identified as bisexual reported that others identify him as heterosexual. When asked why he thought he was perceived this way this respondent stated that there were no stereotypical characteristics by which bisexual persons can be identified and in fact people are often surprised to learn that he is bisexual.

Self-Presentation

Respondents also considered how they self-presented to others – Discussed his ‘alternative’ way of being gay and how he actively presents this image to others, and the implications this has for how others perceive him (at least how he perceives others to view him).

“The way I walk. My physical appearance and the way I carry on. Mostly people think of a gay man like (speaking in high pitch voice) “oh hi Johnny!” you know they have flamboyance. They don’t know that gay men can also have a very deep voice, also get down there, talk in deep octaves. I’m a member of a neo-panther leather club you know so we do community events and some of those guys if we walk in Harlem they run. Because some of them are 300 pounds of muscle, 200 pounds. They’re very thuggish looking.”

For respondents who were transgender how they felt others identified them changed based on the progress they had made with their transition. For example a respondent who was transitioning from male to female and had self-identified as a heterosexual woman discussed how when she first began transitioning from male to

female people it was often assumed that she was gay. Now that she passes more easily as a woman she had to correct people less often about her sexuality, although she has to do so on occasion. Similarly another respondent self-identified as queer but perceived others to identify him as gay or lesbian responded

“Yeah, well because other people, you know I don't always know what other people are thinking so it's always what I'm trying to guess. I guess then, uh, because of my gender presentation and I think people will, people will often look at me and think that I am lesbian rather than thinking that I'm transgender you know and transitioning. So actually that's sometimes very annoying. Because people, you know think because of how I look they think, they put me into this specific category which you know even if it's well intentioned then it's not what it is.”

22. People are different in their sexual attraction to other people. Which best describes your feelings? Are you...

- Only attracted to females1
- Mostly attracted to females2
- Equally attracted to females and males.....3
- Mostly attracted to males4
- Only attracted to males5
- Not sure6

A major theme that emerged from the evaluation of this question was that respondents' answers to this question were very inconsistent, indicating that this question may lack reliability. Upon first hearing the question, some respondents changed their answer multiple times. Other respondents' narratives from the cognitive interview did not match how they initially answered this question, and for others, their responses to this question were not consistent with their responses to the two previous questions. The cause of these inconsistencies seems to stem from the fact that term “attraction” was a very ambiguous concept for most respondents, even with the qualifier “sexual.” Although many respondents understood this question as asking about sexual attractions that involved physical arousals that they may experience toward a particular gender, or desires to engage in sexual behaviors with particular genders, others used broader definitions of attraction while answering this question. For example, respondents reported being attracted to particular genders at an aesthetic level, for example admiring someone's beauty, or desiring to emulate a member of the same sex. Others included non-sexual types of attraction when answering their question, such as social characteristics that they were attracted to in a partner. One woman, who thought of her attraction to her husband while answering, gave the following examples of how she was attracted to him: “He's tall, good-looking, has a beard, he's a good person, he's very kind, he does dishes, he vacuums, he clean house, he cuts grass.”

The ambiguity of the term attraction was clearly problematic for some respondents. For example, one respondent initially responded to this question “mostly attracted to females,” but then later during the cognitive interview stated that she was “only attracted to females.” When asked why her answers differed, she asked to hear the

response categories again and then again changed her answer to “mostly attracted to females,” showing a mixed emotion in her selection. She stated, “most of the time there is a couple walking by and I look at the woman, the girl, the female.” When probed about sometimes looking at a man she said sometimes she’ll look at the man because “there is a beautiful in the human being, that’s what I’m looking for...the beautiful human being, a well-built human being even though I am not attracted to men.” Similarly other respondents also changed their answers during the cognitive interview, citing a larger definition of attraction that included nonsexual attractions.

References

- Creswell, John W. 1998. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks: Sage Publications.
- Mead, George H. (1934). *Mind, Self, and Society*. Chicago, IL: University of Chicago Press.
- McCall, George, J. (2003). The Me and the Not-Me: Positive and Negative Poles of Identity. Pp11-25 in Burke, Peter J., Owens, Timothy, J., Sherpe, Richard T., and Peggy A. Thoits (Eds) *Advances in Identity Theory and Research*. New York: Kluwer Academic/Plenum Publishers.
- Miller, K. (2009, October 22) *Cognitive interviewing*. Paper presented at the Workshop on Question Evaluation Methods, Hyattsville, MD.
- Lincoln, Yvonna, and Egon G. Guba. 1985. *Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications.
- Strauss, Anselm C., and Juliet Corbin. 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park: Sage Publications.
- Tourangeau, R., Rips, L.J., & Rasinksi, K. (2000). *The psychology of survey response*. New York: Cambridge University Press.
- Willis, Gordon B. 2005. *Cognitive Interviewing: A Tool for Improving Questionnaire Design*. Thousand Oaks, CA: Sage Publications.

Appendix

Round 1 Questionnaire:

DEMOGRAPHICS

1. Are you male or female?

- 1 Male
- 2 Female

2. Are you now married, widowed, divorced, separated, never married or living with a partner?

- 1 Married
- 2 Widowed
- 3 Divorced
- 4 Separated
- 5 Never married
- 6 Living with a partner

3. Do you consider yourself to be heterosexual or straight, gay or lesbian, or bisexual?

- 1 Heterosexual (straight)
- 2 Gay or Lesbian
- 3 Bisexual

4. What is the HIGHEST level of school you have completed or the highest degree you have received?

- | | | | |
|----|--------------------------------------|----|---|
| 0 | Never attended/
kindergarten only | 12 | 12th grade, no diploma |
| | | 13 | HIGH SCHOOL
GRADUATE |
| 1 | 1st grade | 14 | GED or equivalent |
| 2 | 2nd grade | 15 | Some college, no degree |
| 3 | 3rd grade | 16 | Associate degree:
occupational,
technical, or vocational
program |
| 4 | 4th grade | | |
| 5 | 5th grade | 17 | Associate degree: academic
program |
| 6 | 6th grade | 18 | Bachelor's degree (Example:
BA, AB, BS, BBA) |
| 7 | 7th grade | 19 | Master's degree (Example:
MA, MS, MEng, MEd, MBA) |
| 8 | 8th grade | 20 | Professional School degree
(Example: MD, DDS, DVM,
JD) |
| 9 | 9th grade | | |
| 10 | 10th grade | 21 | Doctoral degree (Example:
PhD, EdD) |
| 11 | 11th grade | | |

5. Do you consider yourself to be Hispanic or Latino?

- 1 Yes
- 2 No

6. What race or races do you consider yourself to be? [Mark all that apply]

Note: Respondents will be shown a flash card with the following response categories, or they will view the response categories on a computer screen.

- | | | |
|---|------------------------|--|
| 1 | White | 10 Chinese |
| 2 | Black/African American | 11 Filipino |
| 3 | Indian (American) | 12 Japanese |
| 4 | Alaska Native | 13 Korean |
| 5 | Native Hawaiian | 14 Vietnamese |
| 6 | Guamanian | 15 Other Asian |
| 7 | Samoaan | *16 Some other race (see footnote below) |
| 8 | Other Pacific Islander | |
| 9 | Asian Indian | |

*16 Some other race – This response item will not be offered as a choice to the respondent. However, if it is mentioned by the respondent, it will be marked on the interviewer’s copy.

GENERAL HEALTH

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

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

The next questions are about certain chronic health conditions which you may have. We are interested in ‘long-term conditions’ that have lasted or are expected to last 6 months or more and that have been diagnosed by a doctor or other health professional.

8. Do you have high blood pressure?

- 1 Yes
- 2 No

9. Do you have emphysema or chronic obstructive pulmonary disease (COPD)?

- 1 Yes
- 2 No

10. Do you have diabetes?

- 1 Yes
- 2 No

11. Do you have coronary heart disease?

- 1 Yes
- 2 No

ACCESS TO CARE

Now I'd like to ask about your contacts with health professionals.

12. Do you have a regular medical doctor?

- 1 Yes
- 2 No

13. In the past 12 months, how many times have you seen or talked on the telephone about your physical health with:

a) ... a family doctor or general practitioner?

□□□□ Times

b)... an eye specialist (such as an ophthalmologist or optometrist)?

□□□ Times

c)... a dentist or orthodontist?

□□□□ Times

19. What sexual orientation do you consider yourself to be?

- Heterosexual
- Homosexual
- Bisexual
- Other
- Don't know

20. Do you feel like you belong to or relate to one of these groups more than the other?

- Heterosexual
- Gay or lesbian
- Bisexual

21. Do you believe that you are identified more often by other people as belonging to one of these groups?

- Heterosexual
- Gay or lesbian
- Bisexual

22. People are different in their sexual attraction to other people. Which best describes your feelings? Are you...

- Only attracted to females1
- Mostly attracted to females2
- Equally attracted to females and males.....3
- Mostly attracted to males4
- Only attracted to males5
- Not sure6

Round 2 Questionnaire:

DEMOGRAPHICS

1. Are you male or female?

- 1 Male
- 2 Female

[PROBE: In your opinion, what does it mean to be male/female?]

2. Are you now married, widowed, divorced, separated, never married or living with a partner?

- 1 Married
- 2 Widowed
- 3 Divorced
- 4 Separated
- 5 Never married
- 6 Living with a partner

3. Do you consider yourself to be heterosexual or straight, gay or lesbian, or bisexual?

- 1 heterosexual or straight
- 2 gay or lesbian
- 3 bisexual

[PROBE: What does being [X] mean? Do the words heterosexual and straight mean the same thing to you, or do you think they mean different things? How about the words gay and lesbian? Bisexual?]

4. What is the HIGHEST level of school you have completed or the highest degree you have received?

- | | | | |
|----|--------------------------------------|----|---|
| 0 | Never attended/
kindergarten only | 12 | 12th grade, no diploma |
| 1 | 1st grade | 13 | HIGH SCHOOL GRADUATE |
| 2 | 2nd grade | 14 | GED or equivalent |
| 3 | 3rd grade | 15 | Some college, no degree |
| 4 | 4th grade | 16 | Associate degree: occupational,
technical, or vocational program |
| 5 | 5th grade | 17 | Associate degree; academic
program |
| 6 | 6th grade | 18 | Bachelor's degree (Example:
BA, AB, BS, BBA) |
| 7 | 7th grade | 19 | Master's degree (Example:
MA,MS,MEng,MEd,MBA) |
| 8 | 8th grade | 20 | Professional School degree
(Example: MD, DDS, DVM,
JD) |
| 9 | 9th grade | 21 | Doctoral degree (Example:
PhD, EdD) |
| 10 | 10th grade | | |
| 11 | 11th grade | | |

5. Do you consider yourself to be Hispanic or Latino?

- 1 Yes
- 2 No

6. What race or races do you consider yourself to be? [Mark all that apply.]

- | | | |
|---|------------------------|--------------------|
| 1 | White | 10 Chinese |
| 2 | Black/African American | 11 Filipino |
| 3 | Indian (American) | 12 Japanese |
| 4 | Alaska Native | 13 Korean |
| 5 | Native Hawaiian | 14 Vietnamese |
| 6 | Guamanian | 15 Other Asian |
| 7 | Samoan | 16 Some other race |
| 8 | Other Pacific Islander | |
| 9 | Asian Indian | |

7. What sexual orientation do you consider yourself to be? [Read Categories]

- 1 heterosexual
- 2 gay or lesbian
- 3 bisexual
- 4 other
- 5 don't know

[PROBE: What does 'sexual orientation' mean to you? Do you feel like you belong to or relate to more than one of these groups? Have you always been [X]? Do you believe that you are identified more often by other people as belonging to one of these groups?]

8. People are different in their sexual attraction to other people. Which best describes your feelings? Are you...

- Only attracted to females1
- Mostly attracted to females2
- Equally attracted to females and males3
- Mostly attracted to males4
- Only attracted to males5
- Not sure6

[PROBE: What does it mean to be "attracted" to someone? What were you thinking when you gave your answer?]

HEALTH INSURANCE

17. Are/is [you/NAME] CURRENTLY covered by any type of health coverage or health insurance? Include government health coverage such as Medicare, Medicaid, VA and military programs and any insurance obtained through a job or purchased directly from the insurance company.

- a. Yes [GO TO 18]
- b. No [ASK ABOUT NEXT HH MEMBER]

[PROBE: Have you heard of these different plans? Do you know the difference between them? What type of insurance do you have? How long have you had it? Have you used it? How does it work? (If no: How long have you been without insurance?)]

18. How do/does [you/NAME] obtain your/his/her health coverage or insurance? Is it through...

- c. A current or former employer or union [GO TO 19]
- d. Purchasing it directly from the insurance company [GO TO 19]
- e. A parent or spouse [GO TO 20]
- f. The government, for example, Medicaid or Medicare, for elderly, low-income or disabled people, or the VA [GO TO 21]
- g. Other/specify _____ [GO TO 17 FOR NEXT HH MEMBER]

19. Is that through some type of self-employment or professional organization?

- h. Yes [GO TO 17 FOR NEXT HH MEMBER]
- i. No [GO TO 17 FOR NEXT HH MEMBER]

[PROBE: What does “professional organization” mean?]

20. How do/does [your/NAME's] parents or spouse obtain their coverage? Is it through...

- j. a current or former employer or union [GO TO 17 FOR NEXT HH MEMBER]
- k. purchasing it directly from the insurance company [GO TO 17 FOR NEXT HH MEMBER]
- l. another family member [GO TO 17 FOR NEXT HH MEMBER]
- m. other/specify _____ [GO TO 17 FOR NEXT HH MEMBER]

[PROBE: How confident are you in your answer? Do you have specific knowledge of their health plan? How?]

21. Is that Medicare, Medicaid, VA or some other type of government coverage?

- n. Medicaid [GO TO 17 FOR NEXT HH MEMBER]
- o. Medicare [GO TO 17 FOR NEXT HH MEMBER]
- p. VA [GO TO 17 FOR NEXT HH MEMBER]

q. Other/specify _____ [GO TO 17 FOR NEXT HH MEMBER]

[PROBE: Have you heard of these different programs? Can you describe the difference between them?]

[GO THROUGH THIS SERIES FOR EACH PERSON IN R's HH.]
CANCER ATTITUDES; FEMALE VERSION – [To be self-administered by the respondent]

Please circle the single number (on a scale from 1 to 5) that best describes how **concerned you feel right now** about the following things:

FEELINGS OF CONCERN NOW

	<u>Extremely</u>	<u>Not at all</u>	<u>Hardly</u>	<u>Somewhat</u>	<u>Very much</u>
22. Breast cancer occurring in me.....	1.....	2.....	3.....	4.....	5
23. My family's history of cancer.....	1.....	2.....	3.....	4.....	5
24. What I can do to prevent breast cancer....	1.....	2.....	3.....	4.....	5
25. Breast cancer hiding silently in my body...	1.....	2.....	3.....	4.....	5
26. Not being able to avoid getting breast cancer..	1.....	2.....	3.....	4.....	5
27. How I would feel if I had breast cancer.....	1.....	2.....	3.....	4.....	5
28. My chances of getting breast cancer in the future...	1.....	2.....	3.....	4.....	5
29. Getting breast cancer without my knowing it.....	1.....	2.....	3.....	4.....	5
30. Finding out if I have breast cancer.....	1.....	2.....	3.....	4.....	5
31. What I can do to detect breast cancer early	1.....	2.....	3.....	4.....	5
32. Inheriting cancer from my "genes".....	1.....	2.....	3.....	4.....	5
33. What having breast cancer would do to my body...	1.....	2.....	3.....	4.....	5
34. Symptoms or signs of breast cancer in me...	1.....	2.....	3.....	4.....	5
35. My chances of dying of breast cancer.....	1.....	2.....	3.....	4.....	5

36. How I would deal with breast cancer if I got it... 1.....2.....3.....4.....5
37. Things I do that affect my risk of breast cancer (e.g., activities, habits, lifestyle, diet) 1.....2.....3.....4.....5
38. How having breast cancer would affect my life 1.....2.....3.....4.....5
39. My personal risk of breast cancer..... 1.....2.....3.....4.....5
40. Things in my life that may cause breast cancer... 1.....2.....3.....4.....5
41. My chances of keeping breast cancer away..... 1.....2.....3.....4.....5
42. Cancer occurring in my relatives..... 1.....2.....3.....4.....5

CANCER ATTITUDES; MALE VERSION – [To be self-administered by the respondent]

Please circle the single number (on a scale from 1 to 5) that best describes how **concerned you feel right now** about the following things:

FEELINGS OF CONCERN NOW

- | | <u>Extremely</u> | <u>Not at all</u> | <u>Hardly</u> | <u>Somewhat</u> | <u>Very much</u> |
|--|------------------|-------------------|---------------|-----------------|------------------|
| 22. Prostate cancer occurring in me..... | 1..... | 2..... | 3..... | 4..... | 5 |
| 23. My family's history of cancer..... | 1..... | 2..... | 3..... | 4..... | 5 |
| 24. What I can do to prevent prostate cancer.. | 1..... | 2..... | 3..... | 4..... | 5 |
| 25. Prostate cancer hiding silently in my body... | 1..... | 2..... | 3..... | 4..... | 5 |
| 26. Not being able to avoid getting prostate cancer.. | 1..... | 2..... | 3..... | 4..... | 5 |
| 27. How I would feel if I had prostate cancer..... | 1..... | 2..... | 3..... | 4..... | 5 |
| 28. My chances of getting prostate cancer in the future... | 1..... | 2..... | 3..... | 4..... | 5 |
| 29. Getting prostate cancer without my knowing it..... | 1..... | 2..... | 3..... | 4..... | 5 |
| 30. Finding out if I have prostate cancer..... | 1..... | 2..... | 3..... | 4..... | 5 |

31. What I can do to detect prostate cancer early 1.....2.....3.....4.....5
32. Inheriting cancer from my “genes”..... 1.....2.....3.....4.....5
33. What having prostate cancer would do to my body... 1.....2.....3.....4.....5
34. Symptoms or signs of prostate cancer in me... 1.....2.....3.....4.....5
35. My chances of dying of prostate cancer..... 1.....2.....3.....4.....5
36. How I would deal with prostate cancer if I got it... 1.....2.....3.....4.....5
37. Things I do that affect my risk of prostate cancer (e.g., activities, habits, lifestyle, diet) 1.....2.....3.....4.....5
38. How having prostate cancer would affect my life 1.....2.....3.....4.....5
39. My personal risk of prostate cancer..... 1.....2.....3.....4.....5
40. Things in my life that may cause prostate cancer... 1.....2.....3.....4.....5
41. My chances of keeping prostate cancer away..... 1.....2.....3.....4.....5
42. Cancer occurring in my relatives..... 1.....2.....3.....4.....5

Cognitive protocol for risk questions

THIS PROTOCOL WILL BE ADMINISTERED AFTER THE SUBJECT COMPLETES ALL ITEMS ON THE BREAST/PROSTATE QUESTIONS.

Now, I'd like to go back over some of questions you just responded to, so that I'm sure I understand your answers (look at subject's copy along with the subject)

- *First, overall- how easy or difficult was this to fill out? Would you say very easy, somewhat easy, somewhat difficult, or very difficult?*
- *Did it seem like the questions were asking about different things, or did they seem to be very similar to one another?*
- *Which, if any, items seemed similar (or different)? {SHOW S THE ITEMS}*
- *Do you think people might find any of the items too personal? [IF YES] Could you say more about that?*
- *These questions asked you about (prostate/breast) cancer – Describe in your own words what this is.*
- *When you were responding to the questions, were you thinking about a particular time period?*

OK, now looking at your answers -

FEELINGS OF CONCERN NOW

Not at all Hardly Somewhat Very much

Extremely

22. PROSTATE cancer occurring in me..... 1.....2.....3.....4.....5

For number 22, “PROSTATE cancer occurring in me” - You said [ANSWER] – Why did you choose that?

23. My family’s history of cancer..... 1.....2.....3.....4.....5

For number 23, about your family’s history of cancer: What kind of cancer were you thinking about here?

Tell me more about your family’s history of cancer

[IF UNCLEAR] Did you include yourself when discussing your family’s history of cancer?

24. What I can do to prevent PROSTATE cancer.....1.....2.....3.....4.....5

***In number 24, what did you think we meant by “what I can do to prevent PROSTATE cancer”?
What kinds of things do you think you can do?***

25. PROSTATE cancer hiding silently in my body 1.....2.....3.....4.....5

26. Not being able to avoid getting PROSTATE cancer1.....2.....3.....4.....5

27. How I would feel if I had PROSTATE cancer.....1.....2.....3.....4.....5

For number 27, why did you say [ANSWER]?

28. My chances of getting PROSTATE cancer in the future
1.....2.....3.....4.....5

Looking at number 28: What do you think your chances are of getting PROSTATE cancer in the future?

29. Getting PROSTATE cancer without my knowing it.....
1.....2.....3.....4.....5

For number 29: How do you think you would know, if you did get PROSTATE cancer?

30. Finding out if I have PROSTATE cancer.....
1.....2.....3.....4.....5

31. What I can do to detect PROSTATE cancer early.....
1.....2.....3.....4.....5

32. Inheriting cancer from my “genes”.....
1.....2.....3.....4.....5

For number 32: What kinds of cancer did you think we meant here when we asked about inheriting cancer from my “genes”?

33. What having PROSTATE cancer would do to my body
1.....2.....3.....4.....5

Looking back at number 33: What would PROSTATE cancer do to your body?

34. Symptoms or signs of PROSTATE cancer in me.....
1.....2.....3.....4.....5

Now, for number 34: What would the symptoms or signs be?

35. My chances of dying of PROSTATE cancer.....
1.....2.....3.....4.....5

For number 35: What do you think someone's chances are of dying from PROSTATE cancer?

36. How I would deal with PROSTATE cancer if I got it
1.....2.....3.....4.....5

For number 15: Have you ever thought about how you would deal with such a thing?

What do you think you might do, to deal with it?

37. Things I do that affect my risk of PROSTATE cancer
1.....2.....3.....4.....5
(e.g., activities, habits, lifestyle, diet)

Number 37 asks about things you do that affect your risk of PROSTATE cancer: What kinds of things come to mind here?

38. How having PROSTATE cancer would affect my life
1.....2.....3.....4.....5

Number 38 asked how having PROSTATE cancer would affect your life: How would it affect your life?

Why did you say [ANSWER]?

39. My personal risk of PROSTATE cancer.....
1.....2.....3.....4.....5

For number 39: How high do you think your personal risk of PROSTATE cancer is?

40. Things in my life that may cause PROSTATE cancer
1.....2.....3.....4.....5

IF ANSWER DIFFERENT FROM #37 ANSWER: For 19: Why did you say [ANSWER].

Why did you say [X] in #37 – about things you do that affect your risk -- and [Y] here?

41. My chances of keeping PROSTATE cancer away.....
1.....2.....3.....4.....5

42. Cancer occurring in my relatives..... 1.....2.....3.....4.....5

For 42: ***What type of cancer were you thinking about here?***

What relatives were you thinking about?

Finally, I have a few more general questions:

(A) Over the last year or so, how much did you think about the types of questions we asked you about today?

(B) Overall, how much would you say you worry about getting PROSTATE cancer – using this same scale (point to scale at top of instrument)?

(C) Overall, how much do you worry about getting cancer in general – again, using the same scale?

If answers to (B), (C) differ: Why would you say you are [ANSWER TO B] concerned about PROSTATE cancer, but [ANSWER TO C] concerned about cancer in general?