Collaborating Center for Questionnaire Design and Evaluation Research

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Results of Cognitive Testing of Questions on Cancer Screening and Sun Safety for the National Health Interview Survey

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INTRODUCTION

This report summarizes findings from an evaluation of proposed cancer screening and sun safety questions intended for inclusion on the 2025 National Health Interview Survey (NHIS)¹. NHIS is an interviewer-administered nationally representative household survey which collects data on the health of the civilian non-institutionalized population of the United States. The main objective of the NHIS is to monitor the health of the United States population through the collection and analysis of data on a broad range of health topics². It is standard practice to evaluate new or modified questions to be added to the NHIS. This helps reduce measurement error and ensures that questions accurately capture data that are aligned with intended research goals of the survey. An evaluation of proposed questions was conducted in both English and Spanish by National Center for Health Statistics' Collaborating Center for Questionnaire Design and Evaluation

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Research (CCQDER) in collaboration with Research Support Services, Inc (RSS) using interpretive cognitive interview methodology. The study was conducted in collaboration with the Division of Health Interview Statistics at NCHS and received both Office of Management and Budget (OMB) and NCHS/CDC Human Subjects approval.

METHODOLOGY

This evaluation of survey questions on cancer screening and sun safety utilized a one-on-one cognitive interviewing methodology. This method enables researchers to understand the mental processes that respondents went through when answering the survey questions within the context of their own lives (Miller, 2011). Using this method, researchers are able to explore construct validity and identify any difficulties respondents encounter in understanding and answering the survey questions (Miller, 2016). Ultimately, the findings from the cognitive interviews help in determining whether questions may be prone to measurement

⁴ Miller, K., & Willis, G. (2016). Cognitive models of answering processes. The Sage handbook of survey methodology, 210-217.



¹ NHIS - National Health Interview Survey (cdc.gov)

² NHIS - About the National Health Interview Survey (cdc.gov)

³ Miller, K. (2011). Cognitive interviewing. Question evaluation methods: Contributing to the science of data quality, 49-75.

error when administered in a survey.

Sample: The cancer screening and sun safety questions were evaluated as part of a larger cognitive interviewing study along with questions on other topics, including gender identity, race/ethnicity, and COVID-19. Sample selection was purposive with the aim of selecting respondents who met criteria relevant to all of the questions under investigation. Because this project included multiple topics, recruitment was based on various factors relevant to the topics being tested including age (which was relevant to the cancer screening questions), race and ethnicity, gender and experiences with COVID-19. Recruitment was carried out through a combination of flyers, special interest groups, and respondent referrals. A total of 150 interviews were completed, 80 in English and 70 in Spanish. (Twenty-two of the Spanish interviews included gender minorities due to a separate evaluation of a gender question.) A demographic breakdown of the respondents appears in Table 1.

Table 1. Respondent Demographics

Demographics	English (n=100)	Spanish (n=50)	Total (n=150)
Race/Ethnicity*			
White	37	5	42
Black	11	1	12
Asian	18	0	18
Middle Eastern or North African	30	2	32
American Indian or Alaska Native	1	2	3
Hispanic	11	47	58
Gender*			
Female	56	31	87
Male	43	19	62
Transgender, non-binary, or another gender	1	22	23
Age			
18-29	29	8	37
30-49	50	28	78
50-64	15	13	28
65 and older	6	1	7

^{*}Numbers do not add to denominators because respondents could select none or more than one category

Data Collection: CCQDER staff and RSS conducted all 150 interviews. Over multiple rounds of testing, researchers from CCQDER and RSS conducted interviews both in-person and remotely. Nine CCQDER interviewers conducted interviews in English, and three RSS interviewers conducted interviews in Spanish and English. All interviewers were skilled in qualitative interviewing techniques. Remote interviews were done over the Zoom for Government video conferencing platform which complies with the NCHS's requirements to use an authorized and secure video conferencing platform. In-person interviews were conducted in North Dakota. Interviews lasted no longer than 60 minutes. Upon completion of the interview, respondents received a \$50 remuneration.

Interview procedures: In the first part of the interview, the questions under investigation were administered to the respondents who chose their responses from the answer categories provided. In the second part of the interview, intensive verbal probing was used to collect response process data. Audio recordings and written notes of interview summaries were collected and used as the basis of data analysis.

Upon completion of the interviews, all written summaries and partial transcripts were uploaded in English into Q- Notes⁵, a software application for data storage and analysis of cognitive interviews. Additionally, the use of Q-Notes allowed the Principal Investigator to monitor data quality as interviews were being completed.

Data Analysis: Analysis of interviews followed the guidelines for cognitive interviewing methodology which is guided by the grounded theory approach. This approach does not aim to test existing hypotheses, but instead generates explanations of response error and various interpretive patterns that are closely tied to the empirical data. This includes the constant comparative method of analysis, in which analysts continually compare data findings to original data^{6,7}. This is an iterative process of data synthesis and reduction⁸. After each interview was conducted, summary notes were written for each question. Summary notes included information on the way in which a respondent interpreted and processed individual questions, what experiences or perceptions a respondent included in formulating a response and any response difficulties experienced by the respondent. After all interviews and summaries were completed, interviews were compared to identify common patterns of interpretation and response difficulties for each question. Sub-group analysis looked at patterns of interpretation and responses as they varied across different groups within the sample.

III. Overall patterns

Cancer screening and Gender

Some of the cancer screening questions focus on particular body parts that are often sex-associated such as breasts and prostate. However, given the variation in gender identification, there is not always a straightforward alignment between body parts and gender identity. To explore how to best ask about sex-associated cancer screening, respondents were divided into three groups of roughly equal size. The groups were assigned in advance to the various rounds of testing (and occasionally on an ad hoc basis due to interviewer error). The first group of respondents were asked only the questions associated with their self-identified sex. The second group were allowed to select which questions they were asked. The third group of respondents was asked all of the questions regardless of their sex. Results indicated that there were no differences in the ways the different groups responded to the questions although when the skip pattern was based on gender, some respondents were not asked the applicable questions.

For the first group, respondents who identified as female were asked the screening questions about breast

⁵ Q-Notes: Analysis Software for Question Evaluation (cdc.gov)

⁶ Glaser, B. and Strauss, A. (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research. Hawthorne, NY: Aldine de Gruyter.

⁷ Lincoln, Y. S. (1985). Naturalistic Inquiry (Vol.75). Sage.

⁸ Strauss, A., & Corbin, J. (n.d.). Basics of qualitative research (Vol. 15). Newbury Park, CA: Sage

cancer and cervical cancer while respondents who identified as male were asked the questions about prostate cancer screening. Although no systematic response error was seen in this group, transgender respondents were not always asked the questions that aligned with their anatomies.

For example, transgender women respondents who identified as female were not asked the questions about prostate cancer screening. When they were asked questions about mammograms and cervical cancer screening, transgender women were able to answer accurately but indicated that the questions did not apply. For example, when asked about cervical cancer screening, one transgender woman answered "no" and said, "Oh that would not really apply to me. I'm not biologically a woman so I don't have those parts." Another transgender respondent was asked about mammograms. She answered "no" and said, "I know they look real, but they aren't, so no. I don't get that."

In the second group, the interviewers asked respondents, "The rest of the questions are about testing for different types of cancer. I have questions about breast cancer, cervical cancer and prostate cancer. Which should I ask you?" Respondents were able to accurately indicate which questions applied to their bodies. For example, a cis-gender female respondent said, "You can ask me about breast cancer and cervical cancer" while a cis-gender male respondent said, "Just the prostate." Similarly, a transgender female said, "You can ask me about breasts and prostate because I have both."

The final group of respondents was asked all of the cancer screening questions regardless of their gender. No response error was seen even when respondents were asked about screening that did not apply to them. For example, one cis-gender male was asked about cervical cancer screening. He answered "no" and explained, "I would say that would be more for the female gender." A cis-gender female was asked about prostate cancer screening. She answered "no" and said, "Uh. Nope. I don't have, like a hidden penis or anything." No response error was seen when respondents were not familiar with the particular tests. For example, one cis-gender female answered "no" when asked about the Prostate Specific Antigen (PSA) test. She explained that when she was pregnant, "They did every test there is to do." She then went on to say, "For that one I'd say no though because I haven't heard of it. They didn't mention that one." Therefore, even though she was not familiar with the PSA test, no response error was seen.

Race, Culture and Sun Safety Questions

Respondents' race and culture sometimes impacted the context of respondents' answers to questions about suntan, sunburn and sunscreen. Respondents who had darker skin sometimes thought the questions were not written with them in mind. When asked about spending time outside in order to suntan, one respondent, who is Black, explained:

I guess I knew that you had to ask everyone the same questions. But in my head, I'm like, he definitely could have skipped that question. He should have just probably skipped it. In my head it was like – I guess that I figured that as you read it you would have thought to yourself oh this is a no-brainer. Like I figured you were answering the question in your head like how I would have answered it anyways. So, um, yeah. You kinda caught me off guard when you said going outside to get sun, I'm like, no. No! I don't go outside to get sun, or do I go outside while it's sunny. Because that's a different answer – Yeah I go outside while it's sunny, but I don't ever go outside because of the sun. I'm Black. I don't need more sun.

This respondent answered "never," so no response error was seen despite her reaction to the question. Similarly, when asked the same question, a different Black respondent simply gestured to her skin and said, "Uhm, no. I think we're all set for that [tanning]."

Some respondents from other countries noted that tanning is an American or western cultural phenomenon.

One respondent said, "Our [Pakistani] skin, we're already tan and we get tan for no reason. Like, we don't want to get more tan [laughs]. We'll be outside 1 hour and just get darker. It's easy for us...For Asians, when we hear Americans put sunscreen to get that [tan], it's so weird for us." A different respondent explained her understanding of the question on her skin's reaction to the sun:

I thought they wanted to test if I had the European mindset of, Europeans are thirsty for the sun. They just want to get in the sun. And if I share that mindset. Which I do not. In Iran there are girls who are super into fashion and they sunbathe purposefully to mimic what Americans do. I wouldn't sit in the sun for more than a few minutes. I would totally try to use sunscreen to protect my skin from darkening.

Similarly, several respondents who wear a hijab noted that the questions on sun exposure were not relevant to them. One said, "I am covered. I do not expose my skin to the sun." However, no response error was seen with any of these respondents.

In a few instances, unfamiliarity with the concepts did lead to potential response error. A few respondents who had recently come to the United States as graduate students were not familiar with the concept of tanning at all. When asked about spending time outside for the purpose of tanning, one said, "Developing a tan? What's that?" He had previously answered "sometimes" to the question and when asked why, he explained that he sometimes has to go outside in the field for his job. Therefore, in this case, unfamiliarity with the idea of tanning lead to response error.

Comparative English and Spanish

Except where noted in the question-by-question findings, there was very little difference in the ways English and Spanish speaking respondents understood and responded to the questions on cancer screening and sun safety.

IV. Question by Question Findings

COLORECTEV_A. These next questions are about colorectal cancer screening. Colonoscopy and sigmoidoscopy are exams to check for colon cancer. Have you ever had either of these exams? Read if necessary: Colonoscopy (colon-OS-copy) and sigmoidoscopy (sigmoid-OS-copy) are exams in which a doctor inserts a tube into the rectum to look for polyps or cancer.

This question was asked to respondents age 30 and older. Some respondents required the help text to be read in order to understand the question. The help text reads, "Colonoscopy (colon-OS-copy) and sigmoidoscopy (sigmoid-OS-copy) are exams in which a doctor inserts a tube into the rectum to look for polyps or cancer." With the help text, almost all respondents were able to answer. A single respondent answered "Don't Know" because she had had a procedure but wasn't sure what it was called. She said, "I'm not sure. It was a long time ago. I think it was an endoscopy though." When asked why she had had the procedure, she said, "To check for hemorrhoids."

While almost all had heard of a colonoscopy, almost no respondents were familiar with a sigmoidoscopy procedure. Most respondent's basic understanding of a colonoscopy was in line with the definition provided in the help text. One respondent described the full procedure:

They go in with a camera into your colon and they look at the walls of your colon to see if there's anything in there in the colon. You have to really clean out your insides, your gut, and you can't eat, and you have to, you know, take these laxatives and it was just a really big production. I was glad to get it over with.

However, some respondents had more colloquial ways of describing the procedure. One respondent said, "To be honest I basically heard that they shove like an instrument up the back end and they kind of just look around and search around and they look for like cancer or whatever."

Respondents answered "yes" if they'd had a colonoscopy for any reason. Several indicated that they had had colonoscopies that were not for cancer screening. For example, one respondent answered "yes" and said, "I had one but it was for stomach pain. They looked for the reason for that. They also didn't find any cancer when they were up there." However, a single respondent answered "no" because even though she had had a colonoscopy, it was not for cancer screening. She said:

Colonoscopy the test as such, yes, but not the test to detect cancer. I had a test when I was very young, they put a small tube in the bottom, in my anus. They kind of evaluated the inside of my intestines and I don't know what else. They did that once when I was a kid because of [a medical problem], I don't remember. But not for cancer or anything like that. So, I do have knowledge of that test.

Respondents answered "no" if they had never had a colonoscopy. A few indicated that they had been told to get one by their doctors but had chosen not to. One respondent said, "I've heard of them. I have been referred for this test, but I don't want to have it, for personal reasons... Sincerely I have no interest in those tests, I tell the doctor I will go but I don't."

Response Error: Potential response error was seen in two respondents. Both respondents answered "yes" although they had not had a colonoscopy. One respondent confused a colonoscopy with a "colposcopy" which is a test to examine abnormal cells in the cervix. The other had taken a screening for colon cancer that involved a stool sample in a take-home kit from the doctor.

Spanish: Spanish Speaking respondents were slightly more prone to indicate that they were not familiar with either procedure, but no response error was observed.

COLORECTYP_A. Have you had a colonoscopy, a sigmoidoscopy, or both? Read if necessary: For a colonoscopy, the doctor checks the entire colon, and you are given medication through a needle in your arm to make you sleepy, and told to have someone take you home. For a sigmoidoscopy, the doctor checks only part of the colon and you are fully awake.

This question was asked of respondents who answered "yes" to the previous question on whether they had had a colonoscopy or sigmoidoscopy. The help text for this question reads, "For one the doctor checks the entire colon; they administer medication through a needle in your arm to sedate you and they tell you that someone has to take you back home. For a sigmoidoscopy the doctor checks only part of the colon and you stay wide awake. Did you have any of these?" However, none of the respondents required the help text.

Most respondents indicated that they had had a colonoscopy. Almost all respondents said that they did not know what a sigmoidoscopy was, but no response error was seen. One respondent said, "You know, I'm an X-Ray tech and I know where the sigmoid colon is but I don't know why they would specifically just do that. But, uh, no. I didn't have that. I had a colonoscopy."

Respondents were generally clear on the timeframe for when they had had the procedures and described it as a memorable experience. One respondent who said he had both the colonoscopy and the sigmoidoscopy said, "First, I had the colonoscopy in 2019 or 2018, now I'm due because it's every 5 years. And I had the other one done, like last year."

COLOREL_A. Have your biological parents, brothers, sisters, or children ever been diagnosed with colorectal cancer?

This question was asked to respondents age 30 and older. Two respondents answered "Don't know" because they were unfamiliar with their family's medical history. One said, "Well, what do you mean parents? Because I, for example, my dad, I don't even know who the hell he is!"

Most respondents answered based on whether there was a history of colon cancer in their immediate family. Respondents distinguished between colorectal cancer and other types of cancers. For example, one respondent who answered "no" said, "A few of my grandparents passed of cancer, but it wasn't colorectal cancer. Stomach cancer, ovarian cancer, lung cancer, but not colon cancer. It's a different cancer."

Most respondents were confident in their knowledge of their family's medical history. One respondent who answered "no" said, "I would know who in my extended family died of cancer. We are tight knit. It's a special cultural thing."

However, a few respondents who answered "no" expressed uncertainty. One said, "None except for my dad. I don't know actually what he died from. I know it was something with his stomach…but I can't say for sure what it was because the information I got was just second hand the person who told me didn't really know." Another respondent said, "I was a 3-year old when my mom died, so I can't say a lot. They always said she started with pain, then they said something about hemorrhage."

Most respondents paid attention to the list of relatives specified in the question. For example, one respondent said, "My aunt...had colorectal cancer, but you didn't ask about my aunt on that list." Therefore, this respondent answered "no." However, a few respondents included more distant or non-blood relatives. For example, one respondent included her grandmother. She said, "My grandmother had colon cancer I believe," while another respondent said, "My sister's husband, my brother-in-law died of that a few years ago." These

respondents initially answered "Yes" but changed their responses to "no" when the interviewer repeated the question.

Response error: Potential response error was seen in the respondents who did not know about their family's medical history and those who included more distant and non-blood relatives as described above.

MAMEV_A. Have you EVER HAD a mammogram? Read if necessary: A mammogram is an x-ray taken only of the breast by a machine that presses against the breast.

This question was asked of 54 female and other respondents, depending on the group they were assigned to as previously described, who were 30 years of age and older. All respondents were able to select an answer from the response options. A few respondents required the help-text to be read. One asked, "I'm sorry, what?" The interviewer repeated the question and the respondent said, "I don't know. What's that?" The interviewer then read the help-text and the respondent was able to answer "no." In another case, a respondent initially answered "yes" but asked, "Just to clarify, is the mammogram just the gyn testing me, examining me, or the machine?" When the help-text was read, the respondent changed her response to "no" and later when the interviewer asked her about her uncertainty, she said, "I don't think I've had a mammogram because my mom had it and she explained to me how it was. It's a machine that pushes your breast. That wasn't it. I was examined by a doctor."

Most respondents were familiar with a mammogram. Those who answered "yes" were able to describe the procedure in varying levels of detail. One respondent gave a detailed description of the experience:

It's kinda like an X-Ray...It's always cold. It's very cold in there. They want you to remove your top and your bra, and it's cold. They do give you the little gown, but you have to take that off for the procedure. Then they squish your breast between two pieces of plastic – and I mean squish it – to take their pictures.

Another said simply, "They put your breasts in that machine and squash it really flat and then I guess basically it's an Xray, isn't it?"

Some respondents who answered "no" had heard about the procedure. One respondent described her apprehension based on what she had heard:

I put it off, I'm nervous, and I believe that it hurts. I've had one scheduled several times and I either just didn't go or I kept putting it off. And I rescheduled it rescheduled it rescheduled it, and then I finally said I'm not coming because I'm afraid.

Gender: Male and transgender respondents were able to answer this question without confusion. One male respondent said, "Nope," and then jokingly pointed to his belly and said, "I may look pregnant but this doesn't apply to me." A transgender respondent answered "no" and explained that her goal is to not call attention to herself:

What I typically do. Don't raise any red flags. Because if I would have said, at my age, you know, I'm in my thirties, early thirties!...So if I would have said I never heard of it or I don't think I need it, or if I would have used I think there was one that said I'm too young or I'm too old, that would have raised a red flag because I'm not too young for one, I'm not too old for one. I'm actually probably at the perfect age to be getting one. And so it would have raised a red flag. It would also have made me look irresponsible. So it was kinda just the safest answer that I heard was, I just didn't think about it. Like it didn't cross my mind.

Response error: Potential response error was seen in a few respondents who thought the mammogram was a breast examination by a doctor. For example, when asked to describe her experience getting a mammogram, one respondent described her experience, "The doctor called me, and I went...He started touching my breasts. He started measuring me. The doctor started looking for things. He asked me if anything hurt and that's all he did."

MAMWHEN_A. About how long has it been since your MOST RECENT mammogram? (within the past year (anytime less than 12 months ago); within the past 2 years (1 year but less than 2 years ago); within the past 3 years (2 years but less than 3 years ago); within the past 5 years (3 years but less than 5 years ago) or within the past 10 years (5 years but less than 10 years ago); more than 10 years ago)

This question was asked of 32 respondents who indicated they had ever had a mammogram (2 were skipped due to time). All respondents were able to choose from the available response options.

Respondents all answered based on when they last got a mammogram. Respondents who had had a mammogram recently and those who had had a mammogram in conjunction with another event were most easily able to recall when their last mammogram was. For example, one respondent answered "Within the past year" and said, "That's easy! I had one 2 weeks ago." Another respondent said, "The last time I had one was in 2016. I was found to have early-stage breast cancer and then I had both of my breasts surgically removed because I have the BRCA gene mutation." Other respondents had a regular schedule for getting the procedure such as every two years at their gynecological checkup or yearly around their birthday.

Respondents who had mammograms more than several years ago were more likely to be uncertain of the exact timing. One respondent answered "Within the past 10 years" and said, "I know it had to be at least 5 years because I can't remember at all. To be exact, I can't say."

What is the most important reason why you have {NEVER had a mammogram / NOT had a mammogram in the past 2 years}? (no reason/never thought of it; didn't need it/didn't know I needed this type of test; doctor didn't order it/didn't say I needed it; haven't had any problems; put it off/didn't get around to it; too expensive/no insurance/cost; too painful, unpleasant or embarrassing; I am too young; other, specify)

This question was asked of 24 respondents who indicated that they had never had a mammogram or had not had a mammogram in the past 2 years (7 respondents were skipped due to time). All respondents were able to provide a response from the available response options.

Respondents all answered based on the reasons they had not had a mammogram recently or ever. Respondents generally answered based on the main reason they had not had a mammogram even when there was more than one reason. For example, one respondent answered "too expensive/no insurance/cost" and said that last time she had a mammogram, it was very painful. However, her main reason for not getting one was that she didn't have insurance and couldn't "get any medical procedures right now."

Some response categories were overlapping. For example, one respondent answered "put it off/didn't get around to it" and said, "Well it's a couple of those. I put it off, I'm nervous and I believe it hurts. I guess that's why I put it off," while another respondent said, "According to my insurance, I'm too young, so they won't pay for it." This respondent answered "Too expensive/no insurance/cost." Some respondents who had overlapping reasons answered "other." For example, one respondent said, "As I understand it, insurance covers it only after a certain age. I think it's not time yet for me and also, I have no symptoms so I don't need it."

CERVICEV1_A. There are two different kinds of tests to check for cervical cancer. One is a Pap smear or Pap test, and the other is the HPV or Human Papillomavirus test. Have you EVER HAD a test or tests to check for cervical cancer? Read if necessary: These are routine tests for women in which a doctor or other health professional takes a sample from the cervix with a swab or brush and sends it to the lab.

This question was asked to 69 adult (18+) female and other respondents, depending on the group they were assigned to as previously described. One respondent answered "Don't know" because even though she knew she had had a pap smear, she wasn't sure if it was to check for cervical cancer. She said, "I'm going to say I don't know. Pap smear? I have had a pap smear, but I don't know if it was to check for cervical cancer. Is that, like, part of the regular pap smear?" Similarly, a different respondent changed her answer. She initially answered "no" and explained, "I've only had a pap smear done." Later the respondent explained that the pap smear is done "to make sure I do not have an infection and to make sure everything is ok in the uterus." Upon reflection, she changed her response to "yes" assuming that one of the tests done during the pap smear was probably for HPV even though she had never heard of the test.

Most respondents were able to demonstrate familiarity with a pap smear by describing it in various levels of detail. One said, "I think what they do is they go inside, they open up your vaginal cavity with a spatula of some sort, and then they go in and they scrape the cervix and you get crampy. And so, yeah, that was my experience." While another described it as, "They stick their metal thing to make it big enough that they can get the swab in, and then swab some cells from the cervix and send them off to be tested."

In fact, most respondents answered based on whether they'd ever had a pap smear even if they weren't sure if it was for an HPV test or not. Most respondents knew what a pap smear was but had not necessarily heard of an HPV test. One respondent said, "Yeah. I had pap smears, but the HPV test- is that a colposcopy? Is that what you're talking about?" Another respondent said, "Sure I've had a pap, but I'm not sure about HPV." These respondents answered "yes" based on having had the pap smear.

Several respondents thought the pap smear and the HPV test were the same thing and also answered "yes." For example, one who answered "yes" said, "I don't know of two different tests for human papillomavirus. I've had a pap smear and I thought it was the same thing. I thought the pap smear was for all of that."

Gender: Males and transgender respondents were able to answer this question without confusion. One male respondent said, "I have not. I don't have a cervix." A few respondents were transgender women and therefore did not have cervixes. They all answered "no." One said simply, "That doesn't apply to me because I'm not biologically a woman."

Spanish: Several Spanish speaking respondents were not familiar with either a pap smear, an HPV test or in a few cases, cervical cancer. One said, "I've never heard of HPV," while another said, "I don't know what a pap smear is." A third respondent said, "Cervical cancer? Is that the same as colon cancer?" These respondents all answered "no."

When did you have your MOST RECENT test to check for cervical cancer? (within the past year (anytime less than 12 months ago); within the past 2 years (1 year but less than 2 years ago); within the past 3 years (2 years but less than 3 years ago); within the past 5 years (3 years but less than 5 years ago) or within the past 10 years (5 years but less than 10 years ago); more than 10 years ago)

The 41 respondents who answered "yes" to the previous question on cervical cancer screening were asked this question. All respondents were able to provide a response.

Respondents had answered the question on cervical cancer screening based on having had a pap smear and consequently, respondents answered this question based on when they had had their most recent pap smear. Respondents who had had a recent pap smear, had a regular schedule for getting a pap smear or who had one in conjunction with some other event were able to easily recall the time period. One respondent answered "within the past year" and said, "I go every year for an annual checkup. I get the pap done then." Another answered "10 years ago or more" and explained that she had her most recent pap smear in 2005. When asked how she recalled the year she indicated she had had one around the same time she had back surgery. "Then I stopped getting them because they are horrible. I was in menopause, had no family issues and there were no problems, so I stopped then."

A few respondents were not sure of the exact timeframe but made a guess. One said, "I don't know. My gut is telling me that it was when I was 25, so 2 years ago but I don't know if that's accurate."

What is the MAIN REASON that you have {NEVER had a test to check for cervical cancer / NOT had a test to check for cervical cancer in the last 5 years}? (no reason/never thought about it; didn't need it/didn't know I needed this type of test; too expensive/no insurance/cost; don't have a doctor; other)

This question was asked of 28 respondents who had not had a check for cervical cancer in the previous 5 years or had never had a check for cervical cancer (4 were skipped due to time). All respondents were able to answer using the available response options.

Since respondents generally understood the cervical cancer screening question as asking about pap smears, most respondents all answered this question based on why they had never gotten or had not recently gotten a pap smear.

Some respondents had a specific reason, such as lack of money, for not getting a pap smear within the past five years. For example, one said, "I was going to a particular clinic but then they just stopped letting me come. You know I need some kind of Medicaid or Medicare and I don't have any of those things. I had a job, but I couldn't afford what they were asking me to pay for the tests." This respondent answered "Too expensive/no insurance/cost." A transgender respondent answered "Didn't need it" and said, "Because we don't have a uterus do we?"

Other respondents chose a single response option but indicated that there were multiple, related reasons why they had not had a recent pap smear. For example, one respondent said, "I would pick a bunch of those options. A, B, and C all relate, to be honest. It's kind of a mix...I would say maybe the main one is I'm not too sure if I need it or not. Which is kind of connected to whether I have a doctor or not." This respondent ultimately chose "Don't have a doctor." Similarly, another respondent said, "It could be multiple- no reason, didn't know about it, doctor didn't order it. I haven't thought about it...I'm young and don't have any problems." In the end, this respondent chose "didn't know I needed it" which she thought encompassed all the other reasons that apply to her.

Response Error: Potential response error was seen in one respondent who didn't understand what a pap smear or an HPV test was. This respondent answered "haven't had any problems" but since she didn't know what it was, she couldn't say for sure whether or why she had never had one.

PSATEST_A. A PSA test is a blood test to detect prostate cancer. It is also called a prostate-specific antigen test. Have you EVER HAD a PSA test?

This question was asked of 50 male and other respondents, depending on the group they were assigned to as previously described, who were 30 years of age and older. (Four were skipped due to lack of time.) Four respondents answered "don't know" because they were not sure if they'd ever had the PSA test. One said, "I don't recall. I really don't. I would think I'd remember something like that. I've had a lot of different blood tests but PSA just does not sound familiar." Another respondent answered "Don't know" but said, "I think they did it. My doctor prescribed a pill to prevent the growth of my prostate and it was a result of the test that he prescribed it."

Most respondents answered based on whether they had had a PSA test. For example, one respondent who answered "yes" said, "Yes and this year I will have it again because I've had prostate issues, enlarged prostate, they have done studies but I have never had cancer. They do a blood test." A different respondent who answered "no" also demonstrated familiarity with the test. He said, "It's a test to detect if there's any cancerous enzymes in your prostate area. It's something that I'm due for soon, like the colonoscopy."

A few respondents answered "no" but indicated they weren't familiar with the test. One said, "Is it a blood test?" Another said, "I don't know what that is," when asked why he had answered "no."

PSASUGGEST A. Has a doctor ever recommended that you have a PSA test?

This question was asked of 35 respondents who indicated that they had not had a PSA test (PSATEST_A). Three respondents answered "Don't know" because they didn't remember being recommended to get a PSA test, but they weren't sure. One said, "I don't recall. I don't think so. You got me thinking. I don't know."

Most respondents answered based on whether a doctor had ever recommended getting a PSA test whether they had gotten a test or not. One respondent who had gotten a PSA test answered "no" and described the interaction with his doctor:

I just went to the doctor one day and asked, 'Hey, how does this work, could I, does it hurt?' and my doctor's very understanding so he said, 'Well, I don't think you need one, but hey, let's run it,' and that's what we did.

Another respondent who had not gotten a PSA test also answered "no" and said, "Not yet. But they will probably start mentioning it now that I am in my forties."

A single respondent answered on the basis of his doctor mentioning the PSA test although it was not recommended. He said, "I get an annual checkup and the doctor had mentioned it, but she also said I did not need to do it yet."

Gender: Female and transgender respondents were able to answer this question without confusion. One female respondent said, "No. I hope not. That would be weird. Just skip those questions about the prostate." A few respondents were transgender women who had had a PSA test previously. One explained that she had a friend who had prostate cancer so she had requested the test from her doctor. Even though she was young and the doctor didn't think she needed the test, he gave it to her to reassure her. Therefore, this respondent answered "yes."

PSAWHOSUGGEST_A. Who first suggested your MOST RECENT PSA test: you, your doctor, someone else, or no one suggested the test?

This question was asked of respondents who indicated that they had had a PSA test (PSATEST_A). Respondents all answered on the basis of who had recommended their most recent PSA test. For example, one respondent answered "doctor" and said, "When I went for a check-up, my doctor said, 'Let's do a

prostatic antigen test to see how you're doing." The respondent who answered "no one" said, "It's not like anyone suggested it. My medical plan includes it in the annual checkup."

PSAINFO_A. Did you use informational materials to help you decide whether to have a PSA test? Informational materials might include pamphlets, videos, or information accessed on a computer or mobile device.

This question was asked of the 13 respondents who indicated that they had had a PSA test (PSATEST_A). Respondents answered based on whether they had reviewed educational materials in order to decide whether to have a PSA test. One respondent answered "no" and said, "I was already pretty well educated on that," while another respondent said, "My doctor did it based on my symptoms."

A single respondent answered based on viewing informational material even though this was not what he used to make his decision. This respondent answered "yes" and said that he saw some information videos on YouTube, but ultimately, he always relies on his doctor's advice and gets whatever tests his doctor recommends.

SUNSKIN_A. After several months of not being in the sun, if you THEN went out into the sun without sunscreen or protective clothing for one hour, which of these would happen to your skin? Would you get a severe sunburn with blisters, have a moderate sunburn with peeling, burn mildly with some or no darkening or tanning, turn darker without sunburn, or would nothing happen to your skin? (get a severe sunburn with blisters; have a moderate sunburn with peeling; burn mildly with some or no darkening/tanning; turn darker without sunburn; nothing would happen to my skin; do not go out in the sun)

This question was asked of all respondents except five who were not asked the sun safety questions due to lack of time.

In general respondents either answered this question based on a hypothetical or on their own experience of sun exposure. All respondents were able to provide a response although for quite a few respondents, the hypothetical nature of the question was challenging. One respondent asked:

So that first part of the question says, after several months without sun. That's a very interesting question because I feel like every day I go outside, it's usually sunny, you know it's like, sunny...Is this question just assuming that there was a time when there was absolutely no sun...like if we went a month and there was no sun?

While another respondent said:

I don't know...that seems like a vague question. I mean, most people go out a lot. I think that that might be a question for somebody who is like immobile. Or someone who has a sedentary lifestyle, who has other health conditions.

Both of these respondents resolved their confusion by answering based on their personal experience of sun exposure.

Other respondents were able to answer based on a hypothetical scenario. One answered "Burn mildly with some or no darkening" and then said, "Hypothetically...That's my best guess, yeah." While another

answered "Have a moderate sunburn with peeling" and explained, "That's probably what would happen. My skin is light, so I think that's what it would look like, based on my skin tone."

Several respondents noted when answering hypothetically that their response could vary depending on factors that were not specified in the question. One respondent said, "I'll answer the third one, but it really depends on the intensity of the sun. I mean, the sun is different when you're sitting on the beach than running errands." Similarly, a different respondent said, "Hmmm. There are so many variables that I would have to ask about, but I would probably burn and peel. So that would be the second one." A third respondent demonstrated how respondents were able to fill in the details of the hypothetical scenario:

This is such a contextual question. Like, where is the sun? If we're in Pennsylvania, then probably nothing [would happen to his skin]. If we're in Cancun? Then, you know – I'm thinking about all the places it would be nice to get some sun – yeah, then it's a very different story. We'll just split the difference and say maybe North Carolina. Probably one of the less severe ones and there, I'd turn a little pink.

Another respondent imagined a slightly different scenario. He answered "Severe sunburn with blisters" and said:

Being in the house for a year and then being outside in a hot summer day, I believe I would get severely sunburned. I don't want to get a burn. I usually go outside every day, so this has never happened to me. I've never been inside for a year.

About half of respondents ignored the hypothetical and answered based on their own experience of sun exposure. For example, one respondent answered "Get a severe sunburn with blisters" and described the sunburns she gets as "very, very painful if you touch it. Flexing my joints is painful, walking is impossible. You feel hot. You definitely don't want anything to touch you, not even clothes. The only thing that seems to help is aloe. It's horrible." Another respondent answered "turn dark without sunburn" and explained "I've never experienced sunburn. I answered this based on my recent week. My wife noticed that my color is maybe a little bit darker now, so I can say I can get darker after being in the sun."

Other respondents thought about incidents of sun exposure as children even though they had not had a sunburn in many years. One respondent answered "moderate sunburn with peeling." She said, "I don't have to guess. I know because as a child when we went to the shore I would get sunburnt. But now as a grown up, no. We are more careful."

A single respondent answered "Don't go out in the sun" because she avoids the sun and she wears a hijab so her skin is never exposed.

Response categories: At times, respondents had difficulty choosing between the response categories when they felt that the categories did not accurately describe their experiences. For example, one respondent initially said, "Hmm...I would get a sunburn with peeling and then I would turn a little tan. I don't think that was an option." This respondent eventually answered "moderate sunburn with peeling." Another respondent described a severe sunburn that "turned dark purple it was so bad" but had difficulty choosing the first category because she "never did blister." Similarly, a different respondent initially tried to answer "Burn mildly with peeling." When the interviewer tried to clarify by suggesting the category "Burn moderately with peeling," the respondent said, "Well, it was really a mild burn but on the other hand, I did peel." She decided to choose the category that included peeling.

A few respondents described turning red but did not consider it sunburn. One respondent answered "turn darker without sunburn" even though he typically turns red with sun exposure. He explained:

It wasn't really on there but I would say I'd be a little bit red. It wouldn't be to the point of a burn because it doesn't hurt. At all. But I would definitely be red. I think the answer I said was darker...to me, turning red is not a good color, so it's darker. To me, when the question said darker it means more of a tan. But since there wasn't a 'turning red but not burning' answer, I gave you the 'darker' answer.

A few respondents noted that they get rashes from sun exposure, and did not see this experience represented in the response options. Most of these respondents answered as best they could from the available response options. For example, one said, "I guess you could say the third option. I get a little rash but it's not every time. Sometimes I get a little red but no rash at all." However, done respondent answered "don't know" because her primary symptom from sun exposure is a severe rash. She said, "It's not a burn at all. It's a rash."

SUNTAN_A. When spending time outdoors, how often do you try to get some sun for the purpose of developing a tan? Would you say always, most of the time, sometimes, rarely, or never?

This question was asked of all respondents except five who ran out of time to complete the interviews. All respondents were able to provide a response except for a single respondent who did not understand the question well enough to provide a response. She said, "I do go outside. I try to go out everyday...and sit on my porch. It rains a lot here, so you don't get a lot of sun. I'm not sure." Indeed, for many respondents, there were three different and sometimes competing parts to this question: 1. Spending time outdoors; 2. Try to get some sun; 3. For the purpose of developing a tan. Although other respondents were able to answer the question, some still expressed confusion about how to balance these three elements of the question. For example, one respondent described his difficulty saying:

That was a hard one because I think that it's both. A lot of the time I'm subconsciously like yes, I want to be darker, but it's not the sole focus. It's primarily swimming so we do a lot of, like, lake days in the summer so like I'm going outside to swim, not necessarily to get darker, but I think that it's a plus, like I like to tan.

This respondent ultimately answered "most of the time" because usually she spends time outdoors in order to do activities and also to tan. Another respondent expressed similar difficulty. She said, "Ahh...that's a convoluted question for me. It's a tough one because I DO get sun everyday, but it's not for the purpose of getting a tan, so I'm stuck on how to answer this one." When pushed to provide a response, the respondent said, "If it's worded the way you worded it—for the purpose of getting a tan—I'd say never."

In fact, some other respondents were also able to answer based on whether they intentionally try to darken their skin when they are outdoors. For example, one respondent answered "never" and explained, "I don't have time to sit out in the sun for a tan. I wish." Another respondent explained his answer saying, "Because most of the time that's what I want to do when I go outside, is I want to get some color. It helps boost my mood. Especially when you are stuck inside for the winter." Another respondent answered "never" and explained:

I've never been a suntan person. I grew up on an island, so to me, that was just life, being out in the sun, so I purposely don't go out in the sun for that. I know instinctively the sun will do that to my skin. I don't need to tan for any reason. Some people feel they look better nicely tan. I don't have that.

However, other respondents weren't thinking of intentionally tanning. Some thought of whether or not they get a tan (unintentionally) or whether they are able to get a tan. For example, one respondent answered

"sometimes." She explained that she doesn't try to tan but sometimes "when I'm on a cruise or something" she ends up with darker skin. Another respondent answered "never" and explained, "I don't tan. I beige or burn. Even when I try."

Another group of respondents didn't think about tanning at all but instead focused on other benefits of being in the sun. One respondent answered "always" and said, "Well I just like being in the sun...I'm kind of like a lizard, in the fact where I just sit and like, soak it up, and I think it feels good. I'm very anal about sunscreen though, and I do wear sunscreen (grimaces) 95% of the time I do, you know, especially if it's that hot, like UV 7 or 8." Several respondents specifically mentioned Vitamin D like one respondent who said, "Yeah. I said 'most of the time' because in winter we try to sit outside also to get some vitamins. Vitamin D and stuff." Similarly, a third respondent answered "sometimes" and explained:

After work I usually try to take a walk so that I'm actually exposed to the sun. I also try sometimes on the weekends to spend some time in a park. Just to get some more sun. I think it's healthy for vitamin D and also any sort of acne. And then I just enjoy the experience of being under the sun...I don't really go out for the purpose of that [tanning]. It's [tanning] just a consequence of me wanting to be outside, so I kind of just accepted it.

ANYSUNBURN_A. During the past 12 months, did you ever have a sunburn?

This question was asked of all respondents except five who ran out of time to complete the interviews. Most respondents understood this as a question about whether their skin had turned red from sun exposure in the past year. For example, several respondents talked about specific incidents when they had forgotten sun protection. One of these respondents described an incident:

Actually I did get a sunburn last year when I went to the beach because I think we were trying to get quickly out there, to the beach before it got too crowded, and I left the sunscreen. I left the sunscreen and then I fell asleep out there without the sunscreen and I definitely got a sunburn.

Other respondents burn regularly enough that they could not recall specific incidents but were sure that they had burned in the past year. For example, one respondent said, "I'm sure I have. I'm going bald, so I'm sure I had sun up there." Similarly, another respondent said, "My face will burn or my shoulders. I can't think of any times I've been really badly burnt, but I go to the lake a lot and there were probably 3-4 times."

Respondents who answered "no" described ways that they protect their skin from the sun or described how their skin type is not prone to burning. One respondent said, "I get the sunscreen for babies. And I wore, you know, long sleeves and jeans." Another said, "With my skin, I don't burn. I don't think I've ever burned."

Potential response error was seen with a few respondents who were not exactly clear on the definition of sunburn. For example, one respondent described turning slightly red but did not think it was severe enough to count as a sunburn. He said:

What defines a sunburn? Did you need to get a skin graft? Did you just need a bottle of Sunbum [after sun] to clear something up? I had a vacation in the first week of February – we were down in Florida – and I got a little too much sun on my head and shoulders. It wasn't severe. Would I call it a sunburn? Probably not. Would a doctor call it a sunburn? Yeah, I probably got too much UV. That's a very...there is a lot of room for interpretation with that question.

Another respondent answered "yes" but he described turning red from heat rather than from the sun. This respondent was originally from East Asia and was not familiar with the concepts of sun tanning and sunburn.

He said, "When I was in [home country], there was a temperature of 52, 48 [degrees Celsius] something like that. Especially heat, sweat, so um...when I was there I went outside in the open air then, and, I really felt a lot of sunburn with the heat.

NUMSBURNS_A. During the past 12 months, how many times have you had a sunburn?

This question was asked of the 50 respondents who indicated that they had had sunburn within the past year. Answers ranged from one to "maybe fifty?" sunburns in the past year. Some respondents remembered specific incidents and were easily able to recount the exact number of sunburns. For example, one respondent answered "one" and described the incident, "It was last August because we go back to the lakes every year and we were out on the boat and you know, in the pool, all outside…all the ways to get sunburned."

Most respondents, however, were not sure of the exact number. One respondent initially reacted to the question, "Do people actually remember this?" For these respondents, it was easier to provide an estimate like one respondent who said, "I'd say like 15? I guess? That's a good ballpark, maybe." Some respondents explained how they came up with their estimates. For example, a different respondent described her thought process:

I know that twenty sounds like a lot, but I feel like it is because I'm out a lot during the summer. I didn't want to pick too many days and seem dramatic. But I thought about the months of summer, so there are thirty days in a month and I go out about half of those days....I don't know, I picked thirty originally but that seemed like too many, so I was like twenty.

In addition to difficulties in recounting the exact number of sunburns, a few respondents weren't sure what to count as a sunburn. One respondent explained how this impacted his response:

That's 2 things that I was unsure about. One is, what counts to me as a sunburn. Because I've gone on hikes where I get a little bit red on my arms but then there's nothing afterwards. Whereas I can also think of times where I've been at the beach. I've seen my color change and then for a week after I've been putting aloe on to avoid peeling. So I was estimating, but on 2 counts. What do I think you consider a sunburn vs. what I would consider an actual sunburn - real red over more than just a little corner of my arm. I'd say that was less than 10, but I went up to 10 to add those other times when I would've gotten lightly burned.

A single respondent answered "Don't know" because the context of the question did not make sense to him. He is originally from East Asia and is not familiar with the concept of suntan and sunburn. To him, sunburn means "when your skin gets red from excessive heat." For this question, he said, "I protect [my skin] when I go outside. Because the sun temperature is high. The heat is so intense, people do not put their skin out bare in the sunshine. I don't know how often I have felt this heat. It's ambiguous."

SUNBURN1_A. The next six questions refer to the most recent time you were sunburned. Think about the MOST RECENT time you got a sunburn. Were you working at your job when you got sunburned?

This question was asked to the respondents who said they had had a sunburn in the past year. All respondents were able to provide a response, and all understood that this question was asking if they had been working the last time their skin was damaged by the sun. However, a few respondents were not exactly sure when their most recent sunburn was. These respondents offered plausible guesses. For example, one respondent

answered "no" and said, "I don't really know when it was but I go to the lake a lot, so it was probably at the lake. It wouldn't be when I'm working."

Other respondents were able to identify the specific circumstances of their most recent burns. For example, one respondent answered "Yes" and explained I'm a nanny. I pick the kids up from school. I play with them outside or we'll go to the park together. And that's why I got sunburn. When you're with kids, you're not thinking, let me reapply my sunscreen." Similarly, another respondent answered "no" and said, "Yeah, it was when we went to Disney. We rented an Air BnB and it had a pool. We were all outside in the pool. We had a covering outside the house, but we still got a burn."

SUNBURN2_A. Thinking about the MOST RECENT time you got a sunburn...were you trying to get a tan?

This question was asked of all respondents who indicated they had had a sunburn in the past year. One respondent was unable to provide a response because he did not understand the concept of sun tanning. He had grown up in a country where tanning is not a common cultural practice.

Other respondents answered based on whether they had intended for their skin to darken or not. For example, one respondent said, "Yeah. I like to get darker," while another said, "No. I never intentionally try to tan."

Responses varied for respondents who thought of tanning as a secondary benefit and not their primary purpose for being in the sun. For example, one respondent described going to the beach. She said, "Yeah. When I go to the beach, my intention is to get a tan. Yeah, it is. But I didn't intend to get burned. Like I said, I forgot to bring the suntan lotion, you know, the sunscreen." However, a different respondent answered "no" because although she put on a bikini and knew she would get tan while she was reading out by the pool, tanning was not her primary activity.

SUNBURN3_A. {READ IF NECESSARY: Thinking about the MOST RECENT time you got a sunburn}...were you being physically active?

This question was asked of all respondents who indicated that they had had a sunburn in the past year and all were able to provide a response. However, a few respondents were not exactly sure when their most recent sunburn had been. These respondents offered plausible guesses. For example, one respondent answered "yes" and said, "If I'm outside. If I'm in the sun, I'm probably moving around, so yes."

Most respondents made a distinction between doing physical activities such as fishing, swimming, boating or walking versus "Just sitting there sizzling in the sun." For example, one respondent answered "yes" and said, "We were, like, hanging out on the beach, throwing the football around and stuff." Another respondent answered "no" and said, "I was just laying on the beach. I just went out there and I was tired, I just fell asleep. I went to sleep for a couple of hours and I got up and I was like, oh my god." A third respondent answered "yes" and described the day's activities:

So we drove out to [a pond], it's down like thirty minutes, and we go out to the lake. They have, like, a lake there, it's like a pond-lake, I don't know. And there's like a barbeque area, and so we were like drinking, and we were having like a little lunch and then we were, like, swimming all day and going back and forth in and out of the water. Yeah, so I was like, yeah, we were being active, swimming.

A few respondents were thinking specifically of exercising, so even though they were doing physical

activities, they answered "no." For example one respondent said, "We were swimming, so no." When asked what she thought the question was asking she said, "Was I playing basketball, was I out for a run? Was I exercising?" This respondent answered "no" because she was "just casually swimming" and not exercising.

SUNBURN4_A. {READ IF NECESSARY: Thinking about the MOST RECENT time you got a sunburn}...were you spending time in, on, or near the water, such as at a pool, lake, or ocean?

This question was asked of all respondents who indicated that they had had a sunburn in the past year and all were able to provide a response. However, a few respondents were not exactly sure when their most recent sunburn had been. These respondents offered plausible guesses. For example, one respondent answered "yes" assuming that her last sunburn had been during one of her frequent trips to a nearby lake.

Almost all respondents understood this question as asking if they were on or near water when they got their most recent sunburn. One respondent answered "yes" and said, "I spent a lot of time by the apartment pool last summer." Similarly another respondent answered "no" and described working in a field.

A single respondent answered "no" because he was fishing from the shore. He was not in or on the water when he was sunburned. "I wasn't in the boat that time, but I did catch some wall eye," he said.

SUNBURN5_A. {READ IF NECESSARY: Thinking about the MOST RECENT time you got a sunburn...} were you using sunscreen?

This question was asked of all respondents who indicated that they had had a sunburn in the past year and all were able to provide a response. However, a few respondents were not exactly sure when their most recent sunburn had been. These respondents offered plausible guesses. For example, one respondent answered "no" and said, "I'm sure I wasn't. I never do."

Other respondents thought about whether they were wearing sun protection lotion when they got their most recent sunburn. One respondent answered "yes" and described spending all day at a pool on vacation. She said, "We were wearing sunscreen but it was just melting off." Another respondent answered "no" and noted, "If I'd been using sunscreen, I'd probably be fine, but it just wasn't on my to-do list to put sunscreen on."

SUNBURN6_A. {READ IF NECESSARY: Thinking about the MOST RECENT time you got a sunburn...} were you drinking alcohol?

This question was asked of all respondents who indicated that they had had a sunburn in the past year and all were able to provide a response. However, a few respondents were not exactly sure when their most recent sunburn had been or the specific details of the burn. These respondents answered based on a probable scenario. For example, one respondent answered "yes" and explained, "Well...I would have been doing yardwork so I would have had a drink."

Other respondents answered based on whether they had consumed alcohol when they got their most recent sunburn. For example, one respondent answered "no" and said, "I'm under 21 so I can't drink." Another respondent answered "yes" and said, "We were playing frisbee and drinking beer."