

Cognitive Interviewing Study Findings of the Uniform Blood Donor History Questionnaire

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Summary of Findings

This report describes a cognitive interviewing study conducted by the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS) to examine the performance of the long form version of the American Association of Blood Banks (AABB) Uniform Blood Donor History Questionnaire (UBDHQ). The questionnaire is used by most U.S. blood centers to screen potential blood donors. Study objectives were to assess question interpretation, understand potential donors' processes for formulating a response, identify question design problems that could increase inaccurate reports, and compare interpretations between those in different geographic regions. Given current scrutiny of the blood donor deferral policy of Men who have Sex with Men (MSM), interpretations between MSM and non-MSM respondents also were compared. One hundred and sixty-six cognitive interviews were conducted among a diverse group of respondents in five locations across the United States; MSM were intentionally over recruited.

An important distinguishing factor about this questionnaire evaluation is that respondents clearly understood its purpose. All respondents understood that the goal of the questionnaire was to screen out those with blood that could transmit infection. This understanding influenced respondents' interpretation of each question. This interpretation, however, sometimes led respondents to provide answers that were factually incorrect, although they accurately addressed the question's intent. Respondents providing inaccurate answers did so by discounting experiences or events that they did not believe make their blood unsafe. This type of response error existed for

nearly all questions in the questionnaire, as respondents viewed each question as asking whether their blood could transmit infection. Considering respondents' near universal understanding of each question as a screener also explains the little variation in question interpretation found between demographic or regional groups.

This report will first outline overall findings including overarching patterns of interpretation and question response problems. Next, a methods section will detail the rationale as well as the steps used to conduct the study. Finally, a question-by-question review will detail the performance of each question.

Overall Interpretation of Questionnaire Intent: “But my blood is safe”

The following are examples of respondents' interpretation of questions which sometimes led respondents to provide answers that were factually incorrect. When asked why he failed to include a recent trip to Mexico in his response to the question about leaving the United States, one respondent from Los Angeles answered “well I was really only there for a day and it's not like I had contact with anything that would have gotten into my blood.” Another respondent, when discussing his needle use, said “I take B-12 shots but I didn't really count those. I mean it's not like those are going to contaminate your blood or anything.” As these examples illustrate, respondents providing inaccurate answers did so by discounting experiences or events that they did not believe make their blood unsafe.

It is important to distinguish this interpretive phenomenon from the idea that respondents are *lying* when providing inaccurate answers. To be sure, it was not the intent of respondents to knowingly provide deceitful information, but rather to be—as they saw it—helpful, providing the correct information based on their understanding of questions.

Interpretive Variations in Understanding the Concept of ‘Sexual Contact’

The informational material associated with the questionnaire provided a definition of sexual contact as follows:

Definition of “sexual contact”: The words “have sexual contact with” and “sex” are used in some of the questions we will ask you, and apply to any of the activities below, whether or not a condom or other protection was used:

1. Vaginal sex (contact between penis and vagina)
2. Oral sex (mouth or tongue on someone’s vagina, penis, or anus)
3. Anal sex (contact between penis and anus)

Most respondents, however, did not read the educational materials thoroughly, and even among those who read the materials, not all applied the stated definition. In general, respondents understood sexual contact in one of two ways: 1) as oral, anal, or vaginal intercourse where penetration of some kind occurs, or 2) a broader definition including fondling and kissing. Men who had reported having had sexual contact with another man at least once since 1977 were more likely than non-MSM respondents to consider sexual contact in broader terms. It appeared that men who had sexual contact with another man but did not identify as gay (MSMNG) were even more likely to define sexual contact in broad terms. It also appeared that cognitive interview respondents from Washington, D.C., Los Angeles, and Salt Lake City were more likely to conceptualize sexual contact in narrow terms while respondents from Mobile/Biloxi were more likely to conceptualize it more broadly. This is one of the few regional interpretive variations found in this project. Although respondents did not interpret ‘sexual contact’ to mean the same thing, individual respondents’ interpretations did not vary across questions. That is, respondents did not understand ‘sexual contact’ in one way for one question and in another way for a different question. This is counter to previous cognitive interview studies of survey questions that found respondents’ interpretations of ‘having sex’ to differ across questions depending on their interpretation of the particular question. The lack of variation across questions is likely due to the dominant understanding that all questions in the UBDHQ serve as filters in determining whether blood is infectious.

Several questions ask about having had ‘sexual contact’ with a person with particular characteristics in the past 12 months (specifically questions 17-22). In forming an answer, the questions required respondents to consider two primary factors:

1) if and who they had had sexual contact (as they defined it), and 2) whether that partner(s) had the given characteristics asked by the question. For those with multiple partners, the task involved recalling all previous partners, ensuring that those within the specified time frame of 12 months were included. For respondents in monogamous relationships, the task was much simpler in that no recall processing was required.

Regardless of respondents' relationship status, however, the sexual contact questions required that respondents report on others' (i.e. their partner/s) behavior. In this regard, it was impossible for respondents to answer full knowingly as they would be able to for themselves. Therefore, in order to answer, respondents were required to make considerations and rationalizations regarding their partner. The most common response given to each of these questions was "not to my knowledge." While some respondents insisted that they only had sex with people they knew well and so were "absolutely certain" that these individuals did not have the characteristics described in the questions, many acknowledged that there was no way for them to really know whether or not their partner(s) had ever engaged in certain activities. Most of these respondents still answered the questions 'no,' however, indicating that they were "certain enough" and so felt that there was no risk of them having an infection as a result of their partner's potential activities. Although there was generally an acknowledgment of uncertainty, answers were based on the assumption that partners had either been honest or would have been forthcoming and, most importantly, that their blood did not pose a risk.

This finding is consistent with the previous finding: respondents interpret questions through the lens of their own blood safety. For example, one female respondent discounted a sexual experience she had had with a partner who she suspected of having used illegal drugs because she said "well even if he had something, he didn't give it to me so I figured what's the point [of reporting it]. I mean they just want to know if your blood is bad anyway, right?" Although respondents could not be certain of their partners' behaviors, given that their understanding of the questionnaire was to screen out those with unsafe blood, they did feel certain that they were giving accurate and knowable answers.

MSM vs. Non-MSM Interpretive Differences

One specific area given special analysis during this study was that of potential interpretive differences between MSM and non-MSM respondents across all questions. Few interpretive differences were found, including the question about sexual contact with another male. One potential exception is that MSM respondents tended to be more aware of what various sexually transmitted diseases were and had been tested more recently and more often. Another exception is that MSM respondents were less likely to answer questions without referencing a relationship and appeared more likely define ‘sexual contact’ in broader terms. In general, however, MSM and non-MSM respondents interpreted questions through the same general lens.

Regional Variations in Interpretation

Another research question of the study was that of potential interpretive differences between different regions. As with the MSM/non-MSM focus, few regional variations in question interpretation were found. That said, it is worth noting the minor regional variations:

- Los Angeles, CA:
 - Visits to Mexico were often not counted as international travel either because they were less than one day or simply forgotten. This may be due to the proximity of LA to the international border.
 - Respondents were more likely than in other regions to have heard of Babesiosis (although no respondents reported having had it). This is most likely because of a recent outbreak of the disease in the area and its increased mention in local media.
- Salt Lake City, UT:
 - Many respondents processed questions through a religious framework. For example, respondents often prefaced their answers with comments like “well according to the LDS [Latter-Day Saints] religion...” or “because I am Mormon...” in order to explain their responses. This is most likely because of the very high presence of Mormons in the area.

- Mobile, AL / Biloxi, MS:
 - The term ‘hemophiliac’ was most often referred to, and better understood, by respondents as a ‘free bleeder.’

Despite these somewhat minor regional variations, there was no significant impact by region on response patterns. It is possible that other variations in interpretation might exist – for example urban vs. rural – that were not examined in this project.

Respondent Difficulties

By and large, respondents did not experience difficulties answering questions. Since questions were seen as filter questions for infectious blood and since respondents viewed their blood as being safe, uncertainty was typically handled by answering ‘no.’ As discussed above, questions regarding sexual partners—questions that could not be answered full knowingly—were also answered negatively. Questions that used terminology that were unfamiliar to most respondents (e.g. Babesiosis, Crutzfeldt-Jakob Disease, Chagas Disease and donation by apheresis machines) were also almost always answered negatively. As one respondent stated: “When I don’t know something, I just say no.”

For certain questions, however, some respondents did experience difficulty when attempting to answer within the yes/no response categories. Some of these respondents wrote ‘don’t know’ or ‘maybe’ to the side of those questions, while others declined to answer. For example, when answering the question about taking any other medication for an infection, one respondent declined to answer stating “Well I have Herpes and I take medication for that. But is Herpes an infection? Or just a condition? I don’t really know.”

The dichotomous nature of the questionnaire – the available options being only “yes” or “no”, and, more specifically, the lack of a “don’t know” option – compels respondents to answer the best they can with the information available to them. Although some respondents simply failed to answer particular questions, most respondents felt that they needed to answer every question, even if they acknowledged that they could not be 100% certain of the validity of their response.

METHODOLOGY

The method used to examine the performance of the Blood Donor History Questionnaire was cognitive interviewing. Cognitive interviewing is the primary method used by the federal statistical community to ensure data quality. It is also the only known method that can provide insight into question validity, that is, insight into the phenomena that a question actually captures—the substance that makes the statistic. The aim of cognitive interviewing is to investigate how survey questions perform when asked of respondents, specifically, how respondents understand a question and how they go about forming an answer. Cognitive interviewing is a qualitative method that provides rich, contextual information regarding the ways respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and whether or not it ultimately serves the scientific goal. Findings from a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation. (For a more thorough discussion of cognitive interviewing, see Miller, 2011).

Recruitment and Respondent Demographics

To test the newly revised questionnaire, the QDRL conducted 166 cognitive interviews in five locations across the country. These interviews were conducted in Washington, D.C., Los Angeles, CA, Austin, TX, Salt Lake City, UT, Mobile, AL, and Biloxi, MS. These locations were selected to represent the geographic and cultural diversity of the United States. Interviews took place between February 2012 and November 2012. Respondents were recruited through the QDRL database, newspaper advertising, flyers, word-of-mouth, on-site recruitment, and the assistance of on-location facilities.

Table 2 presents respondent demographics for the study. Respondents were selected using a purposive sample. The goal of a purposive sample is *not* to obtain a

statistically representative sample. Instead, respondents are chosen according to characteristics that would screen them into or out of certain questions. Emphasis is on coverage of the survey questions and research topics, *not* the survey population. An attempt was made to capture a diverse range of respondents but particular emphasis was placed on recruiting MSM respondents, whether or not they identified as gay.

Table 2. Respondent Demographics

Interviews Completed:		166
	Count	Percentage
Gender		
Male	104	62.7
Female	62	37.3
Marital Status		
Currently Married	39	23.5
Divorced	26	15.7
Never Married	96	57.8
Separated	2	1.2
Widowed	2	1.2
Refused	1	0.6
Education		
Less than HS degree	4	2.4
High School Degree/GED	18	10.8
Some college, no degree	53	31.9
Associates Degree	25	15.1
Bachelors	40	24.1
Graduate School	26	15.7
Race		
White	80	48.2
African American or Black	14	8.4
Indian American or Alaska Native	2	1.2
Asian or Other Pacific Islander	3	1.8
Multiple	55	33.1
No Answer	8	4.8
Hispanic or Latino	37	22.3
MSM Status		

MSM	59	35.5
MSM not gay	8	4.8
Non-MSM	99	59.6
Age		
18-29	51	30.1
30-49	63	38.0
50-64	36	21.7
65 and over	16	9.6
Site Location		
Washington, DC	40	24.1
Los Angeles, CA	31	18.7
Austin, TX	33	19.9
Salt Lake City, UT	30	18.1
Mobile, AL and Biloxi, MS	32	19.3

Approximately 63% of respondents were male. This slight over-representation is because of the emphasis placed on over-recruiting men who have sex with men, who made up nearly 40% of the entire sample. A diverse range of marital status was also included although more than half were never married. Education levels varied from having less than a high school degree to respondents who had completed a doctorate. The bulk of respondents, 87%, had at least some college education. Slightly less than half of all respondents identified as white although there was a wide range of racial identification, with one-third of respondents claiming multiple racial identities. Additionally, over one-fifth of respondents identified as Hispanic or Latino. A broad range of age was represented among respondents with roughly one-third being under 30, one-third being between 30-49, and one-third being over 50 years of age. Finally, each geographic region compromised roughly 20% of the sample with a slight over-representation in Washington, D.C. as this was the pilot city.

Interviewing Procedures

Respondents were scheduled for specific interview times (with the exception of a few “drop-ins”) and reported to a set location for their interview. Interviews lasted between 30 and 60 minutes with the typical interview lasting from 45-60 minutes. All interviews were audio recorded using a video recorder or a microphone attached to a

laptop computer. Respondents were asked to check an anonymous consent form before the interview began and were also asked to give their oral consent once the taping began. At the conclusion of the interview all respondents were given \$50 as remuneration.

Respondents were then asked to fill out the full length version of the UDHQ as if they were actually about to donate blood. Respondents were also presented with all associated materials (education sheet, medication list, country sheet) before being asked to fill out the questionnaire. At the conclusion, respondents were asked each question and were then asked to explain their answer. Typical follow-up questions included, “How so?” and “Why do you say that?” If a respondent’s answer seemed vague or unclear, the interviewer asked: “Can you give an example to describe what you are talking about?” Specifically for the sexual contact questions, respondents were also asked how they typically defined sexual contact. The culminating text in this report related how respondents understood or interpreted each question and also outlined the types of experiences and behaviors respondents considered in providing an answer.

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). Analysts used Q-Notes, an analysis software tool developed by the National Center for Health Statistics. As data were entered into the Q-Notes software, patterns of question interpretation and cognitive processing difficulties were identified. Some analyses, specifically assessment of question performance and identification of difficulties, were conducted simultaneously with interviews. This iterative process allowed for modified probing questions on what were viewed as emerging key issues as interviews continued.

Analysis of cognitive interviews can be conducted from transcribed interviews or, as is often the case, from interviewer notes. The texts of the interviews (either transcribed materials or interviewer notes) are collated by question so that comparisons can be made systematically across all respondents. Several levels of analysis can typically be performed. First, distinct occurrences in which respondents experience difficulty or confusion while answering are identified. Additionally, specific instances or

patterns of error are also noted and, most importantly, the particular causes of those errors are identified. In addition to response errors, analysis of cognitive interviews can be conducted to reveal patterns of question interpretation. By comparing each respondent's interpretation to a particular question, patterns can be identified and then examined for consistency and degree of variation among respondents. This type of interpretive analysis does not necessarily illustrate overt response errors, but rather provides deeper insight into the substance of the actual meaning that constitutes the survey data.

In order to specify the dimensionality of the themes and categories, respondents' narratives were compared, resolving any discrepancies and noting similarities. Additionally, the relationship of the themes and categories were examined. These core themes served as the unifying link between all patterns and denoted a working theory that depicts the phenomena captured by the survey questions.

Question by Question Analysis of Interpretive Patterns

This section of the report will analyze interpretive response patterns for each individual question. Although general patterns have already been discussed, it is also important to understand how each individual question performed and the various ways in which respondents understood each question. The means by which respondents reached their answer – that is, their cognitive interpretive patterns – will also be discussed.

1. Are you feeling healthy and well today?

One hundred sixty three respondents answered “yes” to this question and three respondents answered no. As the terms “healthy and well” are ambiguous constructs, all cases of response error are difficult to assess. In line with one of the more general findings of this questionnaire, respondents to this question made judgments about their answer based on a perception that they understood the intent of the question as well as what they felt would affect donation. One respondent, for example, indicated that even if she had been on her period and not feeling well, she still would have answered yes

because she didn't see how having your period would affect blood donation. Other respondents said things like "I feel normal. I don't have anything wrong. If I didn't feel healthy enough to donate, then I wouldn't be here" or "I feel fine enough to donate". Another respondent went one step further to say that if he felt healthy enough to go to work, then he would mark yes because that would mean that he was healthy enough to donate.

The phrase "healthy and well" does not relay a universally defined concept. For some, this conveyed an understanding of not being sick, for others it meant being in a positive mental state, and for others it simply meant feeling the way they normally do, however that might be. Many respondents tended to read this question as asking about them being sick rather than asking specifically about how they feel. This is evidenced by respondents' answers to why they gave the answer they did as things like "well I don't feel ill" or "I mean I don't have a cold or anything". Respondents were further asked what it would take for them to answer "no" to this question and would give responses like "things like having a cough or the sniffles" and "having a cold or flu".

Although a majority of respondents read this question as asking about physical health, a number also read it as asking about mental health. When asked why they answered the way they did, these respondents would say things like "it's sunny outside so I feel pretty happy" or when asked the last time they didn't feel happy and well would say things like "well I haven't been depressed really since last winter". One potential explanation for this pattern came from a respondent who explained that he had been diagnosed as bipolar in his late teens and so that now when he thinks about his health he thinks first of his mental health. For this respondent, and likely others, mental health issues had been more of an issue during their life course than physical health issues and so they tended to read health related questions through that lens.

For some respondents, being healthy and well simply meant feeling "at my baseline, how I feel everyday", however that might be. One elderly female respondent who suffers from osteoarthritis noted that she has aches and pains everyday but that that is just a normal part of daily life for her. She answered yes to this question because she said "but this is looking for some sort of disease". Another respondent explained that he had been in an automobile accident 22 years prior and has since lived with pain but that

he has “a higher pain threshold and a lower tolerance to drugs than normal” and so, although in pain, felt normal for his own daily life. For these respondents, the question was not asking so much about how they are feeling as if they are feeling out of the ordinary or worse or not as “good” as they usually do.

2. Are you currently taking an antibiotic?

This question caused some confusion among respondents. Although most respondents were certain that they had taken an antibiotic at some point in their lives and so were familiar with what one was more generally, they were not necessarily sure if certain things they had taken/were taking counted as antibiotics. There were also instances when the respondent was not sure if an antibiotic had been administered to them (during surgery or childbirth, for example). Finally, a couple respondents had been taking antibiotics up until a few days prior to the interview. They were not sure if they should answer yes because the antibiotic may still be in their system a day or two after taking their last dose.

Nine respondents answered yes to this question. Eight of those were verified to actually be taking an antibiotic at that time and there was one case of response error. The most common reason for taking an antibiotic was for a tooth infection. In fact, this reason constituted half of the positive answers. The one case of response error was a respondent who took an antibiotic for a sinus infection but it was two years ago. He did not have conceptual confusion but because he was in a hurry he did not pay attention to the use of the word “currently” in the question.

Respondents were asked if they had ever taken an antibiotic as a means of assessing their familiarity with what one was. No respondent answered that they had never taken an antibiotic. Further, for most respondents, the reason to take the antibiotic was memorable enough that they had some general idea of when the last time they had taken one was. There was, however, some confusion over what might count as an antibiotic. For example, one respondent who was currently using an anti-fungal cream was not sure if this counted. He said that it was, in fact, used to treat a bacterial infection but since he wasn't directly ingesting it he wasn't sure if it still counted. In the end he answered no to this question because he felt that it was only asking about things which

were taken internally since “the cream I’m wiping on my leg obviously isn’t going to impact my blood”.

Other respondents were not sure if they had been administered an antibiotic in certain situations or not. One respondent who had surgery the year before was unsure if an antibiotic was administered. He assumed that one must have been since it was a surgical operation but he was not told that it had been so he wasn’t sure. He decided to answer no to this question because “well I never had to take one like on my own so I guess it doesn’t really count”. Either way, this would not have been an issue since he was not currently taking one but it does point to the potential ambiguities of not only what an antibiotic is but also when one is taken.

3. Are you currently taking any other medication for an infection?

This question elicited a wide variety of interpretations from respondents. Not only was the question understood differently as a whole, but the terms “other medication” and “infection” also meant very different things to different respondents. In general, it was read in much the same way as the previous question about currently taking an antibiotic and respondents often saw the two questions as related.

One hundred fifty seven respondents answered that they were not currently taking any other medication for an infection, seven respondents answered that they were, and two respondents left the question blank. One of the respondents who left the question blank did so because he was unsure if prednisone – a steroid that he occasionally takes for asthma – should be counted. The other respondent who left the question blank did so because he said the question was too vague. He said that it depends on how the term “infection” is defined. He indicated that he is currently taking Valtrex for a Herpes infection but wondered “is herpes an infection? Or a condition?”.

There were three cases of response error, all among respondents who had answered “yes”. Two of these were simply cases of the respondent marking the wrong answer – they meant to mark “no” but in their haste marked “yes”. The other case of response error was a respondent who is currently on several prescriptions but none of them are for an infection. For example, he takes medication for high blood pressure and another for neuropathy, “in addition to several multivitamins”. The respondent wanted

to indicate this (in fact, he brought an entire list of all of his medications to the interview with him) and was not sure where else to do it besides this question. This is one example of respondents motivated to be helpful rather than deceitful. When answering the questions, they are guided by the perceived purpose that the questionnaire is evaluating the safeness of their blood.

For many respondents, this question was easy to answer because they were not taking any medications. For other respondents, however, the question was more complicated and based on their own interpretive understanding of whether what they are taking is considered a “medication” and whether what they are taking it for is considered an “infection”. Respondents generally began thinking about this question by deciding if they had what they define as an infection. The term “infection” was defined in various ways but all revolved around the general theme of something that would require medication, and more particularly medication prescribed by a medical professional, to get rid of an infection. For example, one respondent defined an infection as “something I can’t get rid of with something I buy at Wal-Mart” while another said it was a “problem that you can’t get rid of without seeing the doctor”.

Another theme found in understandings of what constitutes an infection is that it was generally considered a condition that was not permanent and could be cured. Cuts and open wounds were among the most popular answers given by respondents when asked what they were considering when answering this question. Interestingly, incurable diseases and long-term conditions, such as many sexually transmitted diseases, were not considered by many respondents. One HIV-positive respondent, for example, answered that he was not currently taking any other medication for an infection because he considers HIV an ongoing infection and was only considering “immediate infections that can be treated by medication” when answering this question.

The meaning of what constitutes medication also varied. Nearly all respondents only considered medications prescribed by a doctor when answering this question. Over-the-counter and herbal remedies were not considered as medications, at least for purposes of this question. When asked if she was taking anything at all, one respondent commented “I mean I take some all-natural stuff but I wouldn’t call it ‘medication’”.

Another respondent said that “Sudafed, Tylenol, that kind of [stuff] doesn’t really count here. What they are looking for is something your doctor gives to you”.

4. Please read the Medication Deferral List. Are you now taking or have you ever taken any medications on the Medication Deferral List?

This question was often found confusing by respondents. The phrasing of “are you now taking or have you ever taken” caused response difficulty among some respondents. Many respondents also were not sure what the medication deferral list was or, if they knew what it was, simply did not look at it before answering the question.

One hundred forty three respondents indicated that they were not now nor had they ever taken any medications on the medication deferral list. Twenty-three respondents indicated that they had taken medications on the medical deferral list in the past, but were not current on any of these medications. In addition, there were 4 cases of response error. One respondent failed to look at the list and then during probing did so and changed his answer from “no” to “yes”. Another respondent changed her answer from “yes” to “no” because upon further inspection of the list she realized that even though she couldn’t remember exactly what anticoagulant she had taken, she was “pretty sure it was not one of these ones”. The third response error was a respondent confused by the phrasing of “ever taken” in the question and then the time frames listed on the deferral list. The fourth case of response error was a respondent who takes a generic of Flomax that he didn’t see listed but felt should probably count.

Many respondents did not look at the list because they said that they were not currently taking any medications. These respondents seemed to overlook the part of the question that indicated “or have you EVER taken”. Other respondents failed to look at the list because they said they had donated before and so they had reviewed it before.

Among respondents who looked at the list, nearly all simply scanned it. The common theme was that respondents would simply scan the first column to see if anything stuck out to them and then moved on to the next question. Only a handful of respondents carefully read the entire sheet and every column.

5. Have you read the educational materials today?

Only 18 respondents marked that they had not read the educational materials. The reasons they gave fell along the dominant theme of interpretation for the overall questionnaire – an assumed understanding of medical risk, questionnaire intent, or subject matter knowledge. The other 148 respondents all indicated that they did read the educational materials. This is not to say, however, that the remaining respondents actually DID read them, only that they indicated that they did.

Most of the respondents who answered (admitted?) that they had not read the educational materials said that if they had been at an actual blood donation center or “if this had been for REAL”, then they would have read the materials more closely. One respondent indicated that they knew this was just to understand the questionnaire and not to actually donate blood and so there was a “lack of medical risk”. Another respondent stated that, “I figured since there wasn’t going to be a quiz at the end it wouldn’t matter if I read it”. This fell along the general interpretation summed up by another respondent who said, “I just kinda skimmed for the bold and the capital letters and figured if it were important, it would be there”. Respondents in these instances felt that it was not really their responsibility to bother with “all these details just to donate” because they were either sure that their blood was clean or that it would get tested even if it wasn’t.

Another reason cited by some respondents for not reading the educational materials was that they were frequent donors and so were already very familiar with the questionnaire and the procedure. In all instances where this was cited as a reason, the respondent had, in fact, been a donor on multiple previous occasions. One respondent gave her reason for not, as she put it, “paying as much attention as other people probably should” because she “used to donate all the time before I had Hep C so I already knew what it said”.

Several respondents also cited a presumed knowledge of what they felt was the subject matter of the educational materials – even though they did not read them. When asked how closely they looked at the materials, one respondent, who works in IT for a pediatric AIDS foundation, stated, “I just glanced through them...because I work in

AIDS so I think I know a decent amount about it”. Another respondent answered, “I’m a nurse so I already know all this medical stuff”.

6. In the past 48 hours... Have you taken aspirin or anything that has aspirin in it?

One hundred forty respondents answered “no” that in the past 48 hours they had not taken aspirin or anything that has aspirin in it. Twenty six respondents answered “yes” that they had. Some of these answers, however, were incorrect in that the products that the respondents took actually do not contain aspirin. For example, Aleve, Tylenol PM, and ibuprofen were all counted among these respondents as having aspirin in them – they do not. In this case, the respondents understood the question, but did not know what does and does not have aspirin in it. Thus, the question assumes respondents have knowledge (that respondents themselves assume they have), that they actually do not. It also has the potential to generate false positive responses.

There were four cases of response error with this question (the above cases do not count as response error because the respondent understood the question, but simply did not know the proper information to answer it). In two cases, the respondent had taken aspirin but it was not within the past 48 hours. In one case the respondent simply forgot until probing that they take a baby aspirin every morning as a part of their daily regimen. In the last case, the respondent knew that they had not taken any aspirin but they had taken ibuprofen and wanted to make sure that that was expressed.

Unlike many other questions, the time restriction of this question was not overlooked by most respondents. In fact, only two responded incorrectly because they failed to account for the 48 hours clause. Other respondents were very cognizant of this and although many of them said they had recently taken, or that they regularly take, aspirin, they answered “no” because they had not done so in the past 48 hours.

Many respondents admitted that they knew they had taken or not taken aspirin because of health reasons. For example, a number of respondents include aspirin, or more commonly a baby aspirin, as a part of their daily routine. Some take it “in order to help reduce my chance of having a heart attack” while others take it “just because my doctor said it would be probably be a good idea at my age”. Others were certain that they have not taken aspirin because they say it has negative effects on their health.

Several respondents reported having an upset stomach when they take aspirin and so now they are very careful to avoid it. Another said that it would have negative interactions with her pain medication and so she has to avoid taking anything with aspirin in it.

One noteworthy problem with this question is that respondents are very unclear as to what has aspirin in it and what does not. And while some respondents admitted that they didn't know, most simply assumed that they did. For example, when asked what has aspirin in it, one respondent stated "that's a tricky question. I would be lying if I said I would know any product or something that has aspirin in it". The range of things given that respondents felt had aspirin in them included Tylenol, Aleve, Advil, Alka-Seltzer, Ibuprofen, and several respondents who felt that all cold medications have aspirin in them. In general, respondents seem to think about having taken pain relievers or cold medication of any kind rather than simply specifically aspirin. For example, one respondent said she wasn't sure if aspirin was in ibuprofen or not, "but I know that it is used for the same thing".

This question presented a somewhat unique interpretation pattern from latter questions because respondents tended to err on the side of safety. That is, even if they felt they didn't know the answer (because they were unsure what has aspirin in it or what they assumed was the intent of the question – to ask about pain relievers) many still answered "yes" to be on the safe side. This is in contrast to many of the latter questions, especially those asking about sexual contact, where respondents were much more likely to answer "no" even if they really were not sure. To a large extent this is because respondents understand that taking medication impacts one's blood; therefore, they wanted to ensure this information would be conveyed. On the other hand, questions related to sexual contact, were seen as saying something about their identity and what kind of person they are. For example, when talking about their reasons related to aspirin, respondents would say things like "it's good for your heart", "I only use it when I have a headache", and other comments related to general health. On the other hand, when talking about their sexual contact they would say things like "I'm not that kind of person", "I just don't do things *like that*" or "I just don't associate with *those kinds* of people". Therefore, their sexual contact was not judged to affect the quality of

their blood. In sum, they were generally motivated to report factors they deem to be related to having “safe blood”.

7. Female Donors: In the past 6 weeks... Have you been pregnant or are you pregnant now?

This question was well understood by respondents and there were no difficulties with understanding the construct of being pregnant. There were, however, respondents who lost track of the “in the past 6 weeks” part of the question and so had response error.

Sixty two females answered this question. Fifty seven answered “no” that they have not been pregnant in the past 6 weeks nor are they pregnant now and five answered “yes” that they have been pregnant in the past 6 weeks or that they are pregnant now. Of those who answered no, there was quite a bit of variability as to how they knew for sure but all but a few women were quite certain of their responses. The reasons for certainty came from a number of different reasons – they had had a hysterectomy, their tubes had been tied, they were post-menopausal, they had not had sex for an extended period of time, they are on the pill, and they do not have sex with men were among the reasons cited. One respondent noted “I’m 110% sure I’m not pregnant! I’ve had a hysterectomy AND I’ve been celibate for the last 6 years!”. Another respondent said that she was currently going through menopause and so “I get to have fun now”.

Five respondents answered that they either had been pregnant in the past six weeks or that they are pregnant now. Only one of these, however, was actually pregnant at the time. The other four cases were responses error where respondents had, in fact, been pregnant but the pregnancy had been longer than 6 weeks ago. It should also be noted that although this question indicates that it is specifically for female donors, a number of male respondents also answered the question. In no case, however, did a male respondent answer “yes”.

8. In the past 8 weeks have you donated blood, platelets, or plasma?

This question was more clearly understood by respondents than other questions with temporal limitations. Since donating blood, platelets, or plasma involves going to a

specific location, and undergoing a memorable procedure (particularly in the case of plasma donation), respondents were not likely to forget that they had donated. The event was considered notable.

One hundred fifty two respondents indicated that they had not donated blood, platelets, or plasma in the past 8 weeks. Fourteen respondents indicated that they had done so. Nearly all of these were plasma donations, and nearly all respondents indicated that they had donated for financial reasons. In addition, there were four cases of response error. Three cases of response error were from respondents who had indeed donated but it had been more than 8 weeks ago. The fourth case was from someone who gave blood as part of a medical study but it was not a donation.

Many respondents were able to answer this question without much thought because they had never donated either blood, platelets, or plasma. Among those respondents who had indeed donated, there were only the previously indicated four cases when the timing of 8 weeks in the question caused response difficulties. That is, an even greater number of respondents had donated blood than indicated yes to this question, but they had done so more than 8 weeks before.

9. In the past 8 weeks have you... Had any vaccinations or other shots?

This question was problematic in that it was likely to generate false negatives. That is, respondents were prone to answer “no” to this question even if they had, in fact, had a vaccination or other shot in the past 8 weeks. Response error is attributable to either comprehension (what counts as “other shot”) or, less frequently, recall.

One hundred forty eight respondents answered “no” to this question that in the past 8 weeks they had not had any vaccinations or other shots. Eighteen respondents answered “yes”. Of those who answered yes, a majority were considering flu shots. Other reasons to have had a vaccination or shot in the past 8 weeks included vaccinations for a planned trip abroad, a tetanus shot after stepping on a nail, numbing medication for an oral procedure, cortisone for back pain, and an HPV vaccination.

There were four cases of response error for this question. One respondent left the question blank and during probing said that although she had had a flu shot she wasn’t sure if that actually counted. She thought they were asking more about “vaccinations and

other shots you would need to like leave the country and stuff”. Another respondent who gets regular shots for psoriasis did not count that shot because he said he missed the part where it asked about “or any other shot”. The third case of response error was a woman who just had a Hep A shot two weeks ago but simply forgot about it until probing. The final case was someone who was counting a flu shot they had received, although they had gotten it almost a year ago.

The dominant “vaccination or other shot” that came to the mind of most respondents was the flu shot. This not only accounted for the majority of “yes” responses but was the dominant theme during probing as well. Some respondents simply forgot to count it as a shot including one woman who said “oh yeah, I get that every year. I guess I just forgot that’s a real shot”. Other respondents said that although they thought of the flu shot, they would not count it. One reason for this cited by a respondent was that he only counts “serious things, like polio”. Another echoed this sentiment saying “I just think of big time stuff like pneumonia and pertussis”.

In addition to whether or not the flu shot counted, there was also some confusion over what else might lead to a positive response to this question. Other types of shots that came up included one woman who had recently gotten a facelift and did not count her injections of antibiotics, a woman who had a shot of anesthesia but didn’t count it because “it wasn’t like a shot administered for vaccination and whatnot”, a diabetic who gives himself shots of insulin but doesn’t count them because “it’s not a syringe kind of shot. It’s just a regular insulin shot”, and someone who had received a shot of numbing medication but didn’t count it since “it wasn’t for like a disease or something”.

10. In the past 8 weeks have you had contact with someone who had a smallpox vaccination?

One hundred sixty four respondents answered “no” that in the past 8 weeks they had not had contact with someone who had a smallpox vaccination. Two respondents answered “yes”. One of those respondents was counting it because he and his wife had been vaccinated “in the mid-2000s and I wasn’t sure how long ago counted so I just said ‘yes’ to be safe”. The other respondent said she knows her husband had gotten a shot because he is in the army and she has contact with him every day.

The central interpretive issue with this question centers around the issue of what counts as contact. One respondent, who was unsure of how the smallpox vaccination is administered, said “I wouldn’t know. I would just assume that I haven’t only because it seems that we had smallpox vaccinations back in elementary school. If I would have thought about the question I probably would have said yes because everybody has probably had a smallpox vaccination. It’s like asking if you’ve ever been in contact with anyone who has eaten an egg ever”. Another respondent got right to the issue by saying “Well I don’t honestly [know how I would know] and what do you mean by contact, like close contact?...if it’s just casual contact with customers, coworkers, then I don’t know. If it’s intimate contact then the answer is no.” This respondent said she was specifically thinking of sexual contact because that it was unclear to her what kind of contact the question was actually asking about.

In general, respondents understood contact in this question in one of three ways – sexual contact, contact specifically with children, and general contact from daily interactions. The most common interpretation was that the question was meant to include everyday contact with people. For example, one respondent who clearly differentiated sexual contact from everyday contact stated, “Also, I don’t know what this means – contact. Because it’s not sexual contact. It just says “contact”, right?.....I understand the meaning of sexual contact but wasn’t sure what just “contact” means. I mean we might be having “contact” right now because we’re in the same room talking!”. Another respondent echoed this understanding saying “contact just means being in the same space, like in the same room” and yet another respondent when asked what contact meant agreed saying “I’d say like a handshake, or maybe even just being in the same room”.

For a number of respondents, the term “contact” in this question, particularly because it asks about a vaccination, led them to think first of contact with children. They associated having had a vaccine with being a child and so this understanding then led them to think of “contact” only with children. When asked how she knew her answer to this question, one female respondent answered “well because I haven’t been around any little kids”. Another said “I’m not around children much” and when asked what they thought the vaccine was for they answered “I don’t know what that is. I was thinking

‘small’...is that for little kids?’. She went on to say that she ended up answering “no” because “I don’t specifically have information for a “yes” answer”.

Although most respondents clearly differentiated “contact” in this question from “sexual contact” as used in other questions, some still carried over the interpretation that this question was asking specifically about sexual contact. When asked what “contact” meant to him, one respondent sarcastically answered “well I guess something sexual. I’m sure they’re not just asking about a handshake now are they?”.

Both of the positive responses to this question raise a broader problem many respondents had in interpreting this question – they were unsure whether it is asking about contact with someone who had ever had a vaccination, but that contact was in the past 8 weeks, or contact with someone who had had a vaccination, but that the vaccination was in the past 8 weeks. Both of the respondents who answered yes seemed to feel that it was asking about contact with someone in the past 8 weeks who had ever had the vaccination. Others, however, interpreted the question the other way. One respondent said, “well I know I’ve had contact, you know sexual and stuff, with people who’ve been vaccinated but that was when they were little kids”.

Some respondents also read this question as asking about having had contact with someone who had smallpox, rather than someone who had had the vaccine for it. When asked why he answered “no”, one male respondent said, “I don’t think so...but most likely not. I don’t really know the symptoms of smallpox though so I wouldn’t really know if I’ve come into contact with this or not...but I haven’t like been around anybody who looks really sick or anything”. Another respondent noted that “not that I know of. I don’t know how I would know unless they had really bad, bad skin and I saw stuff that I would want to stay away from. If it looks itchy, I stay away from it”.

A broader understanding of the question was that this kind of vaccine was something that people have as a child. When asked whether or not they themselves had had one, responses such as “I’m sure I did when I had all my other vaccinations” or “yeah I’ve had all my childhood shots” were relatively common. Very few respondents were aware that this is not a standard childhood vaccine or that the disease is one that has been virtually eradicated. Those who were aware of this, however, also tended to be aware that a smallpox vaccine would leave a distinct mark on the arm and so there

answers as to how they were sure included things like “I wouldn’t know but I guess if I really wanted to I could just go around checking people’s arms” and “that’s easy. Because they don’t give those to anybody anymore”.

11. In the past 16 weeks... Have you donated a double unit of red cells using an apheresis machine?

Only two respondents answered yes to this question. A majority of the remaining respondents seemed relatively confused by the terminology. The dominant interpretive pattern among these respondents was that since they were unfamiliar with the terminology (“double unit of red cells” and/or “apheresis machine”) they assumed they had not done so. This is despite the fact that many of them had, in fact, previously donated plasma and so presumably had been hooked up to an apheresis machine. The typical response, however, is summed up by a respondent who said that the question “had a lot of words I just didn’t understand” and another who said “I don’t even know what that is, so I guess no”.

Another reason that respondents gave for being sure of their answer was that they had not donated anything in the last 16 weeks (or ever) and so it was not relevant that they knew what the terms were because they knew that they simply had not donated anything. One respondent summed this up by saying “I don’t donate nothing to nobody so I was sure this wasn’t me”. These respondents rarely considered what an apheresis machine might be because they knew they had not donated anything.

12. In the past 12 months have you... Had a blood transfusion?

This question was relatively straight forward for respondents to understand. The concept of a blood transfusion was known to respondents and there was a feeling that it is a significant enough life event that one would know if they had had one or not. That said, there were a few cases where respondents had had a serious medical procedure but were unsure if there had been a blood transfusion.

Four respondents answered that they had had a blood transfusion in the past 12 months. Two of these, however, were response error – one because they said they just were not paying close enough attention and the other simply said “never” but was unable

to give an explanation for why they had marked “yes” other than to just keep repeating “never had one”. Of the remaining two respondents who had in fact had a blood transfusion in the past 12 months, one was for a stabbing and the other for a problem of internal bleeding.

In addition to those who knew for sure that they had had a blood transfusion, there were several respondents who were unsure if they had or not. One respondent indicated that she had to have “extra blood” during a recent surgery but then asked “does that count? Does all of your blood have to be replaced?” (it should be noted that this surgery was outside of the 12 month time frame so the respondents answer of no was correct either way). In a couple of other cases the respondent noted that they had been in the surgery in a condition where they were relatively unaware of what was being done to them and so could not be totally sure that they had not received a transfusion during that time.

13. In the past 12 months have you... Had a transplant such as organ, tissue, or bone marrow?

The concept of a transplant was well understood by respondents. Most respondents also had a good grasp on what might count as an organ, tissue, or bone marrow. There were, however, a few exceptions where respondents knew they had had a transplant but were not sure if what they had transplanted counted.

No respondents reported having had a transplant such as organ, tissue, or bone marrow in the past 12 months. Five respondents had previously had a transplant but none of them were in the past 12 months so they all marked “no” to this question. There were no difficulties among any of the respondents understanding that this question was only asking about the past 12 months. There was one case of response error with a respondent who had had an ACL reconstruction on his right knee and they had used a donors Achilles tendon. This respondent did not count this as a transplant, however, because they felt it was more of a reconstruction. In addition, one respondent left the question blank because they had gotten a shoulder replacement but were not sure if that counted as a transplant. “It wasn’t really a transplant,” she noted, “but more of a replacement. I really wasn’t sure how to answer that so I just put that question mark

there and figured I would ask you later”. There was also some ambiguity among the three additional respondents who had mentioned having previously had a transplant. One of these respondents had had their neck replaced and since the replacement “includes bits of titanium and bits of cadaver” they decided that this should count. Another respondent had a plate put in their head “but it’s not bone, its cranial plastic” and so wasn’t sure if this counted but didn’t think so. A third respondent had donated a kidney to her brother and she would consider this as a replacement. She noted, “I went through the entire process of being tested and it was determined that I would be the best match of anyone in the family. So since I went through the whole thing then yes, I would say that counts as a transplant”. This respondent marked “no”, however, as this had not occurred in the past 12 months. Additionally, another respondent said they had donated bone marrow for an NIH project but wouldn’t count this since nothing was actually transplanted into his body.

14. In the past 12 months have you... Had a graft such as bone or skin?

Overall, this question performed well with no cases of response error. Only one respondent had had a graft such as bone or skin in the past 12 months. This respondent asked if a gum graft counted while filling out the questionnaire. She was instructed to answer to the best of her ability and so she decided that “yes, something like that should be mentioned here”. In addition, five other respondents had had grafts before in their lives, but not during the past 12 months. None of these respondents had issues understanding that the question was only asking about the past 12 months and so all answered “no” to this question. Of those five respondents, two had also had gum grafts. Another respondent had a skin graft after a spider bite. The other two respondents did have some difficulty with comprehension. These two respondents had bone replacements and were confused as to whether they would have counted this or not, because in both cases the bone came from a cadaver. One respondent mentioned, “I don’t know. Do dead bones count too?”

15. In the past 12 months have you... Come into contact with someone else's blood?

Overall, this question was interpreted as a blood safety question rather than a literal question, albeit one that was viewed as being ambiguous. This question created a lot of confusion among respondents. It was not clear what was meant by “contact” and it was interpreted in a variety of ways. One respondent, for example, stated that “it’s one of those questions that’s kind of vague. It kind of dances around a topic. I mean what does ‘contact’ mean anyway?”. Some respondents felt that contact meant blood-to-blood contact, while others felt that even getting blood on your clothes would count. There was also very rarely consideration of blood that was not immediately visible (i.e. that which might be found in food or during sex).

In general, respondents felt that the question was asking about “exceptional” events rather than what might be more everyday situations. In other words, events where there is “significant amounts of blood” or “gushing blood” were usually what respondents were considering rather than events like “just putting a Band-Aid on my kids knee”.

Another marked pattern with this question is that responses changed frequently – most often from “no” to “yes” – during probing. The reason is that respondents were asked first what situations they were thinking of when answering this question and secondly if they had considered certain situations like menstrual blood during sex, nose bleeds, or potential food contamination. These situations had not been considered by respondents when answering the question but during probing many respondents acknowledged that they had indeed been, at least potentially, exposed to blood during one of these situations. One heterosexual male respondent, for example, when asked if he had had contact with menstrual blood, said “I actually didn’t think about that and I came into contact with someone else’s blood last night”.

Respondents overwhelmingly felt that they understood the intent of this question as pertaining to blood safety. Therefore, even in cases where there was contact with someone else’s blood, if there was a physical barrier such as gloves or clothing, it was most often not considered for their response. One respondent actually works as a medical technician and so regularly has contact with blood but because they use latex

gloves and the blood never makes contact with their skin, they did not count any of these situations.

Respondents also discounted situations where they felt confident that the blood they had come into contact with was safe. One respondent, for example, has a child with special needs and so occasionally comes into contact with her blood. She doesn't count those experiences, however, and says "I haven't come into contact with anyone's blood that I would worry about". She says she would have answered yes if she had had contact with anyone's blood but her daughter's, like if she had a lover or something, but that she is certain her daughter's blood is safe and so didn't feel it should be counted.

16. In the past 12 months have you... Had an accidental needle stick?

One hundred sixty four respondents answered "no" that in the past 12 months they had not had an accidental stick. A majority of these respondents when asked how they knew said that they either avoided needles in any situation or they had not been in a situation where needles were present. Among those who said that they had been in situations where needles were present, respondents indicated that they were either getting stuck on purpose (for example, for a shot or vaccination) or that they were not in danger of being stuck accidentally (for example, there are needles in the doctor's office but not exposed).

Two respondents answered "yes" to this question. One respondent had been working in a recycling plant three months before the interview and wearing what he described as "garden style gloves". While sorting through the refuse a needle stuck him in the thumb and broke the skin. He called his doctor and they said they did a baseline test for HIV and "other stuff" and gave him a tetanus shot. The other "yes" answer was also the only case of response error. The respondents answered that way because he had recently been stuck by the tip of a knife. He said that they assumed that the question was actually asking about being stuck by any sort of sharp metal because "I assume it's really asking about tetanus".

The concept of what a "needle" is varied among respondents. Most assumed that the question was meant to include medical needles but many respondents were also, or only, thinking of sewing needles. One respondent noted, "since I'm not a drug user I was

only thinking of a sewing needle”. Another respondent went so far as to say that “I was thinking this question was asking about any type of needle.....I would also include push pines for a bulletin board or a clothes pin”.

In order to better understand what kinds of situations respondents were considering when answering this question, they were asked under what circumstances they might imagine someone being accidentally stuck by a needle. Several respondents referenced needles in the trash as a potential situation. One respondent said “like picking up trash or cleaning up things where you didn’t know what was in it”. Another respondent said “I can’t really picture a situation (long pause) I don’t know unless you accidentally reached into something sharp when you thought it was a trash can”. Other respondents mentioned in hospitals “because they have a lot of needles in hospitals so I guess maybe there”. Still others could not imagine a situation in which this could happen other than through drug use – “well I don’t do drugs so that kind of rules that out. And I don’t associate with anybody who does. I guess I can’t really imagine a scenario where I would get accidentally stuck with a needle”.

Questions 17-22:

Questions 17-22 all ask about having had sexual contact with a person of a given characteristic in the past 12 months. There are several overarching patterns of interpretation for these questions that were discussed in the general summary under the section “interpretive variations in understanding the concept of ‘sexual contact’”. Generally speaking, the questions create some difficulty for respondents by requiring them to have more knowledge than they do about someone else.

17. In the past 12 months have you... Had sexual contact with anyone who has HIV/AIDS or has had a positive test for the HIV/AIDS virus?

Eight respondents answered that in the past 12 months they had sexual contact with anyone who has HIV/AIDS or has had a positive for the HIV/AIDS virus. Of these, one was a response error because the event had happened more than 12 months ago. Of the remaining seven, at least three were confirmed to have the HIV virus themselves and so purposively only had sex with other positive people. The remaining respondents said

they knew because they had asked the person their status and the person had indicated that they were positive. One respondent did not answer the question stating “It really begs the question, how does anybody know? I’m acutely aware of HIV/AIDS and I still say how would I ever know?”

HIV was a particularly salient issue on the minds of many respondents. In fact, as previously mentioned, many respondents read the entire questionnaire through the lens of HIV detection. That said, the approaches respondents took to determining, or even caring, about the HIV status of their sexual partners varied considerably. One respondent, for example, always demands to see the actual paperwork indicating that the person is negative. She also carries hers around with her at all times and “always post it on my Facebook page”. At the other end, another respondent simply says he has a “don’t know, don’t care” approach to the issue – “those tests are not full-proof so if I’m gonna get it, I’m gonna get it. It’s all up to God I guess”. Generally, responses fell somewhere between these two positions and indicated something like “I’ve been pretty careful about who I sleep with” or “not that I’ve ever been told”.

As with the other STD’s asked about, respondents typically just assumed that their partners did not have it. One respondent said “I’m absolutely certain nobody I have ever slept with has HIV”. When asked how he knew for “absolutely certain”, the respondent replied, “because I just know”. Another commented, “I don’t usually have to ask that kind of thing. If they have it, I’ll know”. These responses indicating certainty but lacking evidence were also common among respondents who cited condom use as a reason they answered “no”. Respondents would answer things like, “It doesn’t matter if I have or I haven’t because I’m always safe” or “I always protect myself so even if they DID have HIV I wouldn’t get it. But it doesn’t matter because I’ve never slept with anyone who has it anyway”

Other respondents were confident of their status because they had been in monogamous relationships with people since before the HIV virus was first discovered. One respondent, who had been with her husband for 37 years, stated “I’ve been with [husbands name] for 37 years and we didn’t have all that back when we got together”.

A lot of respondents assume that this is the kind of thing someone would be upfront about if they were positive, even if the person didn’t explicitly ask. One

respondent said, “I don’t have to ask because someone who was positive would tell me. I mean, they better tell me!”. Another said, “In this day and age, with as much awareness as there is about this thing, I’m just assuming people would tell someone if they had something as serious as that. I mean, not like over coffee, but before putting their dick in someone’s vagina I’m pretty sure this is the kind of thing that would come up”. In other words, because HIV is understood as a serious infection, some respondents assume a (potential) sexual partner will disclose this information without being prompted.

18. In the past 12 months have you... Had sexual contact with a prostitute or anyone else who takes money or drugs or other payment for sex?

Three respondents answered that they had sexual contact with a prostitute or anyone else who takes money or drugs or other payment for sex. Two of these, however, were response error in that they themselves were prostitutes and had not actually had sexual contact with another prostitute. The one remaining person had actually paid for a massage on a cruise in Mexico and the woman asked him if he would like a “happy ending” and he said yes “in part because I wanted to prove to myself that I am bisexual, not gay”. Other respondents had been with prostitutes at previous points in their lives, but not during the past 12 months.

Although all respondents understood the question as having exchanged some good for sex, there were varying understandings of what would have to be exchanged for it to be considered prostitution. For example, one respondent said “well I’ve had guys buy me dinner with the expectation that we would have sex. Does that count?”. Another respondent had actually paid a woman with the intention of having sex with her for the money exchanged but in the end did not “seal the deal”. He answered no since sexual contact did not actually occur, even though he had paid someone with the intention of it happening.

There were also varying experiences with prostitution that made the concept less straightforward than, perhaps, expected. One respondent answered no to this question but said that he had been to a masseuse and that they had had sex but that he primarily went for the massage. This respondent admitted that he routinely goes to this same masseuse and that sex had occurred on multiple occasions but maintained that he

primarily went for the massage. “Even though money was exchanged and sex was involved I don’t really think of it as prostitution”. He went on to ask me to define prostitute to which I asked him how he would define it. He said “a street worker” which sheds light on another reason why he would not have considered his encounters with his masseuse as prostitution.

Other respondents were not sure if the question was asking only about having directly exchanged goods with someone for the purposes of having sexual contact with them or if it also included having had sexual contact with people who had received goods from others for sexual contact but whom they themselves had not paid directly. In other words, if having sex with people who were prostitutes but who they themselves did not pay for sex also counted. One respondent, for example, had several friends who worked as “rent boys” and he had engaged in sexual activity with several of them. He had not, however, paid them directly and so he wasn’t sure how to answer this question. He decided to answer no since he did not directly pay them. Another respondent said that he didn’t find out his ex-girlfriend was a prostitute until after they had already been dating for a while. He, like the former respondent, decided to answer no because he had never directly paid her for sex.

There were also several other interesting nuances that emerged from this question. One respondent, for example, had had sexual contact with a porn star but wasn’t sure if the porn star counted as a prostitute or not. “I mean he does take money for sex...so does that count?”. (In this case he was clearly only thinking of the term “prostitute” and not the rest of the question). He did not himself pay the person for sex. Even more nuanced within this pattern is a respondent who asked “in my life? Who knows! And is there a time limit on THEIR behavior? How long ago would they have had to have done this for it to count?”.

19. In the past 12 months have you... Had sexual contact with anyone who has ever used needles to take drugs or steroids, or anything NOT prescribed by their doctor?

Difficulties associated with this question can be attributed to asking respondents about someone else’s behavior, about which they may not have full knowledge. Six respondents answered “yes” that they had sexual contact with someone who had ever

used needles to take drugs or steroids, or anything not prescribed by their doctor in the past 12 months. Of these six, three were unaware that their partner was, or had been, a user until after the sexual experience, two also injected drugs with their partner as part of the sexual experience, and one respondent answered in error as he had not even had sexual contact within the last year. One respondent did not answer the question indicating that he wasn't really sure. He had had sex with a guy from his gym and indicated "the guy was like really muscular and pretty obviously using steroids. I'm sure he can't possibly have insurance so I'm sure he's getting them on the black market or whatever and so yeah, I guess maybe the answer yes but I can't be 100% sure".

One theme that emerged among respondents who answered "no" was the idea that one could tell by looking at someone if they were, or had been, a needle user. One respondent indicated "I don't think it's something that people would tell you, but I think you can tell if someone is on drugs. And personally, I wouldn't have sexual contact with anyone that I could tell was using drugs". Another respondent indicated that he would ask to see the person's arms if there were any track marks "but this would only work if they were an addict, not just an occasional user". Another respondent, who was currently in a halfway house for drug addiction indicated that he would know because "given my history...anybody I would be around I would know whether or not they are a needle user. I just know what to look for, especially on the arms".

A potential problem with the question emerged around the "OR". Some respondents read this to indicate that it was asking about someone who had used needles OR someone who had taken anything not prescribed by their doctor. One respondent indicated "initially it seemed like it was about the needle" but was confused by the last part "because anything not prescribed by their doctor seems to be a separate part of the question". She wondered if this could include things like vitamins and herbs. Another respondent had to read the question three times before finally being able to come up with her answer because she thought the first part could include things prescribed by your doctor and the latter part could include anything taken that was not prescribed by your doctor, even if it wasn't taken with a needle.

20. In the past 12 months have you... Had sexual contact with anyone who has hemophilia or has used clotting factor concentrates?

No respondent answered that they had ever had sexual contact with anyone who has hemophilia or had used clotting factor concentrates in the past 12 months. A great number of respondents either did not know what “hemophilia” and/or “clotting factor concentrates” meant. That said, most indicated some general idea, at least to what a hemophiliac is, with answers like “someone who bleeds real easy,” or “someone who has blood issues where it doesn’t stop up right”.

One theme that emerged in the Mobile/Biloxi region was that a number of respondents would ask things like “now by hemophiliac do you mean a free bleeder?”. One respondent even expressed a great deal of knowledge about hemophilia but said it was because “my brother is a free bleeder”. Although the term “bleeders” came up limited times in other cities, it was primarily in the deep south that respondents knew hemophilia but by another name.

21. Female Donors: In the past 12 months have you... Had sexual contact with a male who has ever had sexual contact with another male?

This question was very clear to respondents on a conceptual level but their responses were less grounded in knowledge, and more so in assumption, than on many other questions. Many females admitted that this is not the kind of question they would ever think to ask. For some, the rationale behind not asking was either because they assumed they had not done something like that based on their interpretation of what “that kind” of person would be like or they just assumed that their partner was simply “not like that”. Thus, although the concepts in the question were clear, the methods of arriving at a response were less than certain.

Three female respondents responded that in the past 12 months they had had sexual contact with a male who has ever had sexual contact with another male. One respondent, who was a transman, answered that “that’s just really based on assumption. I assume if they would have sex with me looking like a man then they would have sex with a man”. Another respondent had had sex with a friend of hers that she knew had had sexual relations with another man “although it was just a one-time thing”. The third

female to answer yes to this question was the most explicit having joined in on the sexual relations that occurred between her husband and a male that they had invited for a three-way. She said her husband openly identified as bisexual and that she actually encouraged him to have sexual relations with other men.

There was considerable variability in whether or not female respondents asked their male partners whether or not they had ever engaged in sexual activity with another man. Some respondents made it a practice to routinely ask their male partners this question. One respondent noted that she always asks if her partner has slept with another guy or with a black person because she would never want to be with a man who had been with either of those two demographics.

Other respondents had never even thought of asking such a question. One middle aged woman said, “I wouldn’t even know that. How would I know? How would you ask that question though? Even if I did he wouldn’t be honest I don’t think”. Another respondent echoed similar concerns about their trustworthiness of an answer, even if they did ask – “I don’t think I would know. I wouldn’t think to ask that. And I don’t think I would know because its’ something that someone could easily hide. I would never ask someone that...I would never think so”.

Many respondents simply made the assumption that their partner had never engaged in sexual activity with another man without asking. One elderly respondent summed up a common sentiment by saying, “well I’d like to think not in my younger day but how would I know? In those days, it wasn’t quite as free for questions because it just wasn’t that atmosphere. You just always presumed whether right or wrong they were heterosexual”.

Some respondents did not feel the need to ask because they assumed their partner simply “isn’t like that”. Responses like, “I don’t think he could bring himself to be with another man,” or “oh believe me, I know he definitely would not do that!” were common. These responses were based on assumptions respondents held about what it means to be a heterosexual.

22. In the past 12 months have you... Had sexual contact with a person who has hepatitis?

In general, respondents relied on information about the physical appearance of their partner much more to answer this question than to answer other sexual contact questions. Even if using it to confirm that there was no way to tell, respondents associated hepatitis with physical appearance more so than other STD's when answering these questions.

Only one respondent indicated that they had sexual contact with a person who has hepatitis in the past 12 months. He indicated that it was his ex-girlfriend and that he has Hepatitis B himself. Additionally, two respondents did not answer the question citing inadequate knowledge to give a proper answer.

During probing, respondents were asked "well how would you know this for sure?" The dominant response pattern to that question was a straightforward "I wouldn't" or "I couldn't". Many respondents indicated that there was no way to tell if someone had hepatitis simply by looking at them. One respondent, who opted to simply not answer the question, indicated that there was never any way to really know since even people who are sick often look healthy. He cited the examples of Mother Judd and Pamela Anderson as people who have hepatitis but who look "healthy and normal". Another respondent said that "it's another trick question. It's something that's not visible or even if you've had it I know that it remains underlying in your system or something".

A number of respondents indicated that they make it a practice to ask people if they have any sexually transmitted diseases, although they do not generally include hepatitis among this list. As one respondent indicated "...you just ask people if they are clean...but I don't know if that would cover it. That just covers STD's. Hepatitis isn't really a sexual disease I guess". Another respondent indicated an opposite response citing hepatitis as "right up there with AIDS. Those are the two to really be worried about".

A number of respondents indicated that even if you ask someone if they have it you can only assume that they are telling you the truth citing that "you have to rely on the trust factor" or "the word of someone who is trying to have sex with you, which

could be any word”. Among those who answered in this way, a smaller subset also indicated that people could be honest about thinking they don’t have it but that many people who have hepatitis do not even know it themselves. In general, these respondents were skeptical that anyone could ever give a “right” answer to this question. It is interesting to note, however, that all of them still answered the question “no”.

23. In the past 12 months have you... lived with a person who has hepatitis?

One hundred sixty respondents answered “no” that in the last 12 months they had not lived with a person who has hepatitis. Among those respondents, there were two general themes that emerged as reasons why they gave that answer. Some respondents live alone and so did not have to think about the question because they do not live with anyone. Other respondents do live with other people but answered no based on assumptions – that they know the person well, that they assume the person would have told them, and that they are not sure but assume not. One respondent said “I live with my husband and my son so I know their status and they don’t have it”. Another said “I live with my brother and my best friend and I’m sure that if either of them had anything they would have said something to me by now”. A female respondent living with five roommates said “In reality, I wouldn’t know. I’m friends with my roommates and so probably would know if they had it but I can’t really say for sure”.

Six respondents answered “yes” that in the last 12 months they have lived with a person who has hepatitis. In all of these cases, the person had told them specifically that they have it and so they are sure that they do. One respondent confirmed saying “I have lived with my ex on and off for five years now and I know he has it”. Confirmation from the infected person, therefore, was the only means by which respondents who answered yes to this question weighed their decision.

There were only two cases of open response error with this question. One respondent answered “no” but then during probing said “I share a home with someone who has hepatitis but they aren’t like my partner or anything. I mean we’ve never had sex”. The other case of response error reported living on a military base where he said some of the other guys had hepatitis. This was, however, “some years ago” and so outside of the 12 month time frame specified in the question.

One interesting point to consider with this question is what type of hepatitis is being asked about. Only respondents who answered “yes” indicated thinking of a particular type of hepatitis. When asked, many of the respondents who answered “no” seemed to be aware that there are different types of hepatitis but, as one respondent put it, “I was just thinking of hepatitis more generally, not particular types”.

24. In the past 12 months have you... Had a tattoo?

25. In the past 12 months have you... had ear or body piercing?

These two questions performed in the same way. Both questions elicited a fair amount of response error. The major reason for response error was not that respondents had forgotten whether or not they had a tattoo or a piercing, or were not sure if they did, but rather that they did not realize that the question was only asking about within the last 12 months. During probing, respondents were asked when they received their most recent tattoo or piercing and it was discovered that many had been received years ago despite the fact that they had answered yes to this question.

26. In the past 12 months have you... had or been treated for syphilis or gonorrhea?

One hundred fifty five respondents answered “no” that in the past 12 months they had not had or been treated for syphilis or gonorrhea. Respondents understood that the question was asking about treatment and not just about testing. In fact, some respondents had been treated but never tested. Although some respondents had been explicitly tested for one or both of those diseases, most respondents either admitted that they had never even been tested or that they were only assuming that they had been tested at some point as part of some other procedure. For example, when asked if she had been tested, one female respondent said “no, not that I’m aware of. Other than when I donate plasma they do their own tests but I’ve never had a blood test for those or whatever kind of test they do...I don’t know. I never felt at risk or considered that an issue to be tested for”. As a note, this respondent had not had sexual contact in over six years. Another female respondent said “have I ever been tested? If those are in the regular pap exams then yes. I’m not sure if they are included but I think they are”. Another male respondent answered “you would think they would automatically test for

these when other tests ordered. I mean I don't really know for sure I guess. In any case, I've never had either of these diseases so it doesn't really matter".

Eleven respondents answered "yes" that in the past 12 months they had been treated for syphilis or gonorrhea. Each of these respondents claimed that they no longer had either disease and nobody was currently undergoing treatment at the time of the interview. It should be noted that the seven cases of response error found with this question all came from respondents who had answered "yes". Although all seven of them had indeed been treated for either syphilis or gonorrhea, none of them had been treated in the past 12 months. In fact, one respondent had been treated more than 50 years ago! This provides more evidence that respondents are not interested in lying on the form in order to hide factors that may impact their donation eligibility. To the contrary, respondents are often likely to err on the side of caution and report things they think may be important to blood safety.

27. In the past 12 months have you... Been in juvenile detention, lockup, jail or prison for more than 72 hours?

One hundred sixty respondents answered "no" that they in the past 12 months they had not been in juvenile detention, lockup, or prison for more than 72 hours. Six respondents answered "yes" to this question. There were 8 cases of responses that indicate that this question did not work to capture the intended population. All six of the "yes" responses were again erring on the side of caution. Although they had been in one of these facilities during their lifetimes, they had not been incarcerated during the last 12 months. The other two cases of response error were among respondents who answered "no" but who had, in fact, been incarcerated within the last 12 months. One of these respondents demonstrated a recall issue, initially saying "about a year ago," but when asked for a specific time frame indicated that they had been released ten months ago. The other case was a comprehension issue, with the respondent taking the question very literally. He had been in county jail within the last 12 months but since they didn't see that specifically listed in the question, answered no.

There were two other interesting cases of potential interpretation difficulties with this question. The first is that two respondents had been in jail for 48 hours although in

both cases they said their legal paperwork indicated it had been for 72 hours. They answered no since they had not literally been incarcerated for 72 hours, even though legal paperwork (and by extension, their criminal record) indicates that they have. The other potential interpretation problem was among two respondents who had both been in one of these facilities for more than 72 hours, but not as inmates. One had been there because of employment and the other was taking part in a research project. Both of these respondents answered “no” because they interpreted the question as only asking about inmates.

28. In the past three years have you.. Been outside the United States or Canada?

Fifty seven respondents answered that in the past three years they had been outside of the United States or Canada. There was, however, a fair amount of response error. No respondent failed to include a trip to any country that was considered a far off destination. Trips to Ireland, Egypt, and Australia, for example, were easily remembered by respondents. There was, however, response error based around three themes: 1) confusion over whether or not certain countries counted as being outside the United States (i.e. Puerto Rico, Bahamas), 2) failing to include trips such as day trips to Mexico (a stronger regional theme around Los Angeles), especially when they believe that the visit didn't result in behavior that would have “contaminated” their blood, and 3) failing to take account of the limited bounding issue and including trips that were more than three years ago.

A number of respondents were unclear whether certain destinations counted as being outside of the United States. One respondent, for example, had been to Puerto Rico but said “but I'm not really sure if that counts or not. I mean, don't they vote for our President or something?”. Another respondent had recently been on a cruise but said that he forgot to include stopping in the Bahamas because “I was only there for a couple of days and it was for a cruise so I guess I just didn't think about it”. When asked to what countries outside of the United States or Canada they had been, because of the interpretive lens of blood safety, some respondents were also unsure whether just being in the airport counted as being in the country. One respondent decided that it did count citing his reason as “well I guess they have the same diseases in the airport that they

have in the country”. Finally, it was unclear to a number of military respondents whether or not being deployed somewhere, but staying “mostly on base” counted as “really” leaving the country.

Another common issue among respondents, particularly those from the Los Angeles region, was forgetting trips to Mexico, especially day trips. One respondent had initially indicated that he had never left the United States but when asked directly if he had ever been to Mexico he said “just the border towns, actually I have crossed. I wouldn’t really consider that as counting”. Another respondent said they don’t count Mexico because “it’s not like I get a hotel or anything. I just go over and do my thing and come back so it’s not like I’m really there long enough to catch anything”. As discussed in the general themes section of this report, these respondents were answering this question through the lens of blood donation, namely, that their blood was safe, rather than through a literal understanding of the question.

A third cause of response error among respondents was including trips that occurred longer than three years ago. Respondents did not take account of the three years provision and so included trips that had occurred more than three years ago. This bounding issue is a more general one, however, and not specific to this question.

29. From 1980 through 1996, did you spend time that adds up to three months or more in the United Kingdom?

This was a relatively straight forward question and easy for most respondents to answer. It is difficult to imagine forgetting an event as significant as visiting a foreign country, particularly one that is as far removed as the United Kingdom (visits to Canada and Mexico were more easily forgotten as demonstrated in the question above). The only difficulty for this question arose from bounding issues. There was a pattern of response error among respondents who did not pay attention to the indicated years of 1980 through 1996 and so incorrectly answered yes because they included time spent outside of those years.

30. From 1980 through 1996, were you a member of the US military, a civilian military employee, or a dependent of a member of the US military?

Overall, this question was not well understood by respondents, especially among those whom the question is intending to capture. There was conceptual confusion over terminology used as well as bounding issues caused by the unusual time frame given in the question.

Twenty respondents answered “yes”, that from 1980 through 1996, they were a member of the US military, a civilian military employee, or a dependent of a member of the US military. Of these 20, four were response error – three who had actually left the military prior to 1980, and one who had only been ROTC, not active military, and so reconsidered his answer during probing. The difficulty in keeping these specific years in mind was a problem and even respondents who were certain of their negative responses gave pause at the years mentioned.

There was considerable response error with this question. In addition to these four cases where respondents answered “yes” when they should have answered “no”, 10 respondents had error because they answered “no” when they should have answered “yes”. One respondent simply skipped the question by accident. The other nine cases of error occurred because of the difficulty in understanding the word “dependent” – either respondents did not read the entire question so they did not see that it also includes dependents, or they were unsure what “dependent” means.

31. From 1980 to the present, did you... Spend time that adds up to five years or more in Europe?

This question was considered relatively straight forward and easy for most respondents to answer. A majority of respondents had never been to Europe and so could check “no” without having to tabulate past visits. Even for respondents who had been to Europe this question was relatively easy to answer because given the length of time – five years - they were well aware if they had spent that much time there. For most of these respondents, trips to Europe had been a simple vacation and one that clearly lasted less than five years. Nine respondents answered that they had spent time that adds up to five years or more in Europe. Among those respondents who had spent more than five years there all but one were Europeans and the remaining one was stationed there for an extended period with the military.

32. From 1980 to the present, did you... Receive a blood transfusion in the United Kingdom or France?

This question was considered relatively straight forward and easy for most respondents to answer. A majority of respondents had never been to either the United Kingdom or France and could check “no” without much thought. Among those who had been to the UK or France, most had never received a blood transfusion. Although no respondent answered “yes” to this question, there was one respondent who had both been to the UK and had a blood transfusion but he still had no difficulty in answering this question citing that “it’s not like I’m going to forget where I was when something like that happened and I definitely wasn’t there”.

33. From 1977 to the present, have you.. Received money, drugs, or other payment for sex?

One hundred sixty one respondents answered “no” to this question and five respondents answered “yes”. There were no cases of response error. Overall, the question performed well as respondents seemed to understand what the question was asking and had no difficulties with recall or time frame. Since the question was asking only about their own experiences, respondents did not have to make assumptions about the experiences of others.

Of the five respondents who answered yes, four had received money, drugs, or other payment for sex more than one time. All of these respondents were male. The two heterosexual respondents who answered yes had exchanged sex for drugs, one exclusively with women and the other primarily with women but also with men “or whoever can get me what I need”. The two homosexual respondents who answered yes had exchanged sex for money and had done so exclusively with other men. In these four cases, respondents had engaged in this practice over some period of time with three of them still occasionally exchanging sex for either drugs or money.

A number of respondents indicated that they felt this question was asking if they had ever been a prostitute. Although the question would capture the population of prostitutes, one need not be a prostitute in order to receive money, drugs, or other

payment for sex. This conceptual confusion was not an issue, however, as none of those respondents had ever received money, drugs, or other payment for sex irrespective of being considered a prostitute or not.

There was relative consistency about what respondents felt constituted “or other payment” with common responses including things like dinners, clothes, rent, and jewelry. Respondents clearly understood that this clause was meant to include any other form of material or expense (i.e. rent, vacations) exchange.

34. Male Donors: From 1977 to the present, have you.. had sexual contact with another male, even once?

There were 99 non-MSM respondents (including 62 females and 37 males), 59 MSM respondents, and eight male respondents who had had sexual contact with another man at least once since 1977 but who did not identify as gay (MSMNG). It is important to note that just because a respondent has sexual contact with another man, it does not mean that they are gay either by identity or attraction, but rather *only* that they had at some point some form of sexual contact with another man.

A category of note for this project, and for this question, is that of MSMNG. As mentioned before, these are respondents who have had sexual contact with another man but who do not identify as gay. Of the eight respondents we had who fell into this category, five were determined because of their positive response to having had sexual contact with another man. The other three, although they answered no, that they had not had sexual contact with another man, were classified as MSM because their same-sex contact was revealed during another part of the interview process. The five who answered affirmatively had had varying levels of MSM activity. One respondent, for example, had only had contact with another male once while he was in boarding school, another had done so during a threesome with his wife and a male partner, two had done so with prostitutes, and another simply was not “out”.

There was only one case of a respondent intentionally falsifying his answer to this question. The respondent said that he did so because “they won’t let me donate otherwise”. The respondent feels confident that his blood is safe because he gets regular

testing and does not engage in what he views to be risky activities. His understanding is that there is a blood shortage and he wants to be able to help.

35. From 1977 to the present, have you... had sexual contact with anyone who was born or lived in Africa?

One hundred fifty three respondents answered no to this question, 13 respondents answered yes, and there were five cases of response error. This was another question where respondents had to most often simply make assumptions about their partner(s). Although some respondents directly asked, others assumed they would be told, and the majority looked for superficial indicators such as skin color or speech patterns to make this determination. In order to answer this question, respondents relied on superficial assumptions more than partner consultations or verified information.

The question performed well among respondent who answered affirmatively (with the exception of one potentially ambiguous case discussed below). The respondents who answered yes were all certain that they had had a partner who was either born in or had lived in Africa and were able to recall the country of origin or circumstances under which they found out this information. A number of these respondents were from Africa themselves, a number had lived there themselves for some time, and a number had a particular interest in relationships with Africans.

Respondents made determinations about this question based on either knowing their partner(s) well or making assumptions about their partner based on varying characteristics. For those who knew their partner well they would cite confidence in their answer by saying things like “well I know where my husband is from and it isn’t Africa” or “I don’t sleep with people unless I know something about them...like where they are from”. Other respondents said that they assumed this is the kind of thing that someone would tell you, even if you didn’t explicitly ask. One respondent said, “I typically do not ask them. I talk about my background and they give me their background”. When asked how he would know another respondent said “You’d know. I’m pretty sure they would tell you”. One potential problem here is that even when respondents would ask where their partner(s) was *from*, they did not ask if they had ever *lived* in Africa, even if they had not been born there.

A prominent theme among many respondents was that they conflated being black with being from Africa. Thus, a number of respondents relied on the race of their partner(s) to determine their answer to this question. One middle aged white respondent said “you would think that the race would have to be predominately negroid and I’ve never been with a black person”. Using race as a determining factor when answering this question was not limited by the race of the respondent. One black respondent, for example, said he was confident of his answer because “I don’t date black guys”.

Other respondents thought of national origin when answering this question. One male respondent answered “most of the people I have been with...they have all been American citizens”. When asked directly if they would include people from countries like Egypt or South Africa in this question, responses varied among respondents. Some had reactions such as “oh yeah, I forgot they have white people there!”. Others said things like “if they wanted to know about people from South Africa then they would have said South Africa and not just Africa”. Another respondent said “I wasn’t thinking of countries like Egypt or Saudi Arabia. I know they are part of Africa but I just wasn’t thinking about those”.

Respondents also relied on speech or accents to determine if their partner(s) were from Africa. There was an assumption that someone from Africa would have a distinctive accent. One respondent said “I would know because of the way they talk. That’s how you can tell where anybody is from”. Another commented that “I have a real interest in accents so I always listen for them so I guess that’s how I would know if someone was from Africa or not, by the way they talk”.

A number of respondents relied on multiple means of assessing whether their partner(s) were from Africa. One respondent said that this isn’t the kind of question he would ask but that “I would determine based on a judgment call accounting for the person’s skin color and accent”. Another said “I don’t wanna sound mean but a majority of people from Africa are dark so that’s how I know. Plus they have an accent”.

There were five cases of response error for this question, much of it associated with recall issues. One respondent had simply forgotten about a partner they had been with until probing. Another female respondent had had a sexual encounter with a Nigerian man in 1977. At first she only recalled that it was during the 70’s but when

asked more specifically she remembered it was after she had gotten her degree, which was in 1977. Given the date, this would have affected her answer to the question. Another female respondent simply did not include her ex-boyfriend who had been born in Egypt or that her current boyfriend had been in Morocco for some time visiting. The fourth case of response error was a female respondent who had lived in Africa with her husband for some time but did not think to count him until during probing. Another case of response error is rather ambiguous. The respondent answered “yes” to the question but during probing could not remember if the partner they had in mind was from Jordan or Egypt.

36. From 1977 to the present, have you.. Been in Africa?

This question was considered relatively straight forward and easy for most respondents to answer. A majority of respondents had never been to Africa and so could check “no” without serious consideration. Of the 20 respondents who answered yes to this question, most of them still did not have to spend much time arriving at their answer – a trip to Africa was considered significant enough that it could be easily remembered.

In general, the boundary of what is Africa seemed clear for most respondents. For example, when asked if he counted his visit to the Canary Islands as being in Africa even though they are owned by Spain, one respondent said, “yes, because they are part of the African continent”. Another respondent answered no because “I’ve only been in the airport so I don’t think they even stamped my passport”. For these respondents the boundary of what did and did not count as Africa was quite clear.

A small minority of respondents did experience some confusion with this question surrounding what exactly counts as Africa. One respondent, who had initially answered no but changed his answer to yes during probing, seemed confused about what countries were in Africa. When asked where in Africa he had been, he answered “Syria, Oman, and...well...is Madagascar part of Africa?”. Another respondent also changed her answer from no to yes during probing after recalling a visit to Morocco – “I keep forgetting that that’s in Africa!” she stated.

37. Have you ever... Had a positive test for the HIV/AIDS virus?

One hundred sixty one respondents answered no to this question and five answered yes. However, a notable number of our respondents either had never been tested or assumed they had been tested in circumstances where there is no guarantee that they actually were (during routine blood work or plasma donation, for example). Thus, although these respondents answered truthfully that they had never had a positive for HIV/AIDS this does not indicate that they were, in fact, HIV negative.

Overall, the question was understood by respondents and no respondent had difficulty understanding what an HIV test was (even if they were not sure under what circumstances they were conducted) or was unaware of the HIV/AIDS virus. There were no cases of response error and few respondents had difficulty remembering what they believed had been their most recent HIV test (if they acknowledged having had one at all).

One problem with this question is that many respondents seemed unaware of the circumstances under which an HIV test is conducted. In other words, they made assumptions that their blood had been tested in situations where it likely was not (at least not on an individual basis). A number of respondents, for example, reported that their most recent test was at the time of their last blood or plasma donation. Others situations in which respondents cited that they were tested included during their pregnancy, during routine annual physicals, when obtaining a marriage license, and during a pap smear.

Respondents were also asked about their motivations as to why they had or had not been tested. Reasons for being tested included for military service, pregnancy, international travel, starting a new relationship, being released from prison, because it was free to do so, and to receive a gift card or other compensation. Reasons for not being tested included having been with the same partner for some years, assumptions that they had not been with anyone who has HIV positive, not being “that kind of person”, and not being sexually active.

It is interesting to note that MSM respondents were much more knowledgeable about the circumstances under which an HIV test is and is not conducted. Fewer MSM respondents, for example, relied on blood or plasma donations as a means of determining their HIV status. MSM respondents were also more likely than non-MSM

respondents to get tested as a routine part of their healthcare and so generally had greater confidence in their status.

38. Have you ever... Used needles to take drugs, steroids, or anything NOT prescribed by your doctor?

One hundred fifty nine respondents answered “no” that they had never used needles to take, drugs, steroids, or anything not prescribed by their doctor. Seven respondents answered “yes” that they had. Among those who answered yes, only one was still a “regular” user and he uses them to take meth, although he says “I am trying to wean it down”. Among the other six respondents, use had been temporary and was at some time at least 12 months ago or more. These respondents had used needles to take intravenous drugs, meth, and steroids.

Most respondents interpreted this question as asking about anything “illegal”. One respondent, for example, said that they read the question as asking about “recreational, not hospital drugs” and another said “well anything not prescribed to you by your doctor is illegal so the focus of the question is clearly on illegal substances. Another respondent answered that they had only had a needle in them to get tattoos but that they did not feel that that counted because, although not prescribed by his doctor, they were also not illegal.

One point of potential confusion among respondents was the use of the term “or”. In other words, this question was seen as double barreled by some respondents who read this question as indicating that it means to include “anything not prescribed by your doctor” whether or not it is taken by needle. One female respondent, because of the word “or” said that she thought the word “drugs” in the first part of the question “would include things from your doctor, not necessarily all things not prescribed”. Another respondent came to this conclusion only after re-reading the question several times. She said “to me, it reads separate. And I don’t know if that’s the intent. As I reread it, I take a lot of things my doctor didn’t prescribe but I just don’t take them by needle.”

39. Have you ever.. Used clotting factor concentrates?

One hundred sixty one respondents answered “no” to this question indicating that they had never used clotting factor concentrates. Of those, the vast majority were not certain that they knew what clotting factor concentrates were. Many thought that they were something for hemophiliacs – “I know that’s what hemophiliacs take and I’m not one of those. I just bruise easy. So I have no need to take those”. Others thought they were blood thinners – “that’s like Cumadin, right?”. Still others had ideas that were even further off base – “I know concentrate is like orange juice”.

Two respondents answered “yes” that they had used clotting factor concentrates. Both of these respondents reported that they have taken Plavix. One respondent, however, was still not sure if this was a clotting factor concentrate or not but said, “I put yes here instead of no because on this form there was no other way to tell someone that I took Plavix”.

Three respondents left the answer blank. One did so because she said she didn’t know what they were and so didn’t want to answer. Another asked while filling out the form what they were and when he didn’t receive an answer decided to just leave it blank. The third person left it blank and when asked why said “I’m not certain I know what it is. In the past I’ve donated plasma. Do they use clotting factors in that process?”. When probed further, this respondent said that he thought clotting factors were used in plasma donation “to keep the blood flow going” rather than to stop it.

40. Have you ever... had hepatitis?

One hundred fifty eight respondents answered “no” to this question indicating that they had not ever had hepatitis. Among these respondents there were three patterns by which they arrived at their answer – that they were certain because they had been vaccinated, that they assumed not because they assumed they had been tested along with other more routine blood tests, and that they assumed not because they had never been told that they have it.

Some respondents were certain they had never had hepatitis because they had been vaccinated for it or had been tested, usually for their jobs. A career employee of the State Department indicated that she had to have these vaccinations as part of her employment requirements. Another respondent said that he was tested just last year

when leaving the military as part of their routine exit procedures. Interestingly, these respondents seemed to feel safe in their answers regardless of when they were last tested just so long as they had ever been tested at all. For example, one woman cited being sure because she was tested during her pregnancy. When asked when that was, her response was “fifteen years ago”.

Many respondents simply assumed that they had been tested for hepatitis because they had had a blood test for something else. One woman, for example, said “I had all kinds of blood tests when I was pregnant so I’m sure that is something they look for with that”. Other respondents cited previous testing as their reason for answering no to this question but still seemed less sure of whether or not they had been tested. When asked if he had ever been tested, one male respondent said “you know I’m sure I have. I think I had some screenings that checked me for everything. Every transmittable disease”.

Some respondents answered no to this question and admitted that they don’t think they had ever been tested. When asked about previous testing, one respondent said “unless they tested me when I was in the military not that I know of”. Most respondents in this category made the assumption that if they had ever had it, someone would have told them so. A middle-aged respondent, for example, stated that “nobody ever told me I had it. That’s the only way I know. And I’ve never had anything that I didn’t know what it was”.

Eight respondents answered “yes” to this question that they had ever had hepatitis. Seven of those were cases confirmed by a medical professional. One of those seven, however, indicated that they only found out they had had it when they recently reviewed their medical records. It turns out they had had it in the military but the doctor didn’t tell him at that time and only told him that he was being treated for food poisoning. The eighth respondent had never actually had hepatitis but rather he had been exposed to it and so was treated for it anyway. He said “I’m not really wrong in saying that I had it because they did treat me for it for a whole week. That’s really something to think about too – to be treated for something you never had”.

41. Have you ever... had malaria?

One hundred sixty five respondents answered “no” to this question indicating that they had never had malaria. Although some of these respondents knew what malaria was, many did not. Even among those who did not, they seemed to have a relatively close idea most often associating it with diarrhea, Africa, mosquitos, and/or “something bad”. One respondent, for example, who had never traveled internationally, said “It comes from Africa and it’s like a fever. I don’t really know but that’s my guess”. Another respondent said “it’s something transmitted by little stinging bugs that transmit West Nile, I assume it’s a dysentery disease. I know it’s mainly in third world countries. I’m sort of certain that it involves diarrhea”.

Only one respondent answered “yes” to this question indicating that they had ever had malaria. The respondent was from Cameroon and said that it was very common there. The last time he had it was in 2005, although he had had it “quite a few times, especially growing up”. He said when he came to the United States he “took injections to get rid of it permanently” and that now when he goes home to visit he is certain to take anti-malarial pills to prevent getting it again.

42. Have you ever... Had Chagas' disease?

There were no respondents who answered that they had ever had Chagas disease. In fact, very few respondents admitted that they had even ever heard of Chagas and among those even fewer could describe what it was. There were two general patterns of interpretation with this question – those who knew what it was so they knew they did not have it and those who did not know what it was but assumed they would know if they had it.

The respondents who knew what Chagas disease is were more certain in their responses than those who did not know. For them, it was a matter of recalling that they had never exhibited any of the symptoms or received a medical diagnosis. For respondents who did not know what Chagas disease is, however, the process of arriving at an answer to this question was more a matter of assumption than recall. These respondents assumed that since they were unfamiliar with the disease they must not have ever been diagnosed with it. One female respondent remarked that “If I’ve never heard of it then I’m pretty sure I’ve never had it”.

43. Have you ever... had babesiosis?

Interpretation of this question worked the same as the question about Chagas. In general, respondents answered either because they knew what it was and were certain they did not have it (though knowledge of babesiosis was even more rare than of Chagas) or they did not know what it was and so assumed they did not have it.

There was one regional exception to this question. Due to a recent outbreak of babesiosis in the Los Angeles area, and its resulting increased mention in the media there, respondents in this region were slightly more aware of what it was, or had at least heard of it, than in other regions. It seems likely, however, that this variation was due more to the timing of our interviews than some regional increase in knowledge of this disease.

44. Have you ever... Received a dura mater (or brain covering) graft?

All 166 respondents responded “no” that they had not ever received a dura mater (or brain covering) graft. Although there were no cases of response error with this question, there were also very few respondents who felt that they knew what these terms meant. Among those who did, most noted that they needed the “brain covering” in parenthesis to be able to understand what a dura mater was. They felt that this addition gave them something a bit more concrete and easy to understand. In general, however, respondents simply assumed that, to quote one respondent, “if I had ever had something like that, I’m sure I would have known it”.

45. Have you ever... Had any type of cancer, including leukemia?

This question was relatively straight-forward for respondents to answer. An event as significant as diagnosis with cancer is not one that is easily forgotten. Therefore, respondents were certain that they had never been diagnosed with cancer. This is not to say, of course, that they do not have cancer but rather that they had never been diagnosed with it.

We had 16 respondents answer yes to this question and none of those were cases of response error. These responses arrived at their answer because, for them, the

diagnosis of cancer was what many of them cited as one of the most memorable events in their lives. There were no cases of response error with this question and all respondents had a clear understanding of what cancer is. As mentioned, cancer was seen as a significant enough life event that one would not be confused about having had it.

46. Have you ever... Had any problems with your heart or lungs?

One hundred forty nine respondents answered “no” that they had never had any problems with their heart or lungs. Seventeen respondents answered “yes” to this question. Respondents answered “yes” for a variety of reasons including COPD, congestive heart failure, heart murmur, pacemaker, open heart surgeries, a pulmonary embolism, high blood pressure, a collapsed lung, cardiac stints, unspecified problems with a heart valve, aneurysms, and most commonly asthma. Finally, given that the intent of this question is not clear, cases of response error are difficult to assess.

This question was seen as a vague by many respondents and this generated a variety of interpretations. Given the variations in defining what a “problem” with one’s heart or lungs might be, this question was also prone to a high potential for false negatives. Respondents varied quite a bit in what they felt would and would not qualify as a “problem with your heart or lungs”. This variation occurred among individual conditions as well as among more general means of determining what may or may not count. When asked what specific kinds of conditions they might include as problems, for example, respondents most commonly cited bronchitis, pneumonia, asthma, heart attack, heart murmur, cancer, and smoking. The most *debated* terms for inclusion among respondents were primarily lung issues - pneumonia, bronchitis, and asthma. That is, there was considerable variation among respondents as to whether these issues counted or did not count. Some respondents felt very strongly that pneumonia and bronchitis are definitely issues “because those are like the worst things that can happen to your lungs”. Others, however, took a more moderate tone saying “yeah, those are problems I guess, but they are problems that everybody gets so I wouldn’t really count those”. Asthma was another condition whose classification as a problem varied widely. Some respondents, who had either formerly had asthma or currently still did, answered this question “no” because they felt that asthma wasn’t really a problem per se. Others, however, felt that it

was a problem that should be reported because “people don’t really realize it but it’s a serious disease”. Some respondents even simultaneously counted asthma as both a problem and not one. One respondent said when they were answering the question “I was thinking more of the serious problems...like...um...asthma or lung infections that you get from emphysema....more the serious...heart attacks...they didn’t ask about the little things like do you have asthma or high blood pressure...you know...those things”.

Respondents typically used one of three general overlapping interpretive lenses for determining whether or not to count a particular condition as a problem – 1) if it is serious enough to seek medical treatment from a doctor, 2) if it something that is not controllable and thus affects their daily life, and/or 3) if it is a short-term “incident” or a longer term “problem”.

The key determinant for many respondents in determining what counted as a problem was whether or not a particular condition required seeking medical attention. One respondent had previously suffered from atrial fibrillation of the heart but said “it won’t kill me” going on to say that since it was under control with medication it was not worth reporting. “I’m not a scaredy cat about stuff” she noted. One respondent said he was thinking of “things that could cause me to seek help...like a doctor or a hospital”. Another respondent, who had previously suffered from asthma, said he would only count things “I would see a doctor for”. Another respondent used the logic that this would be determined by a doctor because “if it’s serious enough to be considered a problem then it’s something you should see your doctor for anyway”. Medical opinion was also used to no longer count conditions as problems. One respondent who had been diagnosed with pulmonary stenosis said that, although, he would normally count that for other people, he answered “no” for himself because “in my case my cardiologist told me not to worry about it”.

Another determining factor for respondents when deciding what should and should not be counted as a problem was if they viewed it as something that was controllable and thus would not affect their daily life. Several respondents with high blood pressure and asthma, for example, did not include those conditions because they felt they were either being treated with medications or were not problems that affected them daily. One asthmatic respondent, for example, stated “I have mild asthma. I grew

up with more severe asthma. But I don't count that as trouble with my lungs because it doesn't interfere with my activities".

Closely related to the previous two themes is the distinction many respondents made between what they viewed as "incidents", or one time, temporary occurrences, and "problems", or more serious, long term conditions. In general, if a condition was viewed as something that was not persistent, or that had been taken care of, then it was discounted. One respondent explained the difference saying "If you have bronchitis and you take an antibiotic and you get better then that's an incident. But if you have lung cancer and you're going to die because of it, well then that's a problem". Another respondent who said she considered including her bout with pneumonia from 30 years before decided not to because "it didn't leave any permanent damage".

47. Have you ever... Had a bleeding condition or a blood disease?

One hundred fifty nine respondents answered "no" that they had never had a bleeding condition or blood disease. When asked what kinds of things that would include as one of these, respondents gave fairly consistent answers including leukemia, hemophilia, "blood cancers", and HIV. There seemed to be a clear understanding among respondents of what the question was asking and a medical confidence that they did not have a condition or a disease that would warrant answering "yes".

Seven respondents answered "yes" to this question indicating that they had ever had a bleeding condition or a blood disease. For some, the condition was temporary. One respondent, for example, had a reaction to a drug in 1981 that caused him to "almost bleed out and my platelet count to drop to 0". After he stopped taking the drug, however, he no longer had problems. Another respondent had had severe internal bleeding but it was corrected with surgery and so no longer a problem. Other respondents had more permanent conditions. One has Hereditary Spherocytosis, a very rare disease which causes "my red blood cells to be in the wrong shape". Another respondent had Thalassemia, "a blood disorder that makes me anemic".

There were two cases of potential response error to this question. In both cases, the respondent had anemia but failed to report it. One respondent said that they did not include anemia because "it's not a big problem" and because she could control it. Her

interpretation, consistent with the overarching theme of blood safety, was that it is not something contagious and so did not need to be reported. The other respondent said that although she used to be anemic, she no longer was and that she thinks of anemia as more of a general condition and not specifically as a bleeding condition or as a disease. These types of interpretations mean there is potential for some potentially troubling false negatives.

48. Have any of your relatives ever had Creutzfeldt-Jakob disease?

There were no respondents who answered that any of their relatives had ever had Creutzfeldt-Jakob disease. As with the Chagas and Babesiosis questions, knowledge of what Creutzfeldt-Jakob disease is was relatively rare and even among those who had had it, very few could define it. Among those who could, they simply defined it as “mad cow disease” although even then they were unsure of what exactly that disease was. As with the previous questions of this type, respondents answered “no” primarily based on the assumption that if they had ever had a disease like this then it would have been something they would remember.

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