Cognitive Interview Evaluation of the Blood Donor History Screening Questionnaire
Results of a study conducted August-December, 2001

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1. Introduction

The purpose of this report is to document the background, procedures, and results of a cognitive interview study evaluating a revised version of the Blood Donor History Screening Questionnaire. This questionnaire is a vital component of the blood donor screening process, designed to identify potential donors whose blood may be unsafe due to possible exposure to diseases (e.g., through travel or various behaviors), use of certain medications, or other risk factors.

A Task Force was formed in mid-2000 at the request of the Food and Drug Administration (FDA) to redesign this screening questionnaire. The membership of this Task Force includes representatives from the blood banking industry, the federal government, and health researchers from academic and commercial sectors, who collectively bring substantive and methodological experience necessary to create an effective revision. Increasing donor comprehension and minimizing overall burden were particular emphases of the Task Force, both of which would presumably lead to higher response accuracy. Based on careful review of FDA regulations, principles of questionnaire design, and reactions from focus groups, a revised draft instrument was completed in early 2001.

The Task Force determined that one-on-one cognitive interviews would be an effective component of an evaluation of how well the revised questionnaire meets its objectives. These interviews were conducted at the National Center for Health Statistics from August through December of 2001, and findings were used to create another revision of the instrument (finalized in early 2002).

Most of this report is devoted to a presentation of results of this testing, including reports of overt problems, as well as general descriptions of interpretations, thought processes, and individual circumstances that might reflect upon the accuracy of responses, and recommendations for revisions. The results are preceded by summaries of methodology and description of interview participants, with explanations for how both were selected.
Methods

Rationale for the methodology

The basic procedure of a cognitive interview is that a questionnaire-design specialist administers the questionnaire and adds intensive probes. These probes are chosen to provide insight into problems with comprehension, difficulty recalling necessary information, potential response biases, answer categories that are inappropriate, and so on.

Cognitive interviewing is probably the most appropriate method for evaluating questionnaire drafts in which the basic content of the questions has been determined, but specifics are still open to development. In particular, cognitive interviewing is useful for honing specific word choices, determining whether the response task posed by a question is too complex, and evaluating whether response options match respondent experiences. Results from these interviews are helpful for revising questions, creating new ones, and sometimes deleting unworkable ones.

Other methods can make important complimentary contributions to questionnaire design: for example, focus groups efficiently provide insight into group attitudes and terminology, and field pretests offer a more realistic administration of the questionnaire than interviews in the laboratory. However, cognitive interviewing is uniquely successful at illuminating how participants answer particular questions or why they experience difficulties. Focus group participants often critique questions hypothetically (rather than answering based on their own experiences) or answer based on a “group dynamic” that is absent in the usual survey response process. Similarly, field pretests reveal little about how participants answer questions or about the particular sources of difficulties. Cognitive interviewing overcomes these limitations. In short, it is an efficient, empirical, and detailed methodology for assessing how well questions “work” for individuals who are similar to members of their targeted population.

Cognitive interviewing is sometimes referred to as a “validation” method, but this term is somewhat inaccurate. True validation would entail comparing questionnaire responses to an alternative “gold standard” data source (such as medical records). Such a study would be of great value, but also expensive and labor intensive. More realistically, cognitive interviewing should be viewed as a quasi-validation. In lieu of an externally verifiable data source, we collect narrative responses to probes, and use these to evaluate the veracity of responses to questionnaire items. For example, one question asks “In the past 12 months, have you had sexual contact with a person who has hepatitis?” Probes would be used to assess whether participants know anyone with hepatitis, how they interpret the term “sexual contact,” whether they considered the appropriate time frame while answering, and whether they interpreted the question accurately. Responses to these probes are used to determine whether the question is working as intended.

Procedures

Cognitive interviews for this project were conducted one-on-one in our Questionnaire Design
Research Laboratory (QDRL). Participants were recruited through newspaper advertisements or by re-contacting previous participants who meet study-specific criteria. Prior to selection, prospective participants were screened by telephone to verify eligibility and to obtain additional demographic information, in order to ensure some diversity of age, education, race, and gender.

Upon arrival, participants filled out several forms, including a consent for the interview to be audio-taped with limited video. Laboratory interviews at NCHS are usually video-taped, but due to the sensitive subject matter of some of the questions, we focused the video camera on the interviewing table rather than the participant. This allowed us to record the completion of the questionnaire (noting hesitations and corrections), while providing an additional level of confidentiality to the participant.

Following the paperwork, the interviewer provided a brief overview of NCHS and the purpose of the QDRL. Interviewers then read the following introduction regarding the blood donor history questionnaire:

> Whenever people volunteer to donate blood, they are asked to fill out a questionnaire about behaviors, travel, lifestyle, and health history. The questions ask about factors that might make a person's blood not safe for donation. Answers to these questions don't mean that anyone's blood is definitely unsafe-- it might just mean that a person has a chance of containing material that could affect other people if they received the blood.

Participants were then given the page of educational materials and told:

> If you were actually giving blood, the first thing that would happen is that you would be given some general educational information to read. These are just a few pages that tell a little about the blood donation process in general. Before we get to the actual questionnaire, I'd like you to take a minute to read these few pages now. We want to make sure these are clear and easy to understand. So as you're reading, if anything seems confusing, please let me know-- OK?

When the participant finished, the interview asked a few general questions about the educational materials, such as “Was there anything in those materials that did not make sense to you?” The interviewer also asked if there was any reason that the participant thought that he/she would be unable to give blood today.

The interviewer then gave the questionnaire to the participant and read:

> I'd like you to fill this out to the best of your knowledge and ability. When you're finished, I'll want to talk to you about how you interpreted some of the questions, and how you figured out some of your answers. Some of the questions are personal, but it is very important that we get accurate information from each of them. Keep in mind that this interview is confidential.
Interviewers were instructed to give the participant space to complete the questionnaire without interference, but to be available in the room if the participant had any additional questions. When the participant indicated that he/she was finished, the interviewer began a question by question debriefing. The general strategy of the debriefing was to probe any “yes” responses for additional details about the experience in question, and to probe any “no” responses regarding their certainty. Interviewers also probed regarding interpretations of key terms, their experiences in a broader time frame (e.g., “have you ever given plasma? When was that?”) At various points, interviewers asked participants to explain in their own words what they thought questions were asking, or to talk in general terms about any experiences they had that sounded similar to what the questions were getting at. Many of these probes were scripted in advance, but interviewers were encouraged to use additional probes to follow up on interesting material that emerged while participants answered.

In the final round of interviews, six short vignettes were added to the study. These vignettes described hypothetical blood donors with circumstances potentially relevant to an item on the questionnaire. Participants read each vignettes and were asked what they thought the best answer to each question should be. (For a more detailed description, see the final section of this report.)

Four interviewers worked on the project. Each interview was conducted individually, and interviewers summarized results of each interview independently. All interviews were also transcribed. The analysis in this report was based on the interviewer reports, transcriptions, and review of the actual questionnaires completed by participants.

3. Participants

A total of 35 participants were interviewed for this project. Participants were recruited in three different “rounds” that targeted particular sorts of potential donors, as follows:

Round 1: These participants had never donated blood, but were eligible to do so as far as they knew. The objective of this round was to find relatively “naive” participants who did not have prior experience answering these questions, or perhaps even thinking about these topics. In some ways this group should be similar to first-time blood donors. (n=12)

Round 2: These participants had been deferred from donating blood on at least one occasion in the past. The objective of this round was to collect data from individuals who were likely to answer at least some questions affirmatively, probably providing some different answers than participants in the previous round. In reality, affirmative responses to the questions were fairly well mixed across rounds. For example, in the first round we interviewed a participant who had contracted malaria, and two males who had engaged in sex with other males. In the second round we had more individuals who were deferred for having several diseases and for extensive
Round 3: Participants in this round were selected to fill in gaps in previous recruitments, with a particular focus on young (e.g., six were 21 or younger), non-white (four participants), and less-educated (five had no education beyond high school). We also reserved four slots for people to test an abbreviated version of the questionnaire, designed for more frequent donors. These participants had all donated within the past six months. (n=11)

Within the parameters established for each round, we attempted to capture as much demographic variety as reasonably possible. The demographic background of study participants appears in Table 1, below.

Table 1: Demographic summary of study participants

<table>
<thead>
<tr>
<th></th>
<th>Round 1</th>
<th>Round 2</th>
<th>Round 3</th>
<th>Total</th>
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<td>3</td>
<td>5</td>
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<tr>
<td>Some post H.S.</td>
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<td>4</td>
<td>13</td>
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<tr>
<td>College grad</td>
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<td>6</td>
<td>3</td>
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<tr>
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<td>Asian/Pac Islander</td>
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While participants in this study had remarkably diverse backgrounds and experiences, the sample did have limitations. Ideally, we would have interviewed sufficient participants to cover the full range of experiences addressed within this instrument. Unfortunately, we did not interview anyone who had received clotting factor concentrates, gave double red cells, or had Chagas’ disease, among others; we only interviewed a few participants who engaged in risky sexual behavior. For the abbreviated version of the questionnaire (see Results, Section C) it would have been preferable to interview more people known to have developed significant medical conditions since their last blood donation.

Recruitment is challenging because individuals who have met some of these criteria are relatively rare. Also, we would need to find such individuals (e.g., people with blood disorders) without directly questioning them about the characteristic of interest. Advertising for people who have “blood disorders” would spoil the test, because we would in effect be asking the question in advance. Such recruitment is possible (e.g., through medical records), but was beyond the scope of this project.

Instead, we attempted to maximize the chances that a variety of relevant individuals would fall into our pool of volunteers by chance. For example, the purpose of advertising for individuals who had been deferred from blood donation at least once was to recruit individuals likely to answer “yes” to various questions. Such advertising did generate a considerable variety of participants, although some questions were never answered affirmatively, and some by a very modest number of individuals. It would be useful to conduct additional research with a larger pool of targeted participants who meet certain criteria of interest.

Nevertheless, we believe that the number and variety of participants in this study was sufficient to provide substantial evidence about the quality of the instrument. Interpretations of questions were largely consistent throughout the project, with potential sources of error manifesting themselves clearly. Interviews in the latter stages contained few surprises. Furthermore, the interviewing team consisted of experienced researchers and the methodology for evaluating the instrument has been well-established.
4. **Executive Summary of Questionnaire Issues**

1) Perhaps the biggest challenge for the screening questionnaire is striking a balance between thoroughness and simplicity. Both traits are important, but they are sometimes at odds. A comprehensively thorough instrument, with questions written to account for any potential ambiguity, could be quite tedious. On the other hand, one that is too simple might be open to misinterpretation, and might fail to stimulate memories needed to answer the questions accurately.

This questionnaire seems to strike a successful balance between the two. Interview results suggest the questions are as simple as they could reasonably be, and their meanings are clear in most cases. Where difficulties were identified, it was usually possible to recommend either:

- a minor wording change
- splitting a question into two simpler ones
- expanding supplemental information (such as the educational materials, or guidelines/ definitions available for the staffs of donation centers)

It is important to keep this last option in mind, because the donor history questionnaire is not a stand-alone instrument– it is one component of a sophisticated screening process. The educational materials distributed prior to the questionnaire are extremely helpful for providing key definitions, justifying some of the topics that are covered in the questionnaire, and serving as a motivator to answer as accurately as possible. As a result, the donor history questionnaire does not have to be as self-sufficient as many survey questionnaires, and can successfully employ simpler questions. In addition, the staffs of blood donation centers can be given detailed definitions regarding the meaning of questions. Sometimes it makes more sense to explain fine nuances of meaning within these materials than within the questions themselves, since the details may apply to only a small number of respondents. For example, many respondents will not have heard of clotting factor concentrates, but will be confident that they have never received them. Rather than forcing all respondents to read through a detailed explanation of clotting factor concentrates, it makes more sense to have a definition available for those who ask.

2) As discussed above, one objective of redesigning the donor history questionnaire is to minimize the burden of the instrument. Some questions have been eliminated from previous versions, and words perceived as unnecessary have been omitted.

Reducing burden is a very worthwhile goal (and one that is often inappropriately ignored by questionnaire designers). However, it is possible to underestimate the importance of occasional words or phrases that have significant implications for meaning. One example is the word healthy in the first question. We have reason to believe that healthy and well is considerably less ambiguous than the word well by itself. The burden added by this word is trivial, but it may provide important guidance to some respondents (see comments to Q1). At other times, adding a
few simple words (e.g., *even once* at Q32) could have an important impact on accuracy without affecting burden in any significant way.

3) On a similar topic, several questions combined concepts that might appear loosely associated with one another (e.g., *acupuncture* and *body piercing; needle-sticks* and *coming into contact with someone else’s blood*). This might seem like a justifiable decision to reduce the number of questions, but sometimes it leads to confusion, or respondents’ attention might focus too heavily on one of the two components. Generally, we recommend splitting these into separate questions.

4) False positive errors appeared to be more common than false negative errors. Obviously, false positives are preferable and can often be cleared up in follow-up discussions with blood center staffs. False negatives are potentially more serious. The results below provide details about the false negatives we encountered. Some of these point to the need for a question revision. Unfortunately, some others are attributable to the frailty of human memory rather than a question flaw per se. Intensive probing sometimes brought memories to the surface that had not been included in initial responses (e.g., a sexual partner from African, and a shot that had been received that morning). In lieu of making the instrument considerably longer and more complex, the most effective strategy here is probably to remind donors at various points of the need for careful thought and accurate information.

5) Clearly, respondents will not have complete knowledge about some of the topics addressed in the questionnaire. People may not know for certain whether they have been exposed to the saliva of a person with hepatitis, or whether one of their sexual partners had used needles for drugs. Many responses were qualified by expressions such as “as far as I know”; obviously, the accuracy of their judgment cannot be guaranteed. Responses seemed to be tempered by assessments of risk (e.g., I don’t know anyone who has hepatitis, so chances are I was not exposed to it). Participants who thought they had some risk of exposure (but no definite evidence) tended to have the hardest time answering. “Yes” responses generally indicated certainty that they had been exposed.

6) Several concepts were open to multiple interpretations, most notably “had sex.” We think that respondents will tend to interpret the questions pragmatically rather than literally—meaning that if they thought any form of intimate sexual contact had exposed them to the risk in question, then they would answer affirmatively (even if they did not literally think of such behavior as “having sex.”) Nevertheless, there is no guarantee of consistency, and we support the Task Force’s recent decision to substitute “had sexual contact” (defined in the educational materials) for “had sex” in all questions.

7) The cognitive testing focused on the quality of question wording, but it also became obvious that formatting of the instrument could create some errors. For example, some participants lost track of reference periods (e.g., “in the past 12 months”). This was almost certainly due to the layout of our questionnaire on the page. The final instrument should be designed with such considerations in mind.
5. **Results**

A) **Educational Materials**

In most cases, interviewers gave the educational materials sheet to participants before administering the questionnaire. After reading the materials, interviewers asked if the materials were clear and whether they had any particular comments to make about them.

Most participants read the materials carefully, indicated that the materials were quite understandable and had little further to add. The most common criticism was that the word “phlebotomist” was esoteric and should probably be replaced with something simpler.

Several participants thought that the following read awkwardly: *Do not donate if you... since 1977, are a man who has had sex with another male, even once.*  (Note that the educational materials changed at various points during testing, and several different wordings were used. An alternative version, *Do not donate if you... are a man who has had sex with another male...* was also criticized.) One recommendation was to include a separate header, *If you are a male,* with a sub-heading, *Do not donate if you have had sex with another male, even once, since 1977.*

One participant suggested that an explicit instruction should be added: *Do not use this as an HIV test.*  (This was in fact added on a later version of the form.)

Most other comments were very minor. One participant thought that the materials should state that no reliable test was available for certain diseases (under “Travel”) because this sounded less frightening. Another thought that the phrase “risky for certain diseases” (under “Donation Process”) was awkward. Another was annoyed by the small hearts that were used as bullets and thought the points should be numbered instead.

Some participants expressed minor irritation at several points that seemed illogical. One participant asked why hemoglobin level had any significance. Another wondered why incarceration was a risk factor. Another suggested that the “12 month” reference period on some items was completely arbitrary (“so if it was 13 months that would be OK?”)

There was only one clear case where the educational materials failed to work– a participant who had less than a high school education (and was a slow reader) looked at the materials for about 10 seconds and put them aside, saying that they were fine. It was clear that she had not read them and picked up very little information.

The materials seem to be understandable to most people, and their current level of sophistication seems to be a reasonable compromise between readability and completeness. Still, it is clear that they require a certain level of literacy and willingness to work through them. Blood centers can account for this by emphasizing the importance of understanding the materials, and offering assistance to those who need help.
B) Question-by-Question Results and Recommendations

Are you
1. Feeling well today?

Round 1: Eleven of the twelve participants in this round answered yes to this question. The one who answered no indicated that she was getting over a cold.

Most participants answered this on the basis of their current physical health. For example, some reported that they had no aches and pains, cold symptoms, nausea, fatigue, or other problems. Yet a significant minority of participants (nearly half) indicated that they answered the question based on overall well-being, which could also include emotional demeanor, energy level, optimism, and stress levels. One participant mentioned that if the question had said “healthy” she would have thought of physical health, but “feeling well” called for emotional health to be included as well.

A few participants mentioned that they were thinking primarily about emotional demeanor when answering. One participant’s response was somewhat surprising: he indicated that he was experiencing very serious discomfort due to gout (rating his pain level at 8 on a 10-point scale)—yet he answered yes to the question, primarily because he felt in good spirits. Another participant answered yes, even though her wisdom teeth had been removed a few days earlier and she was still in some discomfort. Her response was also based on an interpretation of the question that was not entirely based on physical health (“I took that as more emotional than physical.”). Given the variety of interpretations of “feeling well,” it may be preferable to ask about “feeling healthy and well” (or simply healthy).

Round 2: All participants answered yes. Interestingly, this group of participants tended to think more in terms of purely physical health than those from the previous round. Their responses were generally based on a lack of cold symptoms, pain, or other ailments.

Still, a few mentioned that they were experiencing minor cold symptoms (one felt a cold coming on, while another had some lingering symptoms), but answered “yes” anyway. Most indicated that if they had a cold they would probably answer “no” to the question, but a few did not (e.g., one participant thought that she would only say no if she was not well enough to get out of the house; several others indicated that they would probably say “yes” even if they had a cold). In spite of this, most participants indicated that they would not attempt to give blood if they felt much less than 100% healthy. That is, some participants thought they would be more likely to withdraw themselves from consideration for giving blood than they would be to answer “no” to this question.
Round 3: Only one of the eleven participants answered no, on the basis of having a cold. The other ten answered yes, generally explaining that they felt “pretty healthy,” had no cold or other symptoms, or were energetic. Occasionally, participants reported that they had minor cold-like symptoms due to allergies or chronic conditions. Another participant, who was pregnant, noted that she had stomach and heartburn problems. However, they answered “yes” to the question because they were not experiencing decreased overall health, and were confident that giving blood would not be a problem.

As in previous rounds, most participants based their answer on either “physical health” or a combination of physical health and demeanor. However, one or two participants explained their answers primarily in mental health terms (e.g., one remarked that sickness is just “in your mind”).

Taken all together, there appears to be considerable variety in the interpretation of this question—people with colds, feelings of fatigue, and allergy symptoms might respond inconsistently. At least part of the problem could be alleviated by including the word “healthy” in the question. If the question is designed to capture individuals with basic, low-level cold symptoms, more specific instructions may be useful.

Note: see also the results from vignettes, in the final section of this report.

Recommendation: Re-word question as “feeling healthy and well today” to emphasize physical health aspects. The additional word does not appear to be redundant, but rather clarifies the intent of the question.

2. Taking any medication on the medication list?

Round 1: All participants answered no. Most reviewed the medication list and did not identify any medication relevant to them. Probes seemed to confirm that participants had not taken any of these medications recently, or even medications for similar purposes. One participant had taken Accutane in the past, but this had been several years earlier. The only clear comprehension problem we observed involved “Growth Hormone.” At least one participant thought this was the same as certain over-the-counter supplements that claim to promote muscle development (one may be called “Creatine”). Such false positives are clearly preferable to false negatives, but it may be useful to consider ways to distinguish these from pituitary-produced hormones.

Most participants were familiar with some items on the list, especially Accutane and Propecia. Most had heard of insulin, although few if any had heard of “bovine” insulin.

A few participants answered “no” without a careful review, apparently because they were not currently taking any medications. In one case, we forgot to provide the participant with the medication list; he answered no anyway because he was not taking any medication. Of course,
this can be a problem, because the medication list refers to some medications taken in the past as well as currently. The tense of the question may inadvertently discourage respondents who are not taking medication from even reading the list. The question needs to be rewritten and/or relocated to emphasize that we are interested in medication usage with several different time frames.

A few participants breezed through the list more quickly than appeared to be ideal. For example, one female participant skimmed the list quickly to be sure that birth control pills were not on it. Another participant called the list “very overwhelming” and also skimmed it quickly to be certain that it did not include anything obviously relevant.

Round 2: All participants answered no. As in the previous round, most participants dutifully read through the list, but some skimmed it quickly since they did not currently take any medications. As discussed earlier, this is a problem because some medications taken in the past also lead to deferral. About half of the participants had heard of one or more of the medications, while the rest claimed that the whole list was foreign to them.

Several participants had taken medications for severe acne in the past, and one was currently taking prednisone for a similar condition. They correctly answered no, but had to read the list thoroughly to be certain that their medication was not on it. One suggested that it would help to include a description of each medication’s purpose next to its name, in order to facilitate the identification process. She also thought this would be helpful because medications have different names, and it is sometimes difficult to tell whether a medication from the past has been represented on the list.

A few other interesting situations emerged: one participant had been deferred from blood donation in the past because she had taken a certain medication— but this medication is no longer on the list. She was unsure whether this was a mistake, or whether it no longer mattered that she had taken this medication, or something else. In any case, she expressed some confusion about what had changed. Another participant answered no, but during probing admitted that he had participated in a drug testing study some years earlier. He had no idea what he had taken and could not be completely certain that he had never taken one of the deferral medications.

Round 3: This question as originally worded was administered to three participants in this round. All answered no, and had never taken any of the medications on this list. One mentioned that she was familiar with Propecia, and another indicated that he was familiar with Accutane, but generally they had not heard of medications on this list.

The problem remained that the question is written in present tense, but the medication deferral list is designed to capture medications taken at various times in the past. To address this problem, we drafted an alternative version of this question:

*Please read* the medication deferral list. *Have you taken any of these medications?*
The purpose of the revision was to leave the reference period open-ended in the question itself. Instead, the relevant time frames appear with each medication on the separate medication list.

This revision was administered to four participants. All four answered no, and expressed similarly modest levels of familiarity with the medications on the list. However, the revision seems to be even more confusing than the original question. Rather than providing flexibility for participants to answer based on each medication for a variety of time periods, this version is simply vague. We think it is probably necessary to ask the question based on one time frame—either by choosing one reference period for all medications, or by breaking the question into components with different reference periods.

**Recommendation**: Add the word “ever” to the revised question, and eliminate the varying time frames from the medication deferral list. Potential donors who answer yes would then be screened further by staff at the donation center to determine whether the medication was actually taken during a time period that calls for deferral. It might be helpful to provide an instruction to review the list carefully. The sheet might appear less overwhelming if the second half of the sheet was put on a separate page, since this might make the actual medication list appear shorter.

3. Currently taking an antibiotic?

**Round 1**: Two participants answered yes, and both answers appeared to be accurate. One was currently taking Amoxicillin, and the other did not mention the specific type (although she did seem to understand what antibiotics do).

Most participants indicated that they had taken antibiotics within the last several years and had a sense that they were for “infections” (some specified bacterial infections). A few participants were not completely sure what antibiotics were for, but were confident that they were not currently taking one—since they were not taking any medication at all.

There is some potential for individuals to have taken a medication and not know that it was an antibiotic, since they are often not explicitly labeled as such. This question counts on the medication being identified by a doctor as an antibiotic (or on respondent recognition of the medication in those terms). However, because participants seemed to understand their general purpose, it seems likely that such medications would be captured either by this question or the following one.

**Round 2**: One participant answered yes—she was currently taking Minocycline for acne. Due to her background (she holds an MPH), she understood the purpose of antibiotics clearly (“the purpose of antibiotics is to eliminate or control a bacterial infection by preventing the bacteria from reproducing or killing it directly.”)
No other participants were currently taking antibiotics. Most had taken them at some point in the past for a variety of reasons (ranging from chest infections to sexually transmitted diseases). Several participants had taken them recently (perhaps a month or two ago)-- one after having a growth removed from his leg, and the other following heart valve replacement surgery. It was not clear when they actually stopped taking the antibiotics, which raises an interesting question: should the word “currently” be taken literally? For example, if someone completed taking antibiotics a day or two earlier, should they answer no to this question? Staff at blood donor centers should be prepared to respond to this.

In general, participants in this round seemed more confident and precise about the general purpose of antibiotics (often citing battles against bacterial infection; other times citing specific instances in which they had taken them, e.g. for respiratory infections).

**Round 3:** This question was administered to seven participants, all of whom answered no (one participant initially checked the “yes” box by mistake, but clarified that she did not mean to.) All responses appeared to be accurate, but it was clear that several participants had no idea what antibiotics were. One thought they were for “something with blood” while another thought that cold medicines were antibiotics. Another participant thought that antibiotics were anti-viral medications.

In spite of these misunderstandings, the question seems to work for most people. A definition of “antibiotic” could be added, although it might be better to leave the question uncluttered and encourage potential donors to ask questions if they are uncertain about whether a medication should count or not.

**Recommendation:** Use current wording. Include instructions in the educational materials encouraging respondents to ask staff at donation centers if they are unsure about any of their answers. Staff should be prepared to respond to queries about whether various medications are antibiotics or not.

4. Currently taking any other medication for an infection?

**Round 1:** All participants answered no. As with the previous question, some participants were sure of their answer simply because they were not taking any medication at all.

Most participants could not think of a medication for an infection that was not an antibiotic. Some participants found this question to be redundant-- in fact, some thought that any medication that fought an infection was an antibiotic by definition. Still, those participants easily answered the question with a “no.”

However, some other participants thought this question was an important complement to Q3. For example, one participant mentioned that he knew of medications for viral and fungal
infections that he would not have included in Q3, but would have included here. A few others were less certain about their answers but also mentioned viruses as the most likely target of these medications. In general, we think that this question will be useful for capturing medications that respondents would have excluded from the previous question.

**Round 2:** All participants answered no. As in the previous round, several participants were not sure what should be encompassed by the term “other medications.” Several people thought that cold medications should qualify, and one participant speculated that aspirin should count because “aspirin brings fevers down.” A few other participants mentioned topical ointments such as Neosporin; one participant mentioned “liquid brown stuff” that she used on a cut. Participant interpretations of the question tended to be broad and inclusive. While inappropriate inclusions could lead to false positives, this is clearly better than false negatives (which we did not seem to encounter).

A particularly unusual response came from a participant who mentioned a homeopathic “onion bag” that is used to treat various ailments. He was not actually using one, but expressed a belief that such remedies would be appropriate to include when answering this question. We suspect that such mentions will be unusual, but this response does highlight the fact that participants may interpret “infection” as any ailment, and include anything designed to fight off such problems in their answers.

**Round 3:** The question was administered to seven participants, all of whom answered no. As in previous rounds, some participants included cold medicines in their responses (reasoning that a cold is an infection of sorts); this may lead to some false positives.

**Recommendation:** Use current wording.

5. Female donors: Are you pregnant?

**Round 1:** Seven females participated in this round. One of them was about eight months pregnant and answered yes. The other six participants answered no and indicated that there was no chance at all that they were currently pregnant. Four of them could be certain because they had been celibate for over a year, and the other two both mentioned that they were taking birth control pills. At least one participant acknowledged that it was not always possible to know whether you are currently pregnant. Still, all participants felt that they had sufficient evidence to answer this question confidently, either based on their recent sexual history, precautions they had taken, menstrual cycles, or a combination of these.

**Round 2:** Six females participated in this round, all of whom answered no to this question. Two participants were beyond child-bearing age, and another had been celibate in recent months. One woman in her twenties claimed that she was sure the answer was no, and also mentioned that she was taking birth control pills. The remaining two participants were both married and in their
early 40s, and had been pregnant before but were quite sure they were not currently pregnant. One of them noted that in the past she had learned about being pregnant approximately three weeks into her pregnancy.

Round 3: Eight females participated in this round. One participant indicated that she was currently pregnant. The remaining seven answered no. However, one mentioned after probing that there was a 50-50 chance that she was actually pregnant. “No” was clearly her most accurate answer, since she did not know that she was pregnant for sure, but her response does confirm that there are definite periods of uncertainty about this. Several women who had been pregnant before indicated that it took a month or two before they knew this.

Inevitably, there is a window of time in which sexually active women of a certain age may not be able to answer this question with perfect confidence. Nevertheless, the question is unambiguous and our participants based their responses on largely reasonable assumptions about behavior and intentions. Occasional false negatives would most likely be with women in the earliest stages of pregnancy.

Recommendation: Unless this question is designed to capture women in the earliest phases of pregnancy, no changes are recommended.

In the past 36 hours have you
6. Taken aspirin or anything that has aspirin in it?

Round 1: Two participants answered yes. One of these participants had actually taken Motrin and acetaminophen within the past 36 hours, but not aspirin itself– he indicated that he thought the question referred to pain relievers in general. In fact, he mentioned that any over-the-counter cold remedies would also be appropriate in answering. Perhaps some of these actually contain aspirin, but he did not appear to put much literal importance on the word “aspirin.” The other participant who answered “yes” was pretty sure that she had taken an aspirin product of some kind, but was not sure exactly what it was (“pain reliever with aspirin, I think it said”).

Two other participants were unsure about their answers. One reported taking Advil but did not know if this contained aspirin. The other considered her answer carefully, believing that the answer was no. However, when considering a cough medicine that might have contained aspirin, she decided to answer yes (“just to be on the cautious side... when you’re giving blood you should be conservative about these things”). She then changed to no, thinking that she had actually taken it more than 36 hours ago. (It is clear from the interview that the “36 hour” time frame was somewhat awkward for recall purposes– for example, if someone fills out the questionnaire at 10 AM, they must figure out that the reference period begins at 10 PM two nights before.) A short time later, the same participant remembered that she takes baby aspirin every other day as a preventive measure against heart attacks. She could not remember whether
she had done this within the last 36 hours or not.

None of the remaining eight participants had taken aspirin or any other pain reliever within the past 36 hours. One had taken aspirin (he was sure that’s what it was) within the past week, but correctly answered no based on the time frame. Of these eight participants, understandings of the term “aspirin” were split down the middle. About half of the participants made clear distinctions between aspirin and other pain relievers— for example, they were very sure that acetaminophen and ibuprofen should not count. Most commonly, it appeared that they made this distinction because they were in the habit of avoiding aspirin. The other half of the participants had little conceptualization of the differences between various pain relievers. Their answers were accurate, since they took no pain relievers at all, but they clearly had little knowledge of the differences between them. However, they expressed little awareness of over-the-counter medications that could contain aspirin.

**Round 2:** Four participants answered yes in this round. Three of these reported taking 81 mg as part of a risk management plan for stroke. Interestingly, two other participants answered no, but reported that they had taken similar doses for the same purpose until recently (one stopped due to low platelets, and the other stopped in the wake of recent heart surgery). While this does not “prove” that respondents will generally remember to include such aspirin in their answers, it does give us some reason for optimism. All of these participants included this aspirin in their answers without any prompting, and the intent of the question was clear to them. The fourth participant who answered yes was less certain about her answer, and wrote a “?” next to her answer. She had used a dab of sports cream on her foot and was pretty sure that it contained aspirin. It was not obvious to her whether this meant she had “taken” it, hence her uncertainty.

The remaining participants seemed to fall into two groups, about evenly split. The first group did not seem to make strong distinctions between aspirin and other pain relievers— they might take aspirin or something else, depending on what was available, and were not sure whether these contained aspirin or not. One of these participants thought that Tylenol should not count as aspirin, but that Advil should. The other group indicated that they took aspirin very rarely, or actually took active steps to avoid it. They generally made distinctions between aspirin, ibuprofen, and acetaminophen. Even so, many of these respondents admitted that they were not completely certain whether various over-the-counter pain medications contained aspirin or not (perhaps one or two participants indicated that they knew very clearly whether or not certain medications contained aspirin).

When asked to name products that might contain aspirin, almost all were very uncertain— one participant mentioned Bufferin, but most had little to offer. In virtually all cases, however, participants were sure about the accuracy of their answers because they had not taken any pain relievers or other medications in the last 36 hours.

Several participants mentioned that if they were in doubt, they would ask the personnel where they were donating blood, recognizing the importance of providing accurate information. False
positives seem more likely than false negatives— the most common error will probably entail respondents including pain relievers that are not aspirin. False negatives might occur with over-the-counter cough or cold medications whose aspirin content is unknown.

**Round 3**: One participant answered yes. He was clearly confused by the differences between aspirin and other pain relievers such as ibuprofen— but in his case the distinction was unimportant since he had taken both. One other participant answered that she did not know; she had taken Advil Cold and Sinus medication and was unsure whether this contained aspirin or not.

The remaining nine participants answered no. At least three of them were clearly confused by the differences between aspirin and other pain relievers. They tended to use aspirin as a generic term that covered all of these. Several participants mentioned that they were not sure if various cold medicines contained aspirin or not.

In short, there is considerable potential for error with this question. False positives based on acetaminophen and ibuprofen are likely to be common. Many participants indicated that they had no idea regarding what might be encompassed under “anything that has aspirin in it.” It is also possible that some respondents would be unaware of the aspirin contained in over-the-counter medication such as Alka-Seltzer and exclude those from their answers.

Some of these errors could be reduced by providing a list of common medications that include aspirin. Respondents could be referred to a separate list so that the questionnaire itself remained uncluttered. Also, in the interest of easing recall burden, it might be better to change the 36-hour reference period to 48 hours, which is probably simpler. There is some chance that routine usage of children’s aspirin could be forgotten, although participants often reported such aspirin in their answers. If the potential for missing this is a serious concern, a prompt could be added to the question, although that would also increase length and might confuse some respondents.

**Recommendation**: Change the reference period to the much simpler 48 hours; this should be much easier to remember. Provide donation center staffs with lists of common medicines that contain aspirin so that respondents can ask for clarification regarding specific medicines.

**In the past 4 weeks have you**

7. Had any shots or vaccinations?

**Round 1**: One participant answered yes. She had initially answered no, but remembered a shot while filling out the questionnaire (before being prompted by the interviewer). She was not entirely sure what it was, but received it because she is pregnant and RH-negative; the shot was apparently for the baby’s protection. She thought it might have been “RH immuno-globulin” or gamma globulin, but was unsure. In any case, she received it several times during her pregnancy, most recently about three weeks prior. She indicated that she was originally thinking only in terms of vaccinations, which is why she almost forgot to report it.
All other participants answered no, and seemed to be fairly sure of their answers. Quite a few participants mentioned receiving a flu shot in the fall of 2000, but excluded this because it was outside the reference period. It would be useful to conduct additional tests during “flu shot season” to see if people accurately included them. A few other participants mentioned that their most recent shots had been for tetanus, but none of these occurred during the reference period of the question.

One participant used to take allergy shots and wondered if they should count. She ultimately decided that they should. Still, this raises the possibility that people might tend to focus on the vaccination aspect of the question, potentially excluding other shots. The participant who answered “yes” (above) almost forgot to include a non-immunization. Some inadvertent exclusions might include shots such as Novocaine at a dentist’s office, which may or may not be significant. However, if the question was rewritten as “vaccinations or any other kind of shot,” it might lead to more complete reporting.

Round 2: One participant answered yes— it was a vitamin B12 shot, which she receives every month. Most other participants mentioned that their most recent shot was a flu shot, administered last fall or earlier. A few others mentioned various vaccinations. One especially interesting participant had recently received Deprovera, a flu shot, a hepatitis vaccine, and a trial HIV vaccine, but answered no because none were within the 4 week reference period.

One participant answered no, but had received a shot of cortisone only the day before. Interestingly, she had tried to donate blood earlier on the day of her interview, and was deferred for this reason. In the interview, immediately after reading the educational materials (prior to answering the questionnaire) the interviewer asked if there was any reason she thought she would be deferred, and the participant mentioned the cortisone shot. Then she filled out the questionnaire, answering no to this question. Only when debriefing on a question-by-question basis did she realize that she had failed to answer the question accurately. This was quite surprising to her: “oh my... I guess I was thinking of upper body... Wow. I forgot. It didn’t register... I guess maybe I was thinking more about vaccinations.” Her forgetting this was all the more remarkable considering that the shot was very painful and the deferral experience fresh in her memory. This experience highlights the fact that interpretations, memories, and attention spans are imperfect. Not only would we have expected a “yes” response, but the participant herself immediately recognized that she had made an error when discussing her answer. The rewording recommended above might have prevented this error.

Round 3: This question was administered to seven participants, two of whom answered yes. One of these responses was a false positive, referring to a shot that she had received the previous March. We did not probe this particular response in depth, but this was not her only false positive response due to time frame. The participant who correctly answered yes had received a flu shot that morning.
One of the participants who answered “no” had received a flu shot six weeks earlier, but answered no after correctly noting the time frame of the question. This participant questioned whether a flu shot was significant enough to count if it was received during the time frame, but decided that it was. Others could not remember receiving any shots within the last year. One participant did question whether a TB test counted as a shot.

Note: See also the results from vignettes, in the final section of this report.

Recommendation: Reword slightly to “vaccinations or any other kind of shot” to emphasize the potential variety of responses and encourage respondents to think carefully about events that might qualify.

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

Round 1: All participants answered no. All participants in this round were selected on the basis of having never given blood, so it was theoretically possible that a platelet or plasma donor could have been interviewed-- but none were.

Only one participant had minor difficulty answering because she was uncertain whether “giving blood” in a medical exam counted (e.g., to have her cholesterol checked). Most of the respondents had only vague understandings at best of the difference between giving blood, platelets, or plasma, but were nevertheless extremely confident that their responses were accurate.

Round 2: One participant answered yes, but admitted he was not sure whether it fell into the reference period. After thinking about the exact date of the donation (which was whole blood), the interviewer figured that the donation had actually taken place about 10 ½ weeks ago. Another participant had also given about 10 weeks ago, but carried a donor card with her. By reading the date of donation, she was able to answer this question accurately.

All other participants answered no, but most had given blood at some earlier time. At least three participants had given platelets in the past, two of whom were familiar with the term “apheresis device.” Several others were familiar with the basic idea of donating platelets/plasma (i.e., that only part of the blood was taken and the rest returned to the donor), even though they had not actually done it.

Round 3: Three of eleven participants answered yes. Probing revealed that one of these events actually fell just outside the reference period– it had been eight weeks and two days. Another of these participants answered yes not due to conventional blood donation, but because she had “given” blood at her doctor’s office. She was not certain this should count but thought it was possibly within the intent of the question. Her last actual blood donation had been several years
earlier. The third respondent reported a standard whole blood donation.

When probed, a majority of participants indicated that they had heard of giving platelets and/or plasma, but only two or three of them had any real idea of what this entailed. We can envision one potential confusion for respondents who had given platelet/plasma and whole blood, but on different time frames. Suppose a respondent had given platelets several years ago, but also whole blood only 6 weeks ago. The respondent’s attention might be drawn more toward the platelet and plasma component of the question, leading to an incorrect “no” response. We did not actually observe this in any interviews and suspect it would be a rare occurrence, but wonder if this might be an issue for those who primarily donate platelets.

Yet on the whole, this question seems to work well. Although we encountered occasional errors regarding the time frame, this seems to be due to limitations of memory rather than any particular problem with the question.

**Recommendation:** Use current wording. The Task Force has also discussed potential use of “donated” instead of “given,” and we think that this substitution poses no comprehension problems. It is possible that plasma or platelet donors could occasionally question the word “donate” (since they were paid), but our experience suggests that the pragmatic meaning of the question would be clear to most people.

In the past **16 weeks** have you

9. **Given a double** donation of red blood cells, using an apheresis device?

**Round 1:** All participants answered no. None had ever given blood, platelets, or plasma, so this was not especially surprising. Only one participant had ever heard of an apheresis device, and he was involved in the pharmaceutical industry. None of them had much idea what this question meant, but were confident that their answers were accurate because they of their lack of experience giving any sort of blood product.

**Round 2:** All participants answered no, and most had never heard of an apheresis device. Most participants were very confident in their answers—this sounded like a very specific event and indicated that they would have known if they had done this.

The only confusion arose from those participants who had given platelets via apheresis and were not sure whether this qualified or not. One participant had usually given “two bags” and wondered if that was what “double donation” referred to. Most respondents will be able to answer this question easily, but those who have had some experience with apheresis devices may need supplemental information to distinguish what they did from a “double red cell” donation.

**Round 3:** All participants answered no, and most indicated that they had never heard of apheresis before.
In all three rounds, the only potential problem we observed was that people who had given platelets via apheresis might erroneously answer yes.

**Recommendation:** Members of the Task Force suggested that the question ask whether the respondent has “donated double red cells, using an apheresis device.” We support this suggestion. Respondents who have donated “two bags” of platelets via apheresis could misunderstand “double donation,” but the alternative would probably reduce the chance of such errors.

In the past **12 months** have you

10. Had a blood transfusion?

**Round 1:** All participants answered no, and seemed to understand the term “transfusion” clearly. Only one had ever received a transfusion at any time—this took place around 1992-93. No other participants had received the blood of another individual at any time.

**Round 2:** All participants answered no, and were quite sure that their answers were accurate during the time frame of this question. Two participants had received transfusions in earlier years, but one of these individuals seemed to misunderstand the term “transfusion”—if this event had occurred during the time frame of the question, he might have answered “no” incorrectly. He thought of transfusions as taking place in situations like wars or accidents, in which someone is bleeding to death. In discussions, he admitted that if this had happened during the past 12 months, he might have considered this to be a transfusion, but was not completely confident. He therefore suggested that the question should read “surgically or non-surgically” in order to encourage people to think along both lines. It may be useful to add something such as “or received another person’s blood for any reason” in order to be more comprehensive.

Interestingly, several other participants were unsure whether they had received transfusions at some point in the past. One participant thought there was a definite possibility that she had received one during breast cancer surgery, but was unsure. Another had also had a surgery, and while she was pretty confident that the answer was “no,” she admitted that there was a slight chance that she had. Another participant had received his own blood during surgery (donated in advance). He did not consider this to be a transfusion, but raised an interesting point—some people might answer “yes” under such circumstances.

**Round 3:** All seven participants answered no, although one raised the possibility that he had received blood years ago during surgery—he was not sure. Although knowledge about this issue is clearly imperfect, there does not seem to be any problem with the question itself. In fact, our experience suggests that respondents would be likely to admit uncertainty if they had been in a recent surgery or accident and were not sure.
**Recommendation:** Use current wording.

11. Received clotting factor concentrates?

**Round 1:** All participants answered no. Most were very sure about their answers, although many noted that they had never heard of clotting factor concentrates before. They generally assumed that these had something to do with clotting problems and/or hemophilia, and knew that such problems did not apply to them. One participant wondered if birth control pills could be considered “clotting factors” since some women use them to control menstruation. Even though she herself was taking birth control pills, she decided to answer no to the question, reasoning that she was not taking them for the purpose of clotting. Another participant also expressed some uncertainty—she had received a transfusion (outside the time period mentioned in this question) and thought it was possible she had received these, but was unsure. Supplemental definitions may need to be available for respondents who express similar uncertainty.

**Round 2:** All participants answered no. As in the previous round, most participants were very sure about their answers and had a good sense of what the question was getting at. A fair number admitted that they were speculating about what clotting factor concentrates were, but they nevertheless felt very sure that they had not taken them.

One participant in this round mentioned that she had surgery for breast cancer several years ago, and was not sure whether she had received clotting factor concentrates at that time. This caught our attention because another participant (in the previous round) had also expressed uncertainty regarding whether she had received them without her knowledge during a medical procedure. It is likely that future donors will express similar uncertainty and may turn to blood center staff members for guidance on how they should respond.

**Round 3:** All seven participants answered no. About half of them seemed to have a general idea of what these were, while the others indicated that they had no idea. Participants often said something along the lines of “if I’d had that, I think I’d know it.” Still, the term “clotting factor concentrates” is esoteric and some respondents may be confused.

**Recommendation:** Consider adding a few definition words in parentheses following the question (e.g., “these help some people form blood clots.”) At a minimum, be sure that blood center staffs are prepared to provide definitions to those who ask.

12. Had a transplant such as organ, tissue or bone marrow?

**Round 1:** All participants answered no. None had any relevant experiences with transplants as far as we could ascertain. The question seemed straightforward to everyone, although a few participants mentioned that they had never heard of “tissue transplants.” When asked what sorts
of things they think of when they hear “transplants,” most replied with kidney, heart, and liver; a few others mentioned lungs, brain tissue, or repeated “bone marrow.”

**Round 2:** All participants answered no. One participant’s cousin had donated a kidney to a brother, and as far as we could tell that was the only personal experience any participant had with transplants. Interpretations were very similar to those mentioned in the previous round, with kidney, heart, and liver mentioned most often. One participant speculated that a facelift might qualify, and this was the only unusual response we received.

**Round 3:** All participants answered no. None had any relevant experiences with transplants as far as we could ascertain. All participants found the question to be straightforward.

**Recommendation:** Use current wording.

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013. Had a graft such as bone or skin?

**Round 1:** All participants answered no, and none had any experience with any kind of graft. Almost all participants were familiar with the idea of skin grafts (although some thought that they were only taken from one’s own skin). Several participants mentioned that they associated grafts with burns. One participant was completely unfamiliar with the term “graft”-- although he was from Cameroon and had some difficulties with English. Two others were unsure about what it meant, but thought that if they’d had one they would have known it. Many others had never heard of a bone graft and expressed confusion about what that might entail.

**Round 2:** All participants answered no, and none had any experience with any kind of graft. Interpretations mirrored those from the first round of testing, although more participants in this round were familiar with the concept of “bone grafts.” A few others were still confused, asking if a bone graft was actually more like a “bone transplant.” As before, several participants mentioned that they thought grafts primarily came from a person’s own skin, not someone else’s.

**Round 3:** All seven participants who received his question answered no. Interestingly, one participant had received a graft earlier, in 1987. He was bitten by a spider and the wound became severely infected. A large section of skin which extended to his leg bone had to be removed, requiring a graft. As in previous rounds, some participants thought that grafts were only taken from one’s own skin, and a few admitted that they had never heard of bone grafts.

**Recommendation:** Use current wording. Provide definitions of grafts to blood center staffs, including additional explanatory material on bone grafts for those who ask.

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14. Had an accidental needle-stick or come into contact with someone else’s blood?
Round 1: All participants answered no. Most seemed to focus more strongly on the needle-stick component of the question than other avenues for coming into contact with someone’s blood. When asked how this sort of thing might happen, most participants mentioned either accidental needle-sticks in a health care setting or being among drug users. When asked about “other ways” that someone might come into contact with other people’s blood, participants commonly mentioned helping someone who was bleeding. Discussing this possibility did not prompt anyone to change his or her answer to the question.

Some participants raised interesting or unusual ideas when discussing this question. One mentioned that French-kissing someone with gum disease would be a way of coming into contact with someone’s blood. Another participant mentioned that people who work with pharmaceuticals stick themselves with needles quite often (but the needles are generally clean, or contain trace amounts of drugs). Ordinarily, such responses might be classified as false positives-- however, he noted that this could still be a concern if the needle was in contact with immune globulin. Another participant pointed out that police and firefighters must come into contact with others’ blood frequently. Finally, one participant thought that the most likely means of being stuck with a needle was by emptying your trash or walking around your apartment building without very solid footwear. We are glad we do not live in her neighborhood.

Round 2: One participant answered yes– he had helped to clean up a bleeding grandchild. All others answered no, and more commonly their attention was focused on the needle-stick component of the question. Generally, it seemed that these participants were more likely to consider events other than needle-sticks than participants in the previous round did. Nevertheless, splitting the question into two parts would separate two concepts that are very different. The participant who answered “yes” pointed out that these components didn’t fit together well: “I thought, gosh, they’re putting grabbing your granddaughter in the same category as a needle-stick!”

One participant indicated that he was not sure what the term “needle-stick” meant, but guessed (correctly, as it turned out). While the term is fairly intuitive, blood center staffs should be prepared to provide a standard definition of “needle-stick” when asked. Another participant mentioned that he had stuck himself with a needle after administering medication to his diabetic dog. He indicated that he would have answered yes to the question if this had taken place within the past year-- but blood center staffs should be prepared to answer questions regarding whether such needle-sticks should count.

It became clear in this round that some participants had different thresholds of classifying various events as “coming into contact” with blood. Most thought that any touching of the blood of another person should qualify as a “yes” response. One participant noted that he could have answered yes in earlier years based on athletic activities in college (boxing, wrestling, football). However, at least one participant thought that contact with blood should only be counted if it had a chance of penetrating him (e.g., through a wound or membrane). His interpretation of the question was not literal, but was rather based on a judgment about whether he had “risky”
contact (in his estimation) with someone’s blood. If the point of this question is to capture any contact with blood, this point could be underscored by adding a phrase such as “in any way.”

Round 3: All eleven participants answered no. Probing indicated that one of these participants might have come into contact with her best friend’s blood while bandaging a cut, but she answered no because “I know that there is nothing wrong with her, so I am not worried.” This is another situation that might be helped by splitting the question into two pieces; the participant might have had a harder time answering “no” if the question simply asked about any exposure to another person’s blood.

All participants seemed to understand clearly that accidental contact with a syringe should count. Oddly, a few participants interpreted the question broadly (e.g., suggesting that someone who pricked themselves with a sewing needle should answer “yes”). In terms of other ways to contact blood, participants mentioned a variety of circumstances including wounds, coughing up blood, fights, or accidents. One participant also mentioned that he had come into contact with someone’s blood during an anal sexual experience several years prior.

Note: See also the results from vignettes, later in this report.

Recommendation: Given that receiving a needle-stick and cleaning up blood are such different experiences, likely to be stored in memory very differently and recalled differently, we recommend splitting this into two questions. If this is not done, we think it is likely that respondents will become too fixated on the idea of “needle-sticks” and may fail to consider other types of contact with blood. Some respondents are likely to request a definition of “needle-stick,” which should be provided. If the question is supposed to capture even superficial contact with blood, consider adding the phrase “in any way.”

15. Had sex with anyone who has HIV/AIDS or has had a positive test for the HIV/AIDS virus?

Round 1: All participants answered no to this question. Five participants could be sure about their answers on the basis of being celibate for the past 12 months or longer (and two reported that they had never had intercourse). Another five participants reported that they had been monogamous for the past 12 months or longer. Obviously, their answers were based on their belief that their partners were HIV negative, which was based on their belief that their partners were faithful. Generally they had no evidence to the contrary and these seemed like reasonable assumptions. One participant was a gay male who reported being monogamous for 20 years, and he too expressed confidence that he had an exclusive sexual relationship with his partner.

Two participants reported having multiple sexual partners in the last year. Both considered themselves to be at low risk for contact with anyone HIV-positive. However, one of these participants admitted that he had engaged in unprotected sex with at least three partners.
answer needs to be interpreted as meaning “I did not have sex with anyone that I know to be HIV positive” rather than an objective assessment of his risk of exposure. The other participant also considered himself to be at low risk, even though in the following question he admitted that at least one of his partners had been a prostitute. Here also, he was saying that he did not knowingly have sex with an HIV-positive person, rather than saying that he engaged in no risky behavior.

Participant interpretations of “have sex” varied. Several participants clearly thought that the term referred specifically to intercourse (at least while answering this question). Others had broader definitions that included oral sex. For many respondents, this distinction will not be important. This study (and earlier ones that we have conducted) suggests that it is relatively unusual to find heterosexual, sexually active adults who have passed an initial “exploratory” sexual phase and engaged only in oral sex. Thus, as long as such individuals’ interpretations include intercourse, it might not matter much whether they include oral sex or not. Variations in interpretations are more likely to be important among (1) homosexuals, and (2) adults with limited experience with intercourse (usually young adults). Both groups could engage in oral sex but interpret the question as referring only to intercourse. But in general (based on the psychology of answering questions), we think that if a respondent believed that they had intimate contact with an HIV-positive individual, they would be likely to interpret the question liberally and pragmatically, rather than based on a specific, pre-conceived definition of the term “have sex.”

Round 2: All participants answered no in this round. Ten of the participants reported being monogamous, and the other two had been celibate during the past 12 months. Generally, they seemed to have conservative attitudes regarding sex– even those who were unmarried and sexually active seemed very risk-averse and selective about their partners.

They all assessed their risk of having sexual contact with an HIV-positive person to be quite low. A few were willing to concede that they did not know absolutely for certain that their partners had been faithful (although none of them believed there was a reasonable chance of infidelity). A few others had not been with their partners for a long period of time, and considered the possibility that some could have carried HIV from before. Yet here also, they thought the chances of this happening were very slim, usually based on an assessment of their partner’s character and likely past behavior. Participants in this round were uniformly confident that their risk level was extremely low.

Round 3: One participant answered yes to this question (a gay male in a monogamous relationship– both he and his partner are HIV positive). Of the remaining ten, five indicated that they were monogamous, and four of these were very confident of their answers. However, the fifth readily admitted that she was not certain about the accuracy of her answer. She was separated from her husband as a result of his infidelity, and she had no way of knowing about his choice of partners. Although she thought it unlikely that he had contracted HIV, she recognized that his behavior increased his risk at least to some degree.
Two other participants indicated that they were sexually active but not necessarily monogamous. The remaining three participants reported that they were celibate.

Participants were probed regarding whether they considered oral sex or other activities as “having sex,” and responses were about evenly mixed: about five participants thought it was unambiguous that oral sex qualified as having sex, while the other six thought that the term “having sex” referred specifically to intercourse. However, even these latter six participants were unanimous in their opinion that if someone had engaged in only oral sex with an HIV-positive individual, then “yes” would be the most appropriate response. One participant explained this as the difference between a “technical” and “ethical” answer to the question— the technical or literal answer could be no, while the ethical answer should be yes.

In all three rounds, it was clear that definitions of “having sex” were varied, with some counting oral sex and others not. As mentioned above, such variety of interpretation is only likely to be important for those who engage only in sexual activity that does not include intercourse— usually homosexuals or young heterosexuals. Furthermore, participants’ literal definitions of “having sex” seem to have been overruled by pragmatic definitions (i.e., participants attempted to judge what information the question was trying to capture beyond its literal meaning). For most participants, the question seemed to get at whether they had been exposed to HIV through some sexual contact. Thus, an individual’s definition of “having sex” is less important than their interpretation of what this question is trying to measure. In most cases, responses are likely to be more liberal and inclusive than we might expect based on their definitions. However, exceptions might occur for those who don’t believe that oral sex entails any risk. We encountered few if any participants who thought this was the case, but this could be a problem in the larger population.

The bottom line is that the current wording works most of the time, but it cannot hurt to provide better definitions of what should be included in terms of “having sex.” It is probably better to define relevant sexual contact in educational materials, rather than within the text of questions that pertain to sex. This keeps the questions short and straightforward while providing unambiguous guidance to those in ambiguous situations. Note that this general approach and its rationale should apply to other questions about sexual contact on the questionnaire as well.

**Recommendation:** Use the broader term “sexual contact” in this question, and provide a complete definition of what this entails in the educational materials.

16. Had sex with a prostitute or anyone else who takes money or drugs or other payment for sex?

**Round 1:** One participant answered yes— several months ago he had sex with a prostitute somewhere in the metropolitan DC area. No other participants had such an experience. The description “prostitute or anyone else who takes money or drugs...” seemed to be clear. One
participant summed it up by saying the question referred to anyone who “sells their body.” A few female participants thought it was an odd question for women and that they did not see how it applied to them.

Interpretations of the term “have sex” were not consistent across participants-- and indeed, some participants’ interpretations varied across questions. For example, one participant thought that “having sex” in Q15 referred only to intercourse, but thought oral sex would “count” for this question. Conversely, it is possible that some respondents could exclude receiving oral sex from their answers to this question, although this may not be a serious omission. In any case, we think it is very unlikely that someone would misunderstand the question in such a way to exclude intercourse that took place in exchange for any payment.

**Round 2**: All participants answered no, and indicated that the meaning of the question was very clear to them. Participants suggested that the idea of paying (anything) for sex was very far removed from their lives, mentioning no contact with “hookers” or any other people who engaged in risky sexual behavior. Many participants were monogamous and expressed strong confidence that their response was accurate. A few others reported being completely celibate in the past year.

**Round 3**: All participants answered no and indicated that the meaning was clear to them. As in previous rounds, we observed that some participants’ interpretations of “having sex” were not necessarily durable across questions (i.e., having oral sex with an HIV-positive person should lead to a “yes” while doing that with a prostitute should not). Such judgments appear to be linked to perceived risks. One participant thought even kissing should count as a yes because she believed that STDs could be transmitted in that manner.

**Recommendation**: Use the broader term “sexual contact” in this question, and provide a complete definition of what this entails in the educational materials.

17. Had sex with anyone who has ever used needles to take drugs or steroids, or anything else not prescribed by their doctor?

**Round 1**: All participants answered no. They expressed pretty strong confidence that their answers were accurate, especially when they were celibate or in long-term monogamous relationships. Even those participants who had relatively casual sexual encounters in the past year expressed a belief that their partners were extremely unlikely to have been involved in such behaviors. We have no reason to doubt their assessments, but note that they could be based on optimistic estimates of risk. Respondents would probably need to have very strong suspicions (or direct evidence) before answering yes to the question.

The term “steroids” may have confused a few participants. One participant noted that a boyfriend had taken a powdered supplement to build muscle, and she was not sure whether this
should count as a steroid or not (perhaps missing the part of the question that focused on “needles”). Another participant simply expressed confusion as to whether steroids were usually taken by needles—she answered no, but an experience with non-needle steroids could have changed her answer. Such confusion could create some false positives.

Most participants, however, thought that illegal or “street” drugs were the primary focus of the question, and most commonly mentioned heroin as an example.

**Round 2:** All participants answered no. Their interpretations were similar to those of participants in the first round, and they were similarly confident in their answers (although one participant pointed out that this isn’t the sort of thing that would “come up in a bar”). Quite a few stated that this sort of drug use is simply outside of their realm; they do not do drugs or associate with anyone who does. Many had been in long-term monogamous relationships or were celibate.

Most participants thought the question was asking about individuals who had specifically used needles to take non-prescribed drugs. However, at least two participants thought the question encompassed needles used to take drugs (whether or not prescribed by a doctor) as well as any other drug (by needle or otherwise) that was not prescribed. This interpretation seems to be due to the structure of the question. If the intention is to focus only on drugs with needles, it could be modified to read “Had sex with anyone who has ever used needles to take drugs or steroids not prescribed by their doctor.”

**Round 3:** All eleven participants answered no. Most participants clearly understood the question and the sorts of things that should be included— but interestingly, a few participants thought too broadly, including substances such as marijuana. Broad interpretations did not actually lead to false positive responses during our interviews, and such interpretations are probably more prominent among individuals who have no contact with any illegal drugs. Such individuals might not pay as much attention to details of the question, answering quickly because they know that using drugs of any kind does not apply to them.

Definitions of “have sex” probably varied here as well. However, most participants did not seem to pay much attention to nuances of “sex” here because they easily answered no on the basis of drugs—details about sexual definitions were irrelevant.

**Note:** See also the results from vignettes, in the final section of this report.

**Recommendation:** Reword to “Had sexual contact with anyone who has ever used needles to take drugs or steroids not prescribed by their doctor.” Include full definition of “sexual contact” in the educational materials.

18. Had sex with anyone who has hemophilia or has used clotting factor concentrates?
Round 1: All participants answered no. Most admitted that they had never heard of “clotting factor concentrates” but inferred that they had something to do with hemophilia. Participants who were celibate or monogamous were obviously much more certain about their answers. Some other participants who had more casual sexual contact admitted that they could not be certain, but were generally confident in their responses. However, one female participant thought that hemophilia “was not that big of a deal” and could easily be unknown in a new or casual relationship.

Round 2: All participants answered no. In general, these participants seemed even more sure than those from Round 1 about their answers—either due to monogamy, celibacy, or a sense that they would expect to know someone very well (including medical history) before having sexual contact.

Round 3: All eleven participants answered no. Most had never heard of clotting factor concentrates before, although a few indicated that they had a pretty good idea of what these entailed. As with the previous question, participants did not seem to pay much attention to the nuances of what “having sex” entails, since they easily answered no on the basis of not knowing anyone with clotting factors. The question was especially easy for people who were celibate or monogamous. Others thought it was likely that they would know if they had such contact, although obviously such knowledge could be limited in situations of casual sex.

**Recommendation:** Use the broader term “sexual contact” in this question, and provide a complete definition of what this entails in the educational materials. Blood center staffs should have definitions of “clotting factor concentrates” available to those who ask for them.

19. Female donors: had sex with a male who has ever had sex with another male?

Round 1: All seven female participants answered no. They all reported being sure that their answers were accurate. Generally they reported that they could “just tell,” although at least two participants could be certain because they had not had sex during the past 12 months. The term “had sex with” is potentially open to interpretation. We suspect that when thinking of a male “having sex with another male” they were referring to intercourse, but did not explore this in depth because all of the participants were fairly adamant that the answer was no (regardless of how “have sex” was defined).

Round 2: All six female participants answered no. While a few admitted that “nobody knows for sure,” they were generally confident in the accuracy of their responses. Again, it was not especially fruitful to explore interpretations of “having sex” because they were clear that the answer was no regardless, and such nuances played no role in their responses.

Round 3: All eight female participants in this round answered no. As before, a few admitted that it is impossible to be 100% certain, but were nevertheless quite confident in their responses.
Interpretations of “having sex” varied as with other questions (one participant argued that two men kissing had actually had sex and “it’s just not right”; another thought only intercourse should count). However, most participants thought that they had not had any sexual contact with a male who had any sexual contact with another male—therefore, nuances of the interpretation were unimportant to their decision processes.

Recommendation: Use the broader term “sexual contact” in this question, and provide a complete definition of what this entails in the educational materials.

20. Come into contact with blood or saliva from a person who has hepatitis?

Round 1: All participants answered no to this question. Most indicated that they do not know anyone who has hepatitis at all. A few others talked about the fact that they come into contact with blood or saliva from very few individuals, and were very confident that none of them had the disease. Some participants admitted that it would be hard to be absolutely certain, but virtually everyone expressed confidence in their answers.

Interpretations of what qualifies as “coming into contact with saliva” were varied. Some participants thought “sharing a glass” would qualify, while others thought it would not. One participant expressed confusion because he has friends with hepatitis and has them over for dinner. He was unsure whether that put him in contact with their saliva. In fact, his “no” response to the question was based more on his insistence that “there was no way he had hepatitis,” rather than assessing the chances he had actually contacted saliva from an infected individual.

Round 2: All participants answered no to this question. A few participants did know individuals who had hepatitis outside the time period of the question: one had a boyfriend with hepatitis A in college during the 1970’s, and another had an acquaintance with hepatitis about 10 years ago. A few also mentioned having hepatitis themselves. In addition, two participants reporting knowing someone who currently had hepatitis— they answered “no” because they did not think that they had any contact. Still, they (and other participants) admitted that it was hard to tell for sure that they had not been exposed. For example, one participant noted that a sneeze can spread saliva. They were basically reporting that they had not had an obvious exchange of saliva with someone known to be infected. Generally, any contact with someone’s blood was much more rare. When that happened to one of our participants it was with a child or a spouse, and they were quite sure that there was no hepatitis risk involved.

Round 3: All eleven participants answered no. Most did so on the basis of not knowing anyone who had hepatitis— which meant that they could not have come into contact with blood or saliva from such an individual. Respondents who have some contact with hepatitis-positive individuals will have to make an additional judgment regarding what qualifies as “contact with blood or saliva.” It seems clear that most participants thought that French kissing should qualify, as
should contact with an open wound. More casual contact (such as sharing a glass) might be more ambiguous to some respondents.

One participant in this round lived with her father, who definitely has Hepatitis B and could have Hepatitis C as well. She thought it was very likely that she had shared a glass with her father. However, she indicated that Hepatitis B could not be spread through saliva, only through more intimate contact. She claimed that she would have answered yes if her father definitely had Hepatitis C, since that was more contagious. Thus, her “no” response was based on the fact that she had no contact with a Hepatitis-positive person that could have been contagious— at least as far as she knew. Obviously, the problem is that such individuals could be misinformed about which strains can be transmitted and how.

Note: See also the results from vignettes, in the final section of this report.

Recommendation: Reword to “had any contact” to emphasize that even seemingly casual contact should be captured here. It might also be worthwhile to switch “blood and saliva” to “saliva and blood” to put greater prominence on saliva—such contact is probably more common than blood contact. It may be more complicated than it is worth to add specific examples of “contact” in the question, but blood center staffs should be prepared to answer questions about whether activities such as sharing a glass should count.

21. Had sexual contact with a person who has hepatitis?

Round 1: All participants answered no to this question. In almost every case, they interpreted the term “sexual contact” as referring to intercourse as well as oral sex. No participants thought that kissing alone would qualify as sexual contact. One participant thought that only intercourse should count as sexual contact, although she also reported that she had never had sex (she was a 21 year old college student). Generally participants thought that “sexual contact” and “having sex” were equivalent.

When probed, participants indicated that they were pretty sure their answers were accurate—often because they had been monogamous or celibate during the time period of the question. Participants who had been with multiple partners explained that their answers were obviously only accurate “as far as I know.” One participant assumed that someone with hepatitis would have obvious jaundice and it should be easy to tell, but most seemed to have a more realistic assessment of the difficulties being absolutely certain about this.

Round 2: All participants answered no to this question. Interpretations may have been slightly broader than in the previous round. One participant thought that even kissing could qualify as “sexual contact”; on the other hand, a few thought the question was getting exclusively at
intercourse. As mentioned earlier, we know from other cognitive interview projects that the distinction between intercourse and other sexual activities are somewhat hypothetical for sexually active heterosexual adults, because their sexual contact usually culminates with intercourse. And most thought that oral sex or any “exchange of bodily fluid” was consistent with the intent of this question. One participant thought we should add “with or without protection” to avoid no responses that actually meant “yes, but it was ‘safe’ sex.”

**Round 3:** All eleven participants answered no to this question. Interpretations of “sexual contact” seemed broader than interpretations of “had sex” in the earlier questions—for example, kissing was more likely to be included. This could be because “sexual contact” seems to cover a wider domain, but it may also be because participants perceive kissing as a risk factor for hepatitis (whereas kissing may not be a risk factor in other areas, such as spreading HIV). Here and with other questions, participants seemed to answer based on a pragmatic interpretation of the intent of the question.

Members of the Task Force have also raised concerns that “sexual contact” is a term that could be interpreted differently by various sub-groups of the population (e.g., age or ethnic groups). For example, younger respondents could have narrow definitions of “sexual contact” that would exclude behaviors such as oral sex. We recruited some younger participants and participants from ethnic minorities in this round to explore these potential differences in interpretations. Unfortunately, given the small number of subjects, results were quite inconclusive. Concern about the validity of this term across sub-groups may be legitimate and should be investigated further.

It is important to keep in mind that explanations given in interviews or focus groups regarding “what do you consider sexual contact to mean” are somewhat hypothetical and may not reflect the actual judgement processes employed when answering this question. As mentioned earlier, respondents are likely to evaluate the intention of a question pragmatically. In that light, their interpretations probably make them more likely to include unusual events when answering (if they perceived these events as legitimate risks) rather than to exclude them based on literal interpretations of definitions. In other words, if an individual had engaged in oral sex with someone known to have hepatitis, and they considered that to pose an actual risk of exposure, they would be likely to respond yes—even if they did not consider that to be “sexual contact” in a more neutral context. This tendency to be inclusive is likely to be even greater in the context of donating blood, where respondents are frequently reminded of the need to fully disclose information. The most likely threat to accuracy would be if respondents believed that their particular situation did not put them at risk (e.g., “we share glasses of wine, but you can’t get hepatitis that way.”)

The only ideal test of this item would be to ask it of individuals who had engaged in sexual behavior with hepatitis-positive individuals, and evaluate the accuracy of their response to the question. In lieu of that, we do have some idea about participants’ interpretations of what the question is actually trying to measure.
Note: See also the results from vignettes, in the final section of this report.

Recommendation: Use current wording, but add a definition of “sexual contact” in the educational materials.

22. Been given hepatitis immune globulin (HBIG)? *(Note: this is not the same as hepatitis B vaccine.)*

**Round 1:** All participants answered no to this question. When probed, only one participant indicated that he had ever heard of this. None reported having hepatitis or any experience (as far as we could tell) that might have made them likely to have received HBIG. In spite of the note at the end, at least one participant thought this question was asking about a hepatitis vaccination. It might be worthwhile to add a statement that explains what HBIG is rather than what is isn’t.

**Round 2:** One participant answered yes, but explained that this was “gamma globulin”-- we are not sure whether this is the same thing or not. Incidentally, her response was a false positive due to time frame– she had actually received this in 1983. We tend to think that false positives such as this are due to the format of our questionnaire rather than any particular problem with the question. However, there may also be a heightened tendency to answer yes to a question if it is perceived as referring to something rare or unusual, ignoring particulars such as time periods. It may be necessary to repeat the intended time frame more frequently.

**Round 3:** All seven participants who received this question answered no, and it was pretty clear that they had no relevant experience with this. One or two participants had heard of HBIG before. Several other participants mentioned that they thought HBIG was a sort of vaccine, but were fuzzy regarding details.

**Recommendation:** Use current wording, but consider adding to or modifying the note following the question. It might be useful to explain what the HBIG is, rather than what it isn’t.

23. Had a tattoo applied?

**Round 1:** No participants had a tattoo within the past year. Two participants had gotten tattoos in the past– one several years ago, and the other about 7-8 years ago. This latter participant incorrectly answered “yes” on the questionnaire. However, this false positive is probably due to questionnaire formatting (which did not make the time frame prominent enough). Still, his tattoo experience was unusual to say the least– it was applied in non-sterile conditions using a guitar string by an individual who learned how to apply them in jail!

No participants indicated any difficulty understanding the intent of this item. One participant
quipped that she had recently had a temporary water-based tattoo and was clearly joking.

**Round 2:** No participants had a tattoo within the past year. Two participants had received tattoos in the past, clearly outside the time period of the question, and they answered correctly. There were no indications that anyone misunderstood the question or its intent.

**Round 3:** One participant answered yes– she had received a tattoo in a local parlor less than 12 months ago. The remaining ten participants answered no and their answers all appeared accurate. Several had received tattoos at earlier times in their lives.

**Recommendation:** Use current wording.

24. **Had an ear or skin piercing (including acupuncture)?**

**Round 1:** Of twelve responses, only two said “yes.” Both were false positives that had taken place outside the time frame of the question. Again, this is almost certainly due to the formatting of our particular questionnaire. Both of the false positives pertained to ear piercings that had taken place several years ago. Numerous other participants had received pierced ears in past years and correctly answered “no.” We did not interview anyone who reported ever having acupuncture. It was not completely clear whether we encountered anyone who had a more exotic body piercing.

One participant expressed confusion about the intent of the question. She had received a pierced ear about 25 years ago, and answered correctly. But in discussing her interpretation of the question, she thought it wouldn’t make sense that we were asking about something so seemingly harmless as a standard ear piercing. Here and elsewhere, respondents may answer questions based on inferences about what we “probably mean” rather than the literal wording of the question.

One other participant was confused and left the question blank because he had pierced ears but never had acupuncture. He was not sure how to answer given that question seemed to cover both points. To his credit, he did not simply make an assumption about the intent of the question, but rather raised the issue with the interviewer.

**Round 2:** Only one participant answered “yes,” and this was a false positive that had actually taken place about 15 years ago.

One individual answered correctly, although he did note that he had been deferred from blood donation about seven years ago for this precise reason. He noted that his ear had been pierced at a “very health regulated” establishment that used antiseptic, but that this was the sole reason he was deferred.
One participant answered correctly, but did have acupuncture about 7 years ago. He echoed some commentary from the previous round that the question seemed to put very different activities under the same umbrella— one pertaining to “jewelry” while the other was more medical. He noted that the question was sufficiently clear, but the parenthetical mention of acupuncture was essential or he would never have thought of this. Still, it would be better to separate unrelated ideas such as this.

**Round 3:** Three of the eleven participants answered yes. Two of these referred to tongue piercings. We had been curious whether participants would include tongue piercings since the question actually asks about “skin.” While this does not prove that all respondents will follow suit, it does provide some assurance that positive responses might be seen as appropriate in such circumstances. Still, it might be preferable to use the term “body piercing” which presumably covers more territory than “skin piercings.”

The third positive response was actually in error— she had received pierced ears in 1999. Oddly, even though the interviewer repeated the time frame, the participant insisted upon her answer because holes in her ears were visible and she did not “want to be caught in a lie.” (This participant seemed very concerned about appearing to be honest on all points-- this was not the only question in which she extended the time frame in an apparent effort to include more events in her responses.)

During the testing we have seen that some people find the juxtaposition of topics (ear piercings, body piercings, and acupuncture) to be illogical. Some respondents may find it hard to believe that they should count something as simple as a pierced ear, especially when the question asks about piercings that are potentially much more invasive. Acupuncture and piercings are also seen as events with little in common.

**Recommendation:** Separate acupuncture into a different question. Use the term “body piercing” in place of (or in addition to) “skin piercing.”

25. Had or been treated for syphilis or gonorrhea?

**Round 1:** All twelve participants answered no; no one ever had either disease. There were no indications that anyone had difficulty understanding this question. One participant volunteered that he had been treated for chlamydia some years ago, but understood that this should not be included in his response.

**Round 2:** All twelve participants answered no. One participant had either syphilis or gonorrhea in 1975, and did not include it here due to the time frame of the question. No problems with the question were identified.

**Round 3:** The seven participants who received this question all answered no. One participant
had been treated for one of these diseases in the 1970s. The question appeared to work fine as written.

Recommendation: Use current wording.

26. Been in juvenile hall, lockup, jail, or prison?

Round 1: No participants had been in this situation during the reference period of the question. Two participants had been in earlier years—one for an alcohol related offense, and the other in juvenile hall for two weeks during freshman year in high school. The latter participant erroneously responded yes to the question, losing track of the time frame. (This is the same participant who provided false positives for Q23 and Q24, probably due to questionnaire formatting).

Some participants thought of lockup, jail, and prison as basically the same thing. More commonly, participants viewed them as ranging from places for overnight detention, to somewhat longer stays, to doing hard time. The terms seem to cover all the bases—although a few participants questioned whether “lockup” was appropriate since they viewed this as a low-risk place.

Round 2: No participants answered yes. A few had been temporarily detained in earlier years (e.g., for drunk driving, and a hunting violation). The interpretations of the key terms were consistent with those in the previous round.

One participant raised an interesting issue: she had never been incarcerated, but had once worked for a company that delivered to prisons. While she never had to go inside a prison herself, she thought that her answer should have been yes if she had made such a delivery. Similarly, she thought that anyone who visited someone in jail should also answer yes to this question. This may not be the intent of the question, but the errors from such interpretations would only be false positives.

Round 3: All eleven participants answered no. Most had never been in any of these for any reason, although one participant mentioned stints in juvenile hall (1996) and lockup (1998). Most participants saw these institutions as differing by degree, i.e., with prison being more serious than jail.

One participant works in juvenile detention, but assumed that the question referred to incarceration only (based on information she saw in the informational materials). But she also questioned whether that made sense, since people come into contact with the same individuals either way. She also wondered whether group probation homes should count, since they house some of the same people who appear in lockup or juvenile detention.
A general comment: juvenile hall is only relevant to a very small number of people (those who were juveniles within the past year). The only problem with leaving this in the question is that it won’t make much sense to older (age 20 +) participants. There may be a tendency to confuse them and create some false positives. This is probably not a major problem, but it does add to the burden of the item. Given that juvenile hall applies to a small number of people, may be a relatively safe and supervised place, and that such offenses may be captured by “lockup, jail, and prison” anyway, it is unclear whether this is worth keeping in the question.

 Recommendation: Consider whether juvenile hall is really necessary. Supplement the definitions available to blood center staffs regarding whether visitation in these facilities should count, and possibly whether probation houses count as detention facilities.

In the past 3 years have you
27. Been outside the United States or Canada?

Round 1: Three participants answered yes, but probing revealed that an additional participant had been to the Bahamas in the past year. He answered no because he had never been to Canada—clearly a misunderstanding of the question. It is possible that some people will have a problem thinking of “the United States or Canada” as one entity—given that they don’t think of it as one place, it is hard for them to conceptualize what it means to be outside of it. One alternative would be to ask if respondents had been anywhere outside the United States at all, and then asking for details in follow-up questions (either in writing or orally).

Another participant seemed to consider Hawaii as being outside the U.S. This may happen occasionally, but does not seem to be a major problem. Not only is it a false positive, but the error would be easily identified in most follow-up questioning.

Round 2: Eight participants answered yes (and some of them had been deferred from donating blood for this reason). Their destinations were quite varied, and some of them traveled a great deal.

Probing revealed that one participant had forgotten to include a cruise taken about two and a half years ago. This cruise had touched in several ports, including Mexico and the Caribbean. It is possible that such cruises can be forgotten because they start domestically and the ports of call aren’t really destinations—they are just stopovers. If domestic cruises are common and important to capture, it may be necessary to ask about them specifically. On the other hand, one other participant answered “yes” entirely on the basis of having been on such a cruise.

The question is probably most challenging for people who traveled about three years ago and have to consider whether or not their travel fit the criteria of the question. The participant who forgot about the cruise mentioned that he had to think about this question because he had been to Nova Scotia and Hawaii. He then answered no, forgetting the cruise.
Round 3: Two participants said yes, reporting various travels during the appropriate time period. The remaining participants had not traveled outside the country in recent years.

Some participants occasionally forget travel of this type, and might erroneously include or exclude trips taken near the boundary of the reference period. However, it is difficult to think of a more straightforward way to ask this question.

**Recommendation:** Use current wording. If possible omissions of events such as cruises are a major concern, consider adding a prompt to the question about this.

**Between 1980 and the present** did you

28. Spend time that adds to five (5) years in Europe?

Round 1: All twelve participants answered no. Based on their responses to probes, their answers appeared to be accurate. Four participants had never been there; three had been to Europe, but only prior to 1980. The other five had been to Europe in the time period, but for cumulative times that fell far short of five years– generally a few weeks or months.

Round 2: One participant answered yes– she had lived in Europe from 1990 to 1999. Of the other eleven, two had never been to Europe, and three others had been only prior to 1980.

The remaining six participants had all been to Europe since 1980. Five of these individuals had been on multiple trips to Europe that accumulated to months or in some cases years. While we cannot be absolutely certain that their estimates were correct, they were all very confident that they did not approach the “five year” threshold. Based on their responses to probes, we believe their assessments were correct. We also think that there are relatively few people who fall precisely on this threshold– generally, people have either lived in Europe for a long time or they have been travelers who fall far short of this time span.

One participant suggested that “adds up” would read better than “adds,” and noted that Q30 uses “adds up.” The suggestion seems reasonable, and consistency is desirable.

One participant raised the issue of “what constitutes Europe?” She was unclear whether the U.K. and Turkey should be included.

Round 3: All seven participants who received this question answered no. Only two had been to Europe at all– both for a total of about one month.

**Recommendation:** For consistency with other questions, change the wording to “adds up.”

Blood center staffs should be prepared to provide lists of European countries.
29. Receive a blood transfusion in the United Kingdom? (England, Northern Ireland, Scotland, Wales, the Isle of Man, or the Channel Islands.)

Round 1: All participants answered no. Only four participants mentioned having ever been to the U.K. One participant noted that the definition in parentheses was extremely important.

Round 2: All participants answered no. One participant had received a blood transfusion, but not in the U.K.

Round 3: All seven participants who received this question answered no. There were no apparent problems.

Recommendation: Consider linking this question with Q10, which also asks about transfusions. A global question could ask if the respondent ever had a transfusion; follow-ups could ask whether it was in the last year, and if it had been in the U.K. between 1980 and 1996. There is no overt problem with the current questions, but grouping them together logically could help the overall organization.

Between 1980 through 1996 did you
30. Spend time that adds up to three (3) months or more in the United Kingdom?

Round 1: All participants answered no. Two participants had been there for a total of about a month during the specified time frame– both were very confident that their answers were accurate and that there was little chance that they had exceeded this threshold.

Round 2: All participants answered no, but one of these participants answered incorrectly. He had been in England for less than three months, but had probably spent about six months in the United Kingdom (Scotland in particular, which he visited frequently) during the time frame. This error was due to a misinterpretation of “U.K.”, which he thought referred only to England. The misunderstanding might have been prevented through simple re-formatting– when we formatted the questionnaire for testing, we did not repeat the definition of U.K. that appears as part of Q29. But since this participant had never received a blood transfusion, he skimmed that question, not bothering to read the definition that appeared at the end. This participant’s error underscores the usefulness of repeating this definition whenever making reference to the United Kingdom, since the term may not be understood even by some of its frequent visitors!

Most of the participants who had been to the U.K. thought that their total time spent there was a month or less– not very close to the threshold in the question. One interesting complication for some participants was that frequent travelers to Europe often changed planes or had short layovers in the U.K. That made it somewhat more challenging for them to figure their total time,
but in no case would it have made a difference for their overall answer.

**Round 3:** All participants who received this question answered no. A few had passed through the U.K. briefly but none had visits anywhere close to three months. Interestingly, a few individuals misunderstood the parameters of “U.K.” One initially reported that she had never been in the U.K. but then asked “is London in England?” Another participant also misunderstood the definition, thinking that the U.K. consisted of England alone. As mentioned above, these misunderstandings may have been exacerbated due to our error of not reprinting the definition of U.K. with this question. Also, such errors are probably most common with people who spent very limited time in the U.K., rather than deliberate travelers likely to meet the “three month” threshold– although in the previous round we saw that it could be unwise to take for granted that everyone who travels to the U.K. knows its parameters.

**Recommendation:** Use current wording, but make sure to include a definition of U.K. for all questions that refer to it.

31. Spend time that adds up to six (6) months or more on a military base in Europe?

**Round 1:** All participants answered no. However, one participant mentioned that many years earlier he had been in the Navy and had been on board a ship in European waters for over six months. He had made excursions onto shore which did not accumulate to six months, although he was in the vicinity for longer than that. If this had taken place more recently, should this have counted? Blood center staffs should be prepared to give guidance to potential donors on this point.

**Round 2:** One participant spent about 17 months on various bases in Germany, and correctly answered the question “yes.” Another participant said no, but indicated that she lived in Germany for 2 ½ years so that her husband could work on such a base. She reported that she spent an hour or so on base every few weeks. Clearly this would not accumulate to six months, and her answer was literally correct. The question would probably not capture someone in these circumstances; if it is supposed to, some changes may be required.

All other participants had minimal exposure to European military bases– occasionally, someone mentioned visiting one for an afternoon while in Europe.

**Round 3:** All seven participants who received this question answered no. One participant had visited one very briefly, and others had never been on one.

**Recommendation:** Use current wording. Provide guidance to blood center staffs regarding the situations described above.
Since 1977 have you
32. Received money, drugs, or other payment for sex?

Round 1: Eleven participants answered no. When asked what the question sounded like it was getting at, participants generally indicated that it was asking about “being a prostitute.” All participants thought the question was very clear. Some participants found it a little amusing, while others might have been slightly uncomfortable (particularly since we asked them to talk about the subject in addition to answering the written question.)

One participant answered yes to the question. He explained that this had happened several times, most recently a few years ago. He also claimed that all of these encounters were heterosexual and were for money, not drugs. It is entirely possible that he was not completely forthcoming with us (and he seemed somewhat uncomfortable when discussing the matter)-- but on the other hand, his answer did include potentially embarrassing information that he could have easily kept from us. The fact that even one participant answered affirmatively was rather surprising to us, especially since this round targeted “new donors” rather than previous deferrals. This is probably reason for some optimism.

Round 2: All participants answered no. We did not learn much new about this question in the second round. Interestingly, this batch of participants seemed to actively express anti-drug and sexually conservative attitudes– perhaps because they had all at least attempted to give blood in the past (some had given many times) and a number of them were quite health-conscious. As before, some participants were amused by this line of questioning (one male participant quipped “I wish!”)

Round 3: All eleven participants answered no. The meaning seemed clear to all.

We think that participants in these rounds were forthcoming (and indeed, were surprised to find even one positive response). Unfortunately, cognitive interviewing cannot tell us much about whether prospective blood donors will be completely forthcoming when answering questions such as these. One source of optimism is that many participants expressed an understanding of the importance of obtaining this information to ensure the safety of the blood supply, even when the topic made them somewhat uncomfortable.

However, based on some general principles in social/cognitive psychology, we do think it is possible that respondents could minimize the significance of isolated incidents. Someone who had only engaged in such activities once or twice a long time ago, might answer no if they thought the question was really asking whether they’ve been “a prostitute.” To such a respondent, the larger truth might be that they never were that type of person, even though various circumstances might have led them to engage in isolated sorts of behaviors. If the question is intended to capture even isolated incidents, then the emphasis-adding words “even once” are highly recommended. While these words do not guarantee the accuracy of responses, they do discourage reasoning that occasional behavior should not be counted in this question.
Some Task Force members have argued that these words are irritating to potential donors. Our experience suggests that respondents are less critical or word choices in setting where they are more focused on the potential safety of the blood supply. We also think that the burden of the added words is minimal compared to potential gains in response accuracy.

Another general note: the question uses the term “for sex,” which could be open to multiple interpretations (intercourse only, oral sex, or other activities). No participants made such distinctions, since the question did not apply to them however this was defined.

**Recommendation:** Add the words “even once” to this question. Consider substituting “sexual activity” for “sex,” and update the educational materials to refer to both “sexual contact” and “sexual activity.”

33. Male donors: had sex with another male?

**Round 1:** Five participants in this round were male. Two of them answered yes to this question. One of these participants was a gay male, who indicated that the sex was with his usual partner. He also indicated that he interpreted the term “had sex” fairly liberally, with oral, anal, or vaginal sex qualifying (although kissing alone would not). The other participant who answered yes said that he had sex with another male only once. He described it as “one of those things in high school... people do a lot of things in high school they don’t want to relive again.” He specifically mentioned that the incident involved anal sex.

The other three participants answered no. We did not probe their interpretations in depth, but believe that they interpreted the question broadly and were basically saying that they had never had any sort of sexual contact with another male.

**Round 2:** Six males participated in this round. All of them answered no. Again, probing was limited, but all of them seemed clear that they had no experiences that could qualify for a “yes” response to this question.

**Round 3:** Only three males participated in this round, one of whom answered yes– he was a sexually active gay male. His sex life included intercourse, so he did not need to consider whether other activities qualified as “having sex.” The other two participants were split in their interpretations. One thought that “had sex” in this context referred specifically to intercourse, while the other thought that any contact should count.

Although the question seemed to work as intended, it is clear that the term “have sex” is subject to the same pitfalls here as in other questions. Also see comment for Q32 (above) on the importance of including “even once” in the question.
Recommendation: Use the broader term “sexual contact” in this question, and provide a complete definition of what this entails in the educational materials. Add the words “even once.”

Have you EVER
34. Had a positive test for the HIV/AIDS virus?

Round 1: All participants answered no to this question. Most of them had actually gotten an HIV test at some point in their lives. A few knew that their blood had been tested for various things but did not know whether HIV was one of them— but were still pretty sure that if they had a positive test result they would have known it.

One participant expressed a concern that a lay person might think “positive test” means “good outcome,” and suggested that we find a less ambiguous term. Still, all twelve participants seemed to understand the question clearly.

Round 2: Responses in the second round were very similar to the first— many had received an HIV test that was negative, and a few were not sure whether a battery of blood tests had included an HIV test. One participant reported an unusual situation: she had participated in an HIV vaccine study. As a result of doing this, she had received a false positive HIV test result— yet she answered the question “no.” When asked to reconcile her response to this test result, she emphasized that the test was a false positive, and that this had been verified through very sophisticated examination techniques and apparently including DNA tests. Because she was certain that the positive result was inaccurate, she was very comfortable with her answer to the written question.

Round 3: Two participants answered yes. One was a gay male who has been HIV positive since 1984. The other participant misunderstood the meaning of “positive test”— she had received an HIV test that turned out well, hence her answer that it was “positive.”

We think it is unlikely that the opposite error would occur (i.e., someone’s HIV-positive test result was “bad” so they therefore answered no) because receiving a positive test result would probably be explained to them by a medical professional as a “positive result.” However, such errors are theoretically possible, especially among individuals with low education.

Recommendation: Consider alternatives such as “tested positively” “been told that you have the HIV/AIDS virus,” “learned that you had the HIV/AIDS virus,” or “had the HIV/AIDS virus.” At the same time, keep in mind that alternatives may introduce more complexity than they are worth.

35. Used needles to take drugs, steroids, or anything else not prescribed by your doctor.
Round 1: All of the participants answered no to this question. Virtually everyone thought of “street drugs” such as heroin when they answered and had no experience with anything along those lines. For most (if not all), their only experiences with needles took place at their doctor’s office. One participant seemed to misread the question (thinking that it asked about anything prescribed by your doctor). This is probably an unusual case, but it might be prevented by underlining or emphasizing the word not.

Round 2: All of the participants answered no to this question. Again, they generally referred to street drugs when explaining their interpretation of the question. One participant thought it was strange that we asked only about “your” doctor and should expand that to include any doctor.

Round 3: All seven participants who received this question answered no. Interpretations of the question focused on “street drugs” as in the previous rounds.

Recommendation: Underline the word not to give it added emphasis.

36. Had hepatitis?

Round 1: All participants answered no. One participant conceded that his answer was only “as far as I know.” Another participant volunteered that she wasn’t sure what hepatitis was (but was pretty sure that she did not have it). We observed no problems with the question.

Round 2: Two participants answered yes; all others answered no. One participant claimed that he contracted hepatitis from eating seafood when he was 13 years old. That was 30 years ago and he has had no sign of it since. He thought it might have been hepatitis A, but was unsure. The other yes response came from a participant who had been diagnosed with hepatitis C in 1993. He was unsure about where he got it, and suspected that it could have been from a military inoculation in 1967 that used “air things...if you flinched then blood would shoot out, and of course it shot onto the needle.” He believed that someone else’s blood somehow got injected into him. He also reported receiving a tattoo in 1989, but thought the hepatitis had to “lay around in your system for years” before he would have developed a case of it, and that it was therefore impossible that he contracted it then. He could think of no other risk factors for the disease, being strictly anti-drug and not sexually promiscuous. He reported giving over five gallons of blood since his military service, so one hopes that he did not have hepatitis during that entire time. Incidentally, he had later developed cirrhosis and had received a liver transplant in 1997.

One other participant mentioned that she’d had a boyfriend in college (around 1973) who had hepatitis A. To her knowledge, she never contracted it and she answered no to this question.

Round 3: Of the seven participants who received this question, one contracted hepatitis during
the 70s. He correctly answered yes, even though he was currently free of the disease. He was unsure which type of hepatitis it was.

There are limitations to what people know about their hepatitis status. However, participants who knew they’d had the disease at some point had no difficulty understanding and answering the question accurately.

**Recommendation:** Use current wording.

37. **Had malaria?**

**Round 1:** One participant answered yes. He had contracted the disease in Cameroon (where he lived at the time), presumably from an insect. This took place in 1995. He had no difficulty answering the question accurately. All other participants seemed to understand the question clearly. One participant noted that she had been aware of malaria risks when visiting Korea. Another indicated that he could never have had malaria because “I’ve never been to Africa.”

**Round 2:** All participants answered no. One participant mentioned that he had been in some sort of trial study at Walter Reed Hospital that had to do with this. Another mentioned that she knew people in South Africa who had contracted the disease. The question seems to work well.

**Round 3:** All seven participants who received this question answered no. There were no apparent problems.

**Recommendation:** Use current wording.

38. **Had Chagas’ disease?**

**Round 1:** All participants answered no. Only two participants thought they might have heard of the disease before (although one thought it was the same as Mad Cow Disease). All participants thought that if they’d had this disease, they probably would have known it and were confident in their responses.

**Round 2:** All participants answered no. Two participants mentioned that they had seen the disease mentioned on other questionnaires (one for blood donation, and another for an apheresis donation). All expressed confidence in their answers.

**Round 3:** All participants who received this question answered no. None of them had ever heard of the disease. One participant remarked that he was pretty sure he would know it if he had such diseases “unless they were also known by a much more common name.”
Recommendation: Use current wording. Blood center staffs should have information explaining this disease for those who ask additional questions.

39. Had babesiosis?

Round 1: All participants answered no. None of the participants had ever heard of the disease, but all expressed confidence in the accuracy of their answers.

Round 2: All participants answered no. None of the participants had ever heard of this, but after the interviewer mentioned that it may be transmitted by tick bites, one participant remembered an experience with the disease. His dog had apparently contracted this disease in France. He remembered trying to communicate with a French veterinarian about this, who gave him the name of the disease and mentioned that it probably came from a tick bite. The dog was gravely ill, but did eventually recover after intensive treatment. Presumably, if he had contracted the disease himself, he would have been more familiar with its name. All participants expressed confidence that they themselves had never had the disease.

Round 3: All participants who received this question answered no. None had ever heard of this disease, but when asked, they expressed confidence in the accuracy of their answers.

Recommendation: Use current wording. Blood center staffs should have information explaining this disease for those who ask additional questions.

40. Received a dura mater (or brain covering) graft?

Round 1: All participants answered no to this. Most had never heard of it, although one participant (who worked in the pharmaceutical field) reported that he had actually seen one.

Round 2: All participants answered no to this. A few mentioned that they might have heard of this before (one indicated that she had seen this mentioned on blood donor questionnaires). Another participant confessed that at this point she was skimming the questionnaire quickly and without much thought because it was so obvious that none of the conditions in this series applied to her.

Round 3: All participants who received this question answered no. When asked, participants indicated they had never heard of this.

As with other questions in this part of the instrument, we assume that if an individual had actually had such an experience, they would know it and would be able to recognize it by name. Of course, the only way to evaluate this rigorously would be to interview people known in advance to have had the relevant experiences and examining the accuracy of the answers to their
questions.

**Recommendation:** Use current wording. Blood center staffs should have information for those who ask additional questions.

41. Had any type of cancer, including leukemia?

**Round 1:** All participants answered no. Several participants indicated that they were not aware that leukemia was a form of cancer. While none of them had ever had leukemia— and presumably they would be more likely to know that it was cancerous if they had— this suggests that it is useful to keep “including leukemia.”

**Round 2:** One participant answered yes (breast cancer in 1998). No one else had ever had any form of cancer. As in the previous round, a few participants mentioned that they were not aware that leukemia was a form of cancer. One participant asked if sickle cell anemia was a type of cancer.

**Round 3:** All participants who received this question answered no. Their answers appeared to be accurate, and no problems were discovered.

**Recommendation:** Use current wording.

42. Had any problem with your heart and/or lungs?

**Round 1:** Only one participant answered yes— she reported having asthma. Another participant answered no, but later wondered if she should have said yes because she had asthma. She did not think to include asthma because she hadn’t had any recent attacks— but when she later observed that the question asks “ever,” she concluded that she probably should have answered yes.

Asthma may be included inconsistently in responses. When asked what sorts of things they considered to be “problems with their lungs,” very few participants offered asthma spontaneously. When probed specifically regarding whether asthma should count as a “lung problem,” many agreed that it should, but several were unsure. One participant pointed out that asthma should be considered more of a bronchial problem than a lung problem.

Another participant answered no to the question, but later wondered if she should have answered yes because she has chronic bronchitis (at one point she was hospitalized for this). The fact that her most recent attack had been two years earlier might have been responsible for her not
including this event in her answer. Considered along with the participant who did not include her asthma, these situations may suggest a tendency to not count mid-term or chronic conditions that do not currently bother them. One participant also expressed the opinion that chest colds, even if severe, should not count because they were temporary. Most participants thought of major conditions such as emphysema or lung cancer when they heard the question, and would have answered yes if they had such conditions.

No participants answered yes on the basis of heart conditions, but we asked participants what sort of things they thought would qualify. Most mentioned heart attacks, failure, blockage or various problems with heart rhythm. One participant wondered if she should have included her high cholesterol (but answered no).

Round 2: Three participants answered yes in this round. One participant reported having chest pains and angioplasty four years ago. Another reported major surgery to replace heart valves. Both had no difficulty determining that yes was the appropriate response.

The third participant who answered yes indicated that she had asthma. She expressed uncertainty regarding whether she had answered correctly, since her case was mild and “not really a problem.” She also had a bad upper respiratory infection a few months earlier, but did not include this “because it’s not chronic”; another participant made a similar argument to exclude a similar infection. Another participant mentioned that he had experienced a chronic cough for 12 months, but thought this was not serious enough to qualify as an affirmative response. As in the previous round, participants tended to think that conditions of moderate severity should not be counted, particularly if they did not currently experience symptoms— but they were not completely consistent. Virtually all participants thought that major heart problems, cancers, and debilitating illnesses were in line with the intent of the question.

One other participant answered no, but expressed uncertainty about whether he should have answered yes due to hypertension.

Round 3: One of the participants who received this question answered yes. The condition she mentioned was mitral valve prolapse, which prevents her heart valves from closing completely. This increases concerns about bacteria, so she takes antibiotics for fairly routine events such as going to the dentist or getting her ears pierced.

One of the participants who answered no indicated that she has a “pretty bad case” of asthma and uses multiple inhalers, but that she did not think the question was getting at that. Another participant had high blood pressure and had experienced bad chest colds, but excluded those as not relevant to the question.

In general, this question is plagued by a vague frame of reference, with inconsistent interpretations regarding what should be included and what should not. Respiratory problems appeared to be more ambiguous than heart problems; participants seemed to evaluate the
relevance of asthma and bronchitis inconsistently. Relatively minor heart problems such as heart murmurs also may be evaluated inconsistently. The question also covers an enormously broad range of possible problems.

Recommendation: Consider separating this into two questions about heart and lungs respectively. Doing so might allow respondents to carefully consider a more manageable domain of events for each question. Including examples of relevant “problems” for each might also be useful. At a minimum, blood center staffs should be prepared to answer questions about whether various complaints are consistent with the intent of the question.

43. Had a bleeding condition or a blood disease?

Round 1: No participants answered yes. One participant left the question blank because she was unsure what would qualify as a “bleeding condition.” She mentioned that she was having nearly continuous menstrual flow due to changes in her birth control pills but did not know if this qualified.

A fair number of participants said that they could not think of anything that qualified as “bleeding disorders.” They did not seem to have any ambiguous situations involving their own blood. One participant tentatively offered “nosebleeds”; another suggested bleeding at any unexpected place such as the penis, or blood in stools. Another mentioned menstrual abnormalities, and one mentioned ulcers. It is hard to know what to conclude from such varied interpretations. As with many other questions, it would be useful to interview people who had what we would consider a “bleeding problem” and see if they answered according to expectations.

When asked what they thought of as a “blood disease,” the majority of participants mentioned either hemophilia, leukemia, or both. One participant offered “bad blood” but could not elaborate further. Another mentioned sepsis.

Round 2: One participant answered yes due to endometriosis (which eventually resulted in a partial hysterectomy). No other participants answered no, or reported having any unusual situations regarding their own blood. One participant remembered having hemorrhoids with blood at one point, but did not think this was serious enough to include as a yes.

When participants were asked what should count as bleeding disorders or blood diseases, the most common mentions were hemophilia and leukemia. One participant mentioned menstrual problems, and one mentioned when “bacteria or something else that’s not supposed to be (in the blood).” One other participant thought of tetanus as an example of a blood disease.

Round 3: All participants who received this question answered no. Participants seemed to have consistent interpretations of “bleeding conditions,” citing hemophilia or problems when “your
blood can’t clot.” Participants were a little less certain about what qualified as a “blood disease.” Most thought of actual diseases of the blood such as leukemia. A few thought that blood-borne diseases might also count, but generally these assessments were hypothetical (i.e., no one actually answered “yes” to the question because they had a disease that was carried by blood). In fact, one participant was HIV-positive but answered no because he assumed the question was getting at diseases that affect the blood, rather than diseases carried by blood.

**Recommendation:** Use current wording; alternatives such as “diseases that affect the blood” could be considered, but are wordier and probably no more clear. Provide definitions and examples of “blood diseases” to blood center staffs for respondents who ask for clarification.

### 44. Been in Africa?

**Round 1:** One participant was born in Africa and lived there most of his life— he answered “yes.” All others answered no. One mentioned that she had been to Israel but answered no because that was in Asia. One other participant had to think about this for a minute because he had been in the military and traveled to numerous Mediterranean countries. Ultimately, he was certain that his stops were all European.

**Round 2:** Initially, two participants answered yes. One had been to Egypt for a 10 day tour, and the other had spent about four years in Africa (living there for several years, and visiting her partner’s family who live in South Africa). A third participant originally answered no, but changed it during the interview because he remembered that Morocco was in Africa (“just barely” as he put it). Thus it may be the case that people occasionally forget that some places that are not stereotypically “African” are actually a part of that continent.

**Round 3:** All participants who received this question answered no. It seemed clear to all.

This is generally an easy question-- most people know it if they go to Africa. The only exceptions we can realistically imagine might involve Middle Eastern travel, where the border between Asia and Africa might be somewhat blurry (e.g., Egypt), or perhaps military stopovers where an individual did not realize a country was African. Hopefully such circumstances would be rare.

**Recommendation:** If possible omissions of countries such as Egypt or Morocco, are a major concern, then a prompt could be added at the end of the question. Otherwise, use current wording and be sure that blood center staffs are prepared to answer questions about what should be included in Africa.

### 45. If yes - While you were there, did you receive a blood transfusion or any other exposure to blood?
Round 1: The participant who was born in Africa answered no to this. However, he did mention that he used to be an assistant in his school dispensary and “had to deal with little kids who cut their legs.” He had definitely touched the blood of other individuals in this capacity. The tape of the interview is difficult to make out, but he may have answered no because the blood contact was superficial. It is also possible that the emphasis on “transfusion” overpowered the fact that other “exposure to blood” should also be included. It might be useful to re-organize the question to put emphasis on any contact with blood.

Round 2: None of the participants reported transfusions or any exposures to blood (although in two cases we did not probe further on this question). One participant mentioned that everyone on his Egyptian excursion had serious digestive distress, and they had been “exposed” to something.

Round 3: No participants in this round answered this question.

Recommendation: Reword to “While you were there, did you come into contact with the blood of any other person (including blood transfusions)?”

46. Had sex with anyone who was born in or lived in Africa?

Round 1: Two participants raised serious objections to this question– one only answered with a “?” and later commented “how would I know?” He noted that it was far from obvious whether or not someone had lived there, commenting that “white people live in Africa too.” Another participant, a female, decided to answer yes. Interestingly, she did not know this for sure and could not think of any particular person, and initially answered with no. But especially after considering that the word “lived” could have a broad interpretation, she indicated that she had to err on the side of caution: “I mean, they might have been in the military and lived in Africa...why knows out of the tens of thousands of millions of men that I’ve slept with which one of them could possibly have been in the military for even a week of their lives stationed in Africa?” Although she was speaking in hyperbole (we hope), she seemed to be serious when suggesting that it was a real possibility and that “yes” was the most reasonable answer she could give. She called this “the hardest question on the questionnaire.”

The other ten participants answered no, but a few conceded that it was difficult to know this for sure. Other participants expressed greater certainty, indicating that they were pretty sure they would know this. Nevertheless, it is clear that at least a few participants had sex with individuals they did not know extremely well at some point in their lives. While they are probably correct in most cases, some respondents will answer based on incomplete knowledge.

Round 2: Participants in this round were probably more confident in their answers than those in the previous round (all answered no). Several of them mentioned that they needed to know
someone extremely well before becoming sexually intimate, and would be likely to know about matters such as living in Africa. One participant qualified his answer as being true “as far as I know” but then added that “I’m pretty smart that way.” Another participant quipped that he “almost got lucky” in Morocco.

A few participants raised issues about what would qualify as “living in Africa.” For example, one participant hedged on his answer because one of his sexual partners “might have lived there for a week.” Another noted that his wife had “lived” with him during their 10-day tour of Egypt, but he decided that did not line up with the intent of the question. Another participant also wondered what “living there” entailed, ultimately concluding that something like an extended business trip would not qualify, while longer-term visits (e.g., by missionaries) would. Generally, they seemed to think that “living there” implied that Africa would have been their primary residence and that even long visits would not qualify.

Round 3: All participants who received this question originally answered no. Most expressed strong confidence in their answers. Probing revealed that one of these responses was in error: one participant had sex with someone from Africa. He admitted that he tended to think of Africans as black by default, but his partner had been white and therefore slipped his mind. He did not know what specific country this sexual partner had come from. The participant also made several confusing references to the fact that this “didn’t happen within the last 12 years,” suggesting that he may not have paid full attention to the time frame within the question.

This question, along with the earlier items in exposure to hepatitis, are perhaps the ones most subject to false negatives on the basis of respondent lack of information– although it is not clear that we can do much about this. Some participants suggested that this question (and perhaps the earlier item on hepatitis exposure) should say “as far as you know,” although that creates consistency problems.

Recommendation: Use current wording. Blood center staffs should be prepared to provide guidance to respondents who want to say “not as far as I know” rather than committing to a “no” response.

47. Have any of your relatives ever had Creutzfeldt-Jacob disease?

Round 1: All participants answered no. However, one participant noted that he was less certain about his answer to this than to some other questions because it pertained to all relatives. While he was pretty sure that he would know if he had one of the obscure diseases mentioned here (Chagas’, babesiosis, or CJD), he was not sure that he would know if a relative did. In general, respondents were unaware that CJD had any connection with “Mad Cow” disease, although almost all had heard this colloquial name.

Round 2: Eleven participants answered no. On the whole, their answers were consistent with
those from the first round. Most did not know that CJD had any connection with “Mad Cow” but when told became much more confident that their extended family was free of the disease. Several expressed confusion about how broadly they should interpret “relatives,” but we think it is likely that the interpretation would be broad if based on actual family experience with CJD.

One participant answered yes-- her nephew had died of CJD 15 years earlier. She knew the disease by its proper name (and pointed out although it is now linked in popular understanding with “Mad Cow Disease,” it was not at that time). Her nephew was a dwarf and was taking pituitary gland injections that originated from humans in Africa. He had taken these over a span of many years; doctors suspected that they were the source of his illness. Due to her family experience, she was quite knowledgeable about the disease.

She defined relatives as people having common “bloodlines,” and her nephew qualified (he was her brother’s son). Of course, one could be a nephew by marriage without a blood relationship, which could result in a few more positive responses than is necessary. We point this out as a footnote, but since it applies to such a small group of individuals, we do not recommend making any changes to the question.

Round 3: All eleven participants answered no. Almost all were quite confident in their answers, however “relatives” was defined. Few of them had ever heard of the disease before, but as one participant noted, “if you had it, you would know what this word means. If you don’t know, that means you never had it unless it had another name.” He also thought that if any family member had it, it would be memorable. He noted that his mother had something like “bronchiactasis.” While none of his family had ever heard of this before, the experience made him and family members instantly familiar with the term.

Only one participant indicated that he knew anything specific about CJD, which was that it tended to affect people of Jewish backgrounds.

Another participant answered no, but remembered reading on the medication deferral list that growth hormones were a risk factor. She knew that her grandmother had taken “hormones” for some imbalances and wondered if it was possible that she had this disease. Probing revealed that these hormones were actually dietary supplements sold at a local store. An earlier participant also misunderstood the term “growth hormone” and it may be worth explaining this further in the educational materials. We also think that if participants had more background information about CJD (perhaps mentioning a relationship with “Mad Cow,” which all participants were familiar with) then some misunderstandings along these lines would be avoided.

In all three rounds, definitions of “relatives” were quite varied, with some participants indicating that they would include only immediate relatives (siblings, parents, children); others indicated that they would include anyone with a known blood relationship to them, even if distant. However, we think that if a respondent knew for sure of any relative having this disease, they would be likely to include it because it would be such a noteworthy occurrence. Another
participant was adopted and answered the question based on her adoptive family. If this is a serious concern, the term “blood relative” could be used.

Also, members of the Task Force noted that this header for this section (“Have you ever...”) does not apply for this question. It seems appropriate to move this question into its own section.

**Recommendation:** Use current wording (but not under the current header). If it is important to exclude adoptive relatives or relatives by marriage, then consider the term “blood relatives.” Also, include additional background information on CJD in the educational materials.
C) Results and Recommendations: Abbreviated Version of the Questionnaire

One objective of the third round of cognitive interviews was to provide a brief test of the abbreviated form of the questionnaire, which is intended for repeat donors who had recently given blood. The proposed questionnaire consists of only 24 questions, most of which were drawn directly from the regular instrument. One new question was added as a substitute for more specific questions:

Since your last donation, have you had any new medical problems, diagnosis, or treatments including vaccinations?

This item replaced questions about receiving shots, transfusions, grafts, transplants, contracting STDs, having a positive HIV test, or ever having diseases such as hepatitis, malaria, Chagas’ disease, or problems with heart or lungs. One objective during this round of interviews was to evaluate whether this question serves as an adequate substitute, given that the respondent has been screened in the recent past with the full instrument.

This version of the questionnaire was administered to four participants, all of whom had donated blood within the last six months. All four participants answered no to this question. In most cases, probing did not reveal any remarkable medical experiences that had occurred recently for any of them. One noteworthy exception was that one participant had become pregnant and miscarried since her last blood donation (in June of 2001). This seems to be a significant medical event, although she did not think that this experience applied.

Most of the questions that were superceded by the new item deal with relatively unusual health events. We certainly expect that someone who had received a transfusion or graft, or came down with a disease such as malaria, would remember such events (and various literature suggests that unusual events are particularly memorable). The most likely events to be forgotten are probably ones that are less unique, such as receiving shots. Some events that are remembered could be excluded from responses because they do not seem relevant. That seems to be what happened to the participant who lost a pregnancy but did not report it in her initial answer.

Another issue is whether the recall boundary in the question ("since your last donation") is sufficiently memorable. Respondents may not remember exactly when this occurred in relation to other medical events. We suspect that respondents would be more likely to incorrectly place events within the recall period (a phenomenon known as “forward telescoping”) rather than outside of it, although this is speculation. One alternative would be to use a “fixed” recall period (e.g., six months) for all respondents, which is more precise and will definitely cover the period since the last donation.

Conceptually, this question seems sound. It would have been preferable to test this question on more people known to have had various medical conditions since their last blood donation, but in the testing that we performed, we observed very few problems.
Another change to the abbreviated questionnaire is that most questions about travel are dropped. The only one that remains is:

Since your last donation, have you been outside the United States or Canada?

We observed no problems with this question. One participant had traveled extensively prior to his last blood donation, and easily recalled this fact. This question will ask respondents to report travel in a recall period of no longer than six months, which is probably a reasonable task– it should be at least as accurate as the version of this question on the full questionnaire, which utilizes a three-year recall period.

A general comment: use of the abbreviated questionnaire presumes accuracy of past responses on the full instrument. For example, the abbreviated questionnaire drops items about time spent in Europe between 1980 and 1996. This seems reasonable– one’s answer to this question could not have changed since 1996. The only potential problem would be if the prior response on the full questionnaire was inaccurate due to misunderstanding or mis-remembering. Similarly, consider an “exposure to another person’s blood” that was forgotten during an administration of the full questionnaire. In a subsequent completion of the abbreviated questionnaire, the question would only ask “since the last donation.” This exposure could still be within the 12-month deferral period, but would now be explicitly excluded due to the recall period specified in the question. (Note: the Task Force discussed this potential problem, and proposed that donors would not be eligible for the abbreviated questionnaire until they completed the full questionnaire at least twice. The Task Force has suggested that the second administration of the full questionnaire should be sufficient to minimize response errors and memory lapses.)

These concerns may be minor ones, based on relatively infrequent errors, but the possibilities should be considered. At a minimum, it may be safer to employ a longer reference period than “since your last donation” under the assumption that some events could have been forgotten or misreported at the last donation. Also, the abbreviated instrument is probably not appropriate for individuals who have been recently deferred from donating. This would be especially true if the reference period “since your last donation” is retained, since there could be confusion regarding whether people remembered the deferral as an actual donation.

Obviously, additional caution would be required if any deferral criteria measured on the full instrument is changed. For example, if it was determined that only one total year in Europe since 1980 was grounds for deferral, then all blood donors would need to be re-screened on this criterion. (Note: in response to this potential problem, the Task Force has proposed that whenever a deferral criterion is changed, it would appear on the abbreviated questionnaire for at least one year.)
D) Supplemental Study Results from Vignettes

One limitation of cognitive interviewing is that it is difficult to recruit participants who have actually experienced the full variety of circumstances covered in the questions. Also, while many participants’ experiences dictate clear “yes” or “no” responses, we are especially interested in how individuals on the “cusp” between the two responses decide to answer. For example, a participant in perfect health and good spirits is almost certain to answer the first question positively, but what about participants who have minor cold symptoms? How do participants decide when their circumstances are sufficient to warrant mention? Some situations are even more complicated (e.g., an individual may have had some sexual contact with a drug user, but whether they “had sex” depends on how one defines the term.)

Since it is usually difficult to find such people, we often resort to hypothetical questions such as “what do you consider ‘have sex’ to mean?” These probes are useful, and can highlight a mismatch between respondent interpretations and researcher intentions, but they have limitations. A participant might tell us what she generally thinks “having sex” means, but her thought processes while answering a survey question could be substantially different. Survey response requires additional judgements about the “pragmatic” meaning of the question (i.e., what sort of information the researcher is looking for). For example, the way that a person conceptualizes “have sex” in a particular question might be different than the way that someone would define it in a more neutral context.

An alternative to hypothetical probe questions are vignettes that describe a potentially ambiguous situation; we ask respondents how they think that person should answer the question. The technique is not perfect— it is still hypothetical, and does not require the participant to draw on his own autobiographical memory— but it does require the participant to go through the process of answering a question using the material in a complex scenario.

Six vignettes were written prior to the third round of interviewing describing potentially ambiguous situations relevant to some of the donor history questions. After completing the questionnaire for themselves (but before answering any probe questions about their responses) the eleven participants in this round were told:

*When you filled out the questionnaire, you answered based about yourself and your own experiences. We would now like to know how you would answer the question for people in a few imaginary situations. We are interested in your interpretation of what the most accurate response would be to these questions under each of these circumstances. This handout has six imaginary situations— I’d like you read each one and check whichever box you think is the best answer after each one. If you have any questions about what I’m asking for, please let me know.*

Additional instructions on the “vignette” questionnaire read:
Following each of the questions below, there is a short description of an imaginary situation. Imagine that each individual decided to donate blood, arrived at the donation center, and started to fill out the questionnaire. Then make a decision regarding what you think the most accurate answer would be for them based on their situation.

After completing the vignettes, the cognitive interview began as usual. When interviewers reached the question corresponding to each vignette, they first asked the participant about their own responses to the question, and then asked them to explain their responses to the vignette. Typical probes for the vignettes were: “How did you decide on your answer to this? How easy was it for you to decide on an answer for this situation?”

Responses to the vignettes, and participants’ explanations for their answers, appear below.

Vignette 1

Question: Are you feeling well today?

Jeff has developed a sore throat and is slightly congested– he thinks a cold may be coming on. But he does not have a fever, feels pretty energetic, and is in good spirits.

Based on your understanding of this question and the type of information it is trying to get at, what do you think Jeff’s answer should be?

Nine of the eleven indicated that Jeff should answer no to the question (not feeling well). Participants noted that it “portends to be a cold,” which could be bad for both the blood supply and the donor, and that it “could be evolving into something more serious.” Another indicated that it was “better to err on the conservative side.” Interestingly, a number of participants throughout the rounds of interviewing indicated that the question was getting primarily at energy and demeanor– but when faced with this specific situation thought it was clear that this individual should not give blood.

One participant thought Jeff should answer yes, since he was not feeling affected by symptoms, and generally did not think this was a big deal.

Vignette 2

Question: In the past 4 weeks, have you had any shots or vaccinations?

Maria has not had any vaccinations for several years. She did receive an injection of vitamin B12 about 2 weeks ago. She receives these every month at the recommendation of her doctor.
Based on your understanding of this question and the type of information it is trying to get at, what do you think Maria’s answer should be?

Nine of the eleven participants thought that Maria should answer yes to this question. Their rationale generally centered on the fact that the literal conditions of the question had been clearly fulfilled: she did receive an injection and a needle did go into her skin. The nature of the shot was immaterial.

Two others thought Maria should answer no. Their arguments were that this was a trivial experience and only nominally a “shot.” One argued that her shot was no different than if she had taken a dosage of oral vitamins— it had more in common with taking vitamins by mouth than receiving an immunization.

Vignette 3

Question: In the past 12 months, have you had an accidental needle-stick or come into contact with someone else’s blood?

George has never had an accidental needle stick— but six months ago, his next door neighbor accidentally broke a window and cut his arm. George helped his neighbor bandage the arm, and remembered that a small amount of his neighbor’s blood touched his skin at the time. George is sure that the neighbor’s blood did not touch any area of open skin, or come into contact with his own blood, and he washed the blood off immediately.

Based on your understanding of this question and the type of information it is trying to get at, what do you think George’s answer should be?

Eight participants thought that George should answer yes. Their answers were based on a literal understanding of the question: George had contact with blood, which is what the question asks about. One participant noted that “it only takes a little [blood],” while another suggested that “this calls for a conservative answer.”

Three participants thought George should answer no. It seemed to them that George had addressed the situation immediately and prevented any meaningful exposure from taking place. One pointed out that “it’s not an open wound.” They indicated that the question was getting at risk, and they didn’t perceive any in this situation.

Vignette 4

Question: In the past 12 months, have you had sex with anyone who has ever used needles to take drugs or steroids, or anything else not prescribed by their doctor?
Kim has a boyfriend who has used a needle to inject illegal drugs at least once. They have not had sexual intercourse, although they have had oral sex together.

Based on your understanding of this question and the type of information it is trying to get at, what do you think Kim’s answer should be?

All 11 participants thought Kim should answer yes. One participant later qualified her answer, saying that it depended who performed oral sex on whom.

Some of these participants thought that oral sex should be considered as “sex” under all circumstances. Others were less sure that it was sex, but thought it was “close enough” given the pragmatic goal of the question. Some said that they did not ordinarily think of oral sex as “sex” but that since that could still put the person at risk, “yes” was the best answer.

This vignette was designed to be difficult, but surprisingly, only two participants noted that they struggled to determine the most appropriate answer.

Vignette 5

Question: In the past 12 months, have you come into contact with blood or saliva from a person who has hepatitis?

Sue knows that one of her good friends has hepatitis. This friend has been over to her house for dinner many times in the past 12 months. At least once, Sue remembers that they drank wine out of the same glass.

Based on your understanding of this question and the type of information it is trying to get at, what do you think Sue’s answer should be?

Ten of eleven participants thought that Sue should answer yes. Most suggested that saliva could have been exchanged and that there was a legitimate risk of transmission. A few were not sure that hepatitis could have actually been transmitted in such a manner, but thought that it was better to err on the side of caution. One other participant qualified her answer: if she knew for sure that this was hepatitis B, then she thought Sue could answer no (because “B” could not be transmitted in that manner). Since the vignette did not specify the type, she thought it was appropriate to assume the “worst case scenario” -- i.e., the type most easily transmitted.

The participant who answered no thought the question was trying to capture actual exchanges of body fluids. She did not think that the situation described here would qualify. (Note: this participant also answered no to Vignettes 2 and 3).
Vignette 6

Question: In the past 12 months, have you had sexual contact with a person who has hepatitis?

Felix has recently been dating a woman who has hepatitis. In the last week they have started deep-kissing (or French kissing), but nothing more than that has happened.

Based on your understanding of this question and the type of information it is trying to get at, what do you think Felix’s answer should be?

Originally, nine of the eleven participants thought that Felix should answer yes. Some of these participants thought that kissing met the parameters of “sexual contact” as specified by the question. Others explicitly said that kissing is not sexual contact, but thought that it was still a viable route of transmission, which was really the intent of the question. When there was uncertainty, it was based on whether kissing can spread hepatitis, or what type of hepatitis was involved, rather than whether kissing is “sexual contact.”

The tenth participant originally answered no, but thought it was better to be conservative in responding. The eleventh participant answered no but could not really articulate why he thought that was the better response. (He was not the same dissenter as in Vignette 5.)

Synopsis: As mentioned earlier, vignettes are useful because they require participants to make judgements about meaning in the context of deciding how to answer questions. They are also appealing because they allow us to explore interpretations in a wider variety of experiences than we might capture in participants’ own lives. Vignettes are imperfect because they are somewhat hypothetical, but they are superior to probes about meaning that are not directly tied to the process of answering a question.

Results suggest that most participants tend to interpret questions based on an understanding of what they were trying to do—specifically, screen for risks. In general, this meant that participants answered conservatively, preferring to “err on the side of caution.” These findings seem to match up with those from cognitive interviews, that participants are more likely to include “borderline” behavior in their answer rather than to argue semantic points (e.g., oral sex isn’t really sex). Still, interpretations are not uniform, and respondents may exclude key behaviors from their answers if they believe that they do not pose any legitimate risks to blood safety. It is important for questions to be reasonably specific, and it will probably also be useful to explain why certain behaviors are considered risky in the educational materials.
Appendix: Donor History Questionnaire (as used in Round 1 of the cognitive testing)

Yes
No
Are you 1. Feeling well today?

Taking any medication on the medication list?

Currently taking an antibiotic?

Currently taking any other medication for an infection?

Female donors: Are you pregnant?

Not female

In the past 36 hours have you

Taken aspirin or anything that has aspirin in it?

In the past 4 weeks have you

Had any shots or vaccinations?

In the past 8 weeks have you

Given blood, platelets or plasma?

In the past 16 weeks have you

Given a double donation of red blood cells, using an apheresis device?

In the past 12 months have you

Had a blood transfusion?

Received clotting factor concentrates?

Had a transplant such as organ, tissue or bone marrow?

Had a graft such as bone or skin?

Had an accidental needle-stick or come into contact with someone else’s blood?

Had sex with anyone who has HIV/AIDS or has had a positive test for the HIV/AIDS virus?

Had sex with a prostitute or anyone else who takes money or drugs or other payment for sex?

Had sex with anyone who has ever used needles to take drugs or steroids, or anything else not prescribed by their doctor?

Had sex with anyone who has hemophilia or has used clotting factor concentrates?

Female donors: had sex with a male who has ever had sex with another male?

Come into contact with blood or saliva from a person Who has hepatitis?

Had sexual contact with a person who has hepatitis?

Been given hepatitis immune globulin (HBIG)? (Note: this is not the same as hepatitis B vaccine.)

Had a tattoo applied?

Had an ear or skin piercing (including acupuncture)?

Had or been treated for syphilis or gonorrhea?

In the past 3 years have you

Been outside the United States or Canada?

Between 1980 and the present did you

Spend time that adds to five (5) years in Europe?

Between 1980 through 1996 did you

Spend time that adds up to three (3) months
or more in the United Kingdom?

31. Spend time that adds up to six (6) months or more on a military base in Europe?

Since 1977 have you

32. Received money, drugs, or other payment for sex?

Male donors: had sex with another male?

Not male 999
Have you EVER 34. Had a positive test for the HIV/AIDS virus? 99 34. Used needles to take drugs, steroids, or anything else not prescribed by your doctor? 9


Not been in Africa 9

9 46. Had sex with anyone who was born in or lived in Africa? 99 47. Have any of your relatives ever had Creutzfeldt-Jacob disease? 99