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Attachment 1 – Telephone Questionnaire

Draft Content for Blood Donation Rules Opinion Study (Blood DROPS) Qualitative Telephone Interview Guide

Introduction

Hi, I'm Nicolas Sheon. I work at the University of California, San Francisco. As you know, we're doing some research to find out about views on the current blood donation policies that exclude people with certain risk factors from donating blood. The project is funded by the Food and Drug Administration and the National Institutes of Health.

People have been invited to take part in these interviews based on their answers to a blood donation survey. The goal of this interview is to get more context and insight about current blood donation policies and possible changes. We'd also like to hear about any experience you've had of giving blood in the US.

This interview will be very informal and will take up to an hour. I'd like to record it to make sure that I don't miss anything you say, if that's OK with you. After the interview, the recording will be given a code, transcribed and, after we have analyzed the information, destroyed. Everything we talk about will be kept entirely confidential. If there are any questions you'd prefer not to answer that's no problem at all, just let me know. If you want to stop the interview at any time just let me know; you don't need to give a reason.

Before we start, is there anything you'd like to ask me about the research?

Answer any questions participant has, then go through consent form.

How was it for you taking the survey?

In this study we're interested to hear about people's experience of giving blood and the rules on who should be allowed to donate.

Have you ever been paid for donating plasma?

For the next questions please only think about unpaid donation.

Have you ever donated blood in the US? e.g. At a blood donation center, at work, university campus etc.

How long have you been donating blood?

How often do you donate?

Could you talk me through the last time you gave blood?

Did you go there by yourself or with friends or co-workers?

Where did you go?

What kind of information did you get before you arrived at the blood donation center?

How about after you arrived? Did you feel you got enough information?

How clear were the rules on who could and who couldn't give blood?

How did you find filling in the questionnaire beforehand? How clear was it? Asked about sex with men? How answered? Establish whether last donated before/since sex with men.

How would you rate your treatment by staff?

How convenient was the location/opening times for you?

Were you given any information afterwards? What kind?

Do you think you'll give blood again?

Now I want you to think back about your first time donating blood. What year was this?

What made you decide to give blood that first time?

Friends/colleagues? Workplace/School/Church blood drive? Advertising campaigns? What type? National Emergency, e.g. Sept. 11, 2001? To help others? Friend/family member having had transfusion?

How have your reasons for giving blood changed over time?

Prompt: Is the change related in any way to the ban on MSM giving blood?

Was there anything about your previous experiences giving blood that made you less likely to go back?

Prompt: rules for MSM, others? Time? Location? Information available? Needles? Worried about blood safety? Blood being screened for infections you don't want to know about? Health reasons?

Is there anything that would make you more likely to give blood?

Prompt: more information? Friends who donate? Convenient times/locations? Better advertising? Change to the rules?

Have you ever tried giving blood but were denied? If yes, could you tell me a bit about what that was like?

Did you go there by yourself or with friends or co-workers?

Did the others you went with find out you had been denied?

What kind of information did you get before you arrived at the blood donation centre? How about after you arrived? Did you feel you got enough information?

How clear were the rules on who could and who couldn't give blood?

How did you find filling in the questionnaire beforehand? How clear was it? Prompt: Disclosed MSM?

Were you given any information afterwards? What kind?

How would you rate your treatment by staff?

What have you heard about the rules saying who is and isn't allowed to give blood in the US?

What risk factors exclude people from donating blood? Prompt: MSM; ever received money or drugs for sex the deferral is indefinite; paid anyone else for sex the deferral is 12 months, ever injected drugs for non-medical reasons.

Do you remember how you first found out about these rules?

What do you think of them?

How clear do you think these rules are?

Is the rationale for these rules clear to you?

Do any of these rules as apply to you?

We're particularly interested in hearing your views on the criteria for men who've had sex with men.

The current rule says that any man who has ever had sex with another man since 1977, whether protected or unprotected, is not allowed to give blood.

What do you think about this rule?

Is it fair? Too strict? Not strict enough?

What makes you say that?

What is your understanding of how "sex" is defined by staff who screen donors for eligibility at the blood centers?

Are there types of sexual contact that should count more than others?

How clear is the policy? Could it be better worded?

What would you say are the reasons for the rule?

Prompt: Do you see it as based on scientific evidence? About blood safety? Public interests? Sensible for blood service to be cautious? Discriminatory? In what way?

What about how it compares with rules for other people considered 'at risk'?

What do other people think about the rule?

Prompt: Your friends? Partner(s)? The media? The Blood Service?

How is the rule relevant to you?

What has influenced your decisions about whether to follow the rule in the past?

From the Blood Bank's point of view, the rule is designed as a population screening tool rather than as an individual assessment. How do you feel about this [as a strategy/argument]?

Some people calling for the criteria to be revised argue that, as blood is tested anyway, any new infections will be picked up that way. How do you feel about this?

How much do you see the rule as being about risk/sexual behavior? Orientation?

If we go back to thinking about the rule that excludes men who've had sex with men from giving blood, do you think it should be changed or kept the same?

If yes: What do you think the criteria should be changed to?

What should eligibility be based on? Prompt: Time since you last had sex with a man? If so, how long? How many people you've had sex with? Whether sex was protected or not? Risky sex? Probe reasons for (non)-adherence to rules given in Q6b.

What do you think would be a 'fair' rule? Should there be exceptions and for whom?

How about other men who have sex with men, do you think the same rules should be applied to them? What makes you say that?

Some people argue that any potential risk to blood recipients outweighs the rights of individuals to donate blood. Where do you think the priority should be placed in this debate on safety vs. rights? - potential risk to blood recipients? Individual right to donate blood?

Would the changes you've suggested make you more or less likely to offer to give blood? Why's that? Prompt: Become eligible? More/less likely to go along with the rules? More about risk, less about discrimination? Clearer guidelines?

What about your friends/partner(s)? Would it affect whether they'd offer to give blood? In what way? Prompt: Become eligible? More/less likely to go along with the rules? More about risk, less about discrimination? Clearer guidelines?

If you needed to receive blood yourself, what would you want the rules to be? Why's that?

Who do you think should be responsible for deciding on the rules?

Since 1983, when MSM and other groups then thought to be at risk for AIDS were first banned from blood donation, blood centers have developed more accurate tests for screening blood. These tests have greatly reduced the chances that infected blood will be passed on to blood recipients.

Some countries have already changed their rules on blood donation by men who have ever had sex with another man.

For example, in New Zealand men who have not had sex with a man in the past 5 years are allowed to give blood. What do you think of New Zealand's five-year rule?

In the UK and Australia men who have not had sex with a man in the past 12 months can donate blood. What do you think of the UK and Australia's one-year rule?

In Spain it's based on how many people you have had unprotected sex with recently, whether with men or women. What do you think of Spain's rule based on number of partners?

If the rules were changed in the US to be similar to other countries, what changes would you like to see?

How would revisions to the rules affect your views on the ban on blood donation by MSM?

Would you be more or less likely to donate blood?

Do you see yourself ever being eligible to donate under any of these rules?

Would changes to the rules make you more/less likely to go along with the rules?

Would other MSM be more or less likely to follow the revised rules?

If the rules for MSM were revised, what would be the best way to let people know about it?

Advertising? Prompt: TV? Newspapers/magazines? Internet? By post? Press aimed at gay men?
Radio?

Via health services? At blood donation centres? Organisations working with MSM?

What would you say are the key points to get across?

Prompt: Change to deferral period, rules based on risk not discrimination, better aligned with other 'risk groups'.

Research has shown that quite a few men who have sex with men don't know about the current rules that exclude them from donating in the US.

How could the blood services get that information across more effectively in the future?

How could it be made clearer?

What about the information/advertising available before you get to the blood donation centre?
Would different media/technology help?

Are there ways to improve the ways that blood center staff ask the screening questions?

Are there ways to make the screening questions clearer?

Would the type of person asking the questions make lead you to answer differently? For example, if the blood center staff were gay identified, female, male, more comfortable talking about sex, less judgmental, what other criteria?

Would you prefer answering questions about your sexual behavior to a computer rather than with a live person?

Prompt: Kiosk? Laptop? Tablet such as iPad? Online from home before coming to blood donation center? Voice activated helpline to find out more about why you are/ aren't able to give blood?

If blood donation rules were changed to a one or five year deferral, what advice should they give on donating blood in the future?

If eligibility to give blood were to be based on the number of partners with whom you'd had unprotected sex, what would be the best way to ask the screening questions (to see who is eligible to give blood)?

How would you feel about answering these kinds of questions at a blood donation centre? What about other men who've had sex with a man, how do you think they'd feel?

How do you usually describe your (sexual) orientation? Gay? Bisexual? Straight? Other?

For you, is sexual orientation a matter of who you're attracted to? Who you have sex with? Current relationship? Past relationships? How you relate to people? Where you meet people?

Have you always identified as _____? How has this changed over time? What would you say brought this change about?

How has your sexual identification/orientation affected your views on blood donation?

How important to you are the rules around MSM's eligibility for blood donation?

How has participating in this study changed your views on blood donation?

Thank you very much for your time. Those are all my questions.

What else did you want to add before we finish?