

Moderator's Guide

HRSA Focus Group on Teen Donation (2 hours)

Introduction (5 minutes)

Thank you for coming. My name is _____, and I'll be moderating our discussion today. I really appreciate the time that each of you is taking to attend this group, and I look forward to hearing from you. Before we begin, I would like to start with some ground rules for our discussion today:

- First, did everyone understand the informed consent form? The form was signed by your parents. Do you have any questions about this form? [Answer all questions, and then proceed]
- The purpose of our discussion is to hear your opinions. I want to hear everything you have to say, both positive and negative. There are no wrong answers. I need to know both what you like and don't like.
- Everyone's participation today is important. Part of my job as moderator is to make sure we get a chance to hear from everyone. So, at times, I may call on you, or ask you to shorten your remarks so someone else has the chance to speak.
- I have a set of questions and I would like to ask all of them. There may be times when I need to move us on to another topic, or to focus us on specific topics, so that we end on time. If we have time, we can revisit some of these issues if you wish.
- This is a group discussion, so you don't need to wait for me to call on you to speak. Please feel free to respond directly to other people's thoughts and ideas. However, in order for us to hear everyone's opinion, only one person should be speaking at a time. Please address your comments to the entire group.
- If you have a cell phone with you, please turn it off or silence the ringer. Thanks.
- As a reminder, this discussion is being audio recorded. That will help me to make sure I accurately reflect what everyone says here tonight when I write my report. However, nothing that you say will be linked to you by name, and we destroy the tapes once our report is finalized. I also want to remind you that there are other people observing this discussion. These other observers are also taking notes and will help to make sure that we cover all the information we need to cover today.
- Does anyone have any questions about these ground rules before we get started?

Great. We really appreciate your input.

Why don't we start by introducing ourselves to one another? Please tell us your first name and what school you attend. Let's start with _____.

General Beliefs about Donation (25 minutes)

The main purpose of this group is to discuss organ donation. We're going to talk about why teens do or don't register as organ donors. We are not registering people. I'm only interested in your opinions. Your feedback will help ensure that materials currently developed and designed for teens on this topic will be as helpful and informative as possible.

1. Let's start by talking about organ donation in general. What do you know about this topic?
2. I want to give everyone a moment to do this next exercise on their own. Please write down one word to describe organ donation. [PAUSE] OK, thanks. Now let's share what you wrote and why? [Go around room]
3. What do you see as the benefit of organ donation?
4. What does it mean to register as an organ donor? What happens after you sign up?
5. Who gets organs? How does that process work?
6. What happens if not enough people register as organ donors?

Registration (25 minutes)

Now let's talk about the registration process.

7. As you understand it, how do you sign-up to be an organ donor?
 - a. How old do you have to be?
 - b. How long does it take?
 - c. Do you know anyone who has signed up?
8. Some of you here have a driver's license. Were you asked to sign up to be a donor when you got your license?
 - a. Did you feel pressured one way or the other?
9. Some of you have not gotten your license yet. Are you expecting to be asked about that when you get your license?
10. Have any of you seen any literature or heard anything about donation? [ASK OPEN]. Thanks, now I have a list of possible places. Did you get any information:
 - a. At the DMV
 - b. In a driver's ed class
 - c. In a health class or other class at school
 - d. Via posters or ads – where?
 - e. Social media
 - f. TV show or movies
 - g. Conversation with your parents
 - h. Conversation with your friends
 - i. Conversation with anyone else – who? [siblings, other relatives, etc.]
11. For those of you who have your license already, and did not register to be an organ donor, what was the main reason you did not sign up when you got your license?
 - a. Any other reasons?
 - b. How much attention were you paying to that decision when you made it?

12. For those of who don't have a license yet:
 - a. Why might you sign up?
 - b. Why might you not sign up?
13. Thanks. Let's make a list of all the reasons you think teens might not sign up as organ donors. [FLIPCHART]
14. Now, let's vote for which of these reasons you think are most important. [EVERYONE GETS 3 STICKERS]

Want to Know (15 minutes)

Now let's talk about what information would be helpful to know.

15. What kind of information would **have** be helpful for you to know about donation?
16. Is there anything you would want to know before becoming a donor? What questions do you have?
17. Where would you want to get information on donation? Where would kids facing this decision now want to get information?
18. Other than in this focus group, have you ever talked about donation before? When? Why? With whom?
19. To the best of your knowledge, what do your parents think about donation?
 - a. Have you ever talked to them about it?
20. What about your friends?
 - a. Have you ever talked to them about it?
21. Picture yourself signing up. How would you feel?

Message Testing (45 minutes)

Now I want to show you a series of messages that have been developed about donation. As a reminder, I am an independent researcher. I did not develop these messages. My job is just to get your honest opinions on them. I am going to pass them out and have you rate each one on your own. Then we will talk about it as a group.

Try to view each message independently, as-if you were seeing them on their own. Also try to read them like you were NOT in the middle of a focus group talking about this, but like you would see them if you just came across them somewhere.

Rate each message on a scale of 1 (worst) to 10 (best) on each of the following:

- Gets my attention
- Organ donation helps people

- I like it
- I believe it
- I want to learn more
- I want to sign up

[SHOW EXISTING HRSA MESSAGES FOR TEENS ON DONATION. RATE EACH MESSAGE INDIVIDUALLY AND THEN DISCUSS AS A GROUP]

22. What's your first reaction to this message? Why?

23. Did anything stand out or get your attention?

24. What was the main point of this message?

25. Is this something teens need to know? Does it answer any of your key questions?

26. Does this change in any way how you feel about donation? Why or why not?

[REPEAT FOR EACH MESSAGE]

27. Now let's look at all the messages together. What stands out to you? Why?

28. What seems best suited for a teen audience? Why?

29. What would have been helpful for you when you were getting your license?

30. Which, if any, might have encouraged you to register?

Closing Comments (5 minutes)

This has been a really great discussion.

31. Do you have any other thoughts, comments, or questions on this topic?

Thank you so much. I am working for a government agency called the Health Resources and Services Administration. This agency encourages people to register to become organ donors and provides more information at the website organdonor.gov.

This completes our discussion. I am required by law to report to you the OMB Control Number for this public information request. That number is 0915-0212 which expires **DATE**. I am also required to read you the following statement:

An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0915-0212. Public reporting burden for this collection of information is estimated to average .57 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate

or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 10C-03I, Rockville, Maryland, 20857.