

## **Moderator's Guide**

HRSA Focus Group on VCA Donation (2 hours)

### **Introduction (10 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? 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, and understand and don't understand.
- 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 that I need to get through. 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, please speak only one person at a time, and 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 that I accurately reflect what everyone says here tonight when I write my report. However, nothing that you say will be attributed 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 how long you have lived in this area. Let's start with \_\_\_\_\_.

### **Explanation and Warm-Up (10 minutes)**

The main purpose of this group is to discuss issues related to organ donation and transplantation. According to what you've told us, all of you here support organ donation, and none of you are registered organ donors. We're not here to try to change that, and I'm not going to ask you to sign up at the end of our discussion. I'm only interested in your opinions.

1. Before we start, I want everyone to just mark on this piece of paper how you are feeling about organ donation right now. There are two questions. One is about how you feel about donation, and the other is about how likely you are to register as a donor. [Explain how questions work.] I'll ask you to do these scales a few times during our discussion. Remember: there are no wrong answers. I just want your honest opinions. [See Appendix]
2. Great. Thanks for doing that. Let's get started. When you think of organ donation, what do you think of?
3. What kinds of body parts can be donated? [Probe for things other than organs]
4. How is it decided if someone is a donor? When can that decision be made?

### **VCA Donation (15 minutes)**

I want to spend some time now talking about a new kind of donation, which is called VCA or Vascularized Composite Allografts (VCAs). In this type of donation, structures such as bone, skin, nerves, blood vessels, and muscles may be transplanted. Hand and face transplants are good VCA examples.

5. How many of you have heard of this kind of donation before?
6. What have you heard about it? Where did you hear it? [Ask of all who have heard]
7. How is this different from other types of donation?
8. Do you feel any differently about this than other kinds of donation? If yes, how so? [Probe to see if it is 'ickier']
  - a. We know some people have an "ew" type reaction. Help me to understand that better. Exactly what is that about?
9. Let's go ahead and answer our questions again about how you are feeling. Remember: your honest feedback is most helpful to me. Thanks. [See Appendix]

### **Hands Donation (20 minutes)**

10. Great. Now I want to talk in more detail about different types of VCA donation. One of the things that can be donated this way is hands. How many of you have heard of that?

11. What's your reaction to the idea of donating hands? Why?
12. What questions do you have about this? What would you want to know before you considered donating the hand of a loved one?
13. I want to tell you a little more about how it works. [Pass out fact-based information on hands transplants.] What do you think of this information?
14. Is it helpful? Why or why not?
15. Does this make you more or less interested in this topic? Why?
16. Now I want to share with you a story about someone who received a hands donation. [Share story] What do you think of this information?
17. Is it helpful? Why or why not?
18. Does this make you more or less interested in this topic?
19. What else would you still want to know about this?
20. Let's go ahead and answer our questions again. [See Appendix]

**Face Donation (20 minutes)**

21. This has been really helpful, thanks. Now I want to switch the topic a little. Another thing that can be donated is someone's face. How many of you have heard of that?
22. What's your reaction to the idea of donating a face? Why?
23. What questions do you have about this? What would you want to know?
24. I want to tell you a little more about how it works. [Pass out fact-based information on face transplants.] What do you think of this information?
25. Is it helpful? Why or why not?
26. Does this make you more or less interested in this topic? Why?
27. Now I want to share with you a story about someone who received a face transplant. [Share story] What do you think of this information?
28. Is it helpful? Why or why not?
29. Does this make you more or less interested in this topic?

30. What else would you still want to know about this?

31. Let's go ahead and answer our questions again. [See Appendix]

### **Framing Discussion (15 minutes)**

I want to talk a little more about this material we've been reviewing on this kind of donation. From now on when I refer to VCA I'm talking about hands and face donation and transplantation.

32. I've given you more factual information as well as personal stories about these kinds of transplants. Compare and contrast the two types of information for me.

- Which are you more interested in? Why?
- What made you feel more positively about donation in general?
- What made you more comfortable with VCA/hands/face donation in particular?
- What kind of feelings or questions does the fact-based information raise? What about the personal stories?

33. One of the stories featured a veteran who was receiving a transplant. Was the fact that (he/she) was a veteran important for you? Did it change how you felt about it in any way? Why?

34. There are other kinds of stories we could share as well. I want to ask about your interest in some of those. Please tell me whether you would be interested in this kind of information, and why.

- Information about the science behind this kind of donation
- Stories of surgeons who do this kind of transplant
- Stories about how people's lives are changed by this kind of transplant
- Stories from the families who made the decision to make a gift like this and how they feel about it

35. Let's go ahead and answer our questions again. [See Appendix]

### **Communication Channels (25 minutes)**

36. Now I want you to look at your first answers compared to these latest answers to my two questions. How did learning about VCA/hands/face donation change how YOU feel about organ donation.

- Raise your hand if it made you more positive about donation or more likely to donate. [Get count] Why do you think it had this effect on you?
- Raise your hand if it made you less positive or less likely to donate. [Get count] Why do you think it had this effect on you?
  - What would you need to know to address your concerns?
  - What could you hear about VCA/hands/face donation that would make you still consider being an organ donor?
  - What is your biggest concern?

- c. Raise your hand if it didn't affect you at all. [Get count] Why?
37. Currently, the only way someone becomes a VCA/hands/face donor is if their family agrees after they have died. Often, people themselves or the family have already agreed to donate other organs, and they may be asked to consider this type of donation as well if their loved one is a good match for someone in need. Currently, the family makes the final decision about VCA/hands/face donation.
- How do you feel about this process?
  - Does it change how you feel about VCA/hands/face donation?
38. If you and your family were ever faced with a decision like this about a loved one, do you think you would agree to a VCA/hands/face donation? Why? Would it matter if you had talked about it ahead of time?
- Why would a family donate?
  - Why would a family not donate?
39. Because VCA/hands/face donation is still so rare, a lot of times there are news stories about it so the name of the donor may become public. What do you think about that? Would it affect your decision of whether to donate?
40. VCA/hands/face donation is still a really new medical development, and not a lot of people know about it. Some people may have concerns about these issues. Help us to brainstorm a list of questions or concerns people may have on this topic. [Make a flipchart]
- Of all these questions, which are the most important? [Let everyone vote for their top 3]
41. Where would people want to learn more about this? Where would you go for more information?

### **Closing Comments (5 minutes)**

This has been a really great discussion. Before we close, I have just a few final questions.

42. First, is there anything else you want to say?
43. Finally, 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](http://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 XXX, 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 XXX. Public reporting burden for this collection of information is estimated to average 2.25 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.

Appendix: Attitudes about Organ Donation

**How I feel about organ donation.**



**I will register to be an organ donor.**

