

# **Attachment # 2**

## **Financial Sustainability Study Focus Group Moderator Guide**

**Assessing Biobank Feedback regarding:  
Financial Survey Instrument**

October/November 2012

# Focus Group Moderator Guide

## BBRB Assessing Biobank Feedback Regarding: Financial Survey Instrument

OMB No.: 0925-0642  
Expiration Date: 9/30/2014

### NOTIFICATION TO RESPONDENT OF ESTIMATED BURDEN

Public reporting burden for this collection of information is estimated to average 90 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **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.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0642). Do not return the completed form to this address.

### 1. WELCOME (1 minute)

- a. Good morning/afternoon, my name is [Moderator Name]. I am the BBRB Biobank Financial Sustainability Study Advisor and will be the moderator for today. Welcome and thank you for participating in the Biobank Financial Sustainability Survey Focus Group Discussion.
- b. Many of you may have participated in a focus group previously. A focus group is a small group discussion that focuses on a particular topic in depth. The purpose of this focus group is to discuss the Financial Sustainability Study Survey, specifically to understand your impressions, comments and suggestions regarding the survey. I will be asking your opinions informed by your experiences in biobanking. The information obtained will be used to refine and improve the Survey before we deploy in the coming months.

### 2. GROUND RULES (4 minutes)

Before we begin, I would like to review a few things about how the discussion will work.

- a. In a focus group, there is no right or wrong answers, only opinions, and I'd like to hear from all of you about your perspectives equally. It's important that I hear what each of you thinks. Please talk one at a time and in a clear voice. Because we are taking notes and taping the discussions, I may occasionally interrupt you if two or more people are talking at once to be sure everyone gets a chance to talk and that responses are recorded clearly.
- b. Everyone needs to talk but each person doesn't have to answer each question. If I haven't heard from you I may call on you occasionally. You don't need to address all answers to me; I encourage you to exchange points of view with each other. Also, please feel free to speak up even if you disagree with someone else here. It's OK to disagree, because it's helpful to hear different points of view. I'm also interested in any questions you may have as we go along.

C. This form is not to be submitted to the BBRB. The purpose of this form is to provide information to the BBRB.

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### PRIVACY ACT NOTIFICATION STATEMENT

Collection of this information is authorized by The Public Health Service Act, Section 412 (42 USC 285 a-1). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private under the Privacy Act. Names and other identifiers will be separated from information provided and will not appear in any report of the study. Information provided will be combined for all study participants and report as statistical summaries.

### NOTIFICATION TO RESPONDENT OF ESTIMATED BURDEN

Public reporting burden for this collection of information is estimated to average **x** minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required**

- d. This focus group will be audio-taped so that we can capture all of the relevant quotes and comments. Everything you say is important to us, and we want to make sure we don't miss any comments. Later, we'll go through all of your comments and use them to prepare a report of our discussion. I want to assure you, however, that all of your comments are secure to the extent provided by law, and will be used only for research purposes. Nothing you say will be connected with your name. As well, we would like focus group participants to respect the confidentiality of all responses provided as well. Also, if there are any questions you would prefer not to answer, please feel free not to respond to them.

Does anyone have any questions before we begin?

### **3. INTRODUCTIONS (10 minutes)**

- a. I'm going to ask each of you to introduce yourself to the group. I'd like to ask that you tell us: current position, years in your current position, years of experience in biobanking, the name of the biobank that you represent, and the number of years it has been in operation.

### **4. PERCEPTIONS AND FEEDBACK ON THE SURVEY**

#### **Relevance (20 minutes)**

This survey captures the most important aspects of financial sustainability, funding, and related issues. As you respond, please state whether you agree with this statement and for each of the first five sections of the survey and please rate each section including:

- a. Organizational structure (network / stand-alone)
  - i. Highly relevant to understand biobanking financial sustainability
  - ii. Somewhat related to understand biobanking financial sustainability
  - iii. Not needed to understand biobanking financial sustainability
- b. Current funding sources
  - i. Highly relevant to understand biobanking financial sustainability
  - ii. Somewhat related to understand biobanking financial sustainability
  - iii. Not needed to understand biobanking financial sustainability
- c. Scale of operations
  - i. Highly relevant to understand biobanking financial sustainability
  - ii. Somewhat related to understand biobanking financial sustainability
  - iii. Not needed to understand biobanking financial sustainability
- d. Coverage of current and projected growth
  - i. Highly relevant to understand biobanking financial sustainability
  - ii. Somewhat related to understand biobanking financial sustainability
  - iii. Not needed to understand biobanking financial sustainability
- e. Feedback on new potential funding sources
  - i. Highly relevant to understand biobanking financial sustainability
  - ii. Somewhat related to understand biobanking financial sustainability
  - iii. Not needed to understand biobanking financial sustainability

#### **Complexity (20 minutes)**

The Survey was easy to understand and to use. As you respond, please state whether you agree with this statement and for each of the first five sections of the survey and please discuss and rate each section including:

- a. Organizational structure (network / stand-alone)
  - i. Very easy to understand
  - ii. Some questions were unclear (please let us know which ones need clarification)
  - iii. Most questions were unclear and need better explanation (be specific)
- b. Current funding sources
  - i. Very easy to understand
  - ii. Some questions were unclear (please let us know which ones need clarification)
  - iii. Most questions were unclear and need better explanation (be specific)
- c. Scale of operations
  - i. Very easy to understand
  - ii. Some questions were unclear (please let us know which ones need clarification)
  - iii. Most questions were unclear and need better explanation (be specific)
- d. Coverage of current and projected growth
  - i. Very easy to understand
  - ii. Some questions were unclear (please let us know which ones need clarification)
  - iii. Most questions were unclear and need better explanation (be specific)
- e. Feedback on new potential funding sources
  - i. Very easy to understand
  - ii. Some questions were unclear (please let us know which ones need clarification)
  - iii. Most questions were unclear and need better explanation (be specific)

### **Confidentiality (20 minutes)**

The Survey asks for information that may be too confidential for your organization to disclose under certain circumstances. As you respond, please state whether you agree with this statement and for each of the first five sections of the survey and please discuss and rate each section including:

- a. Organizational structure (network / stand-alone)
  - i. We would share this information publicly with attribution to our enterprise
  - ii. We would share this information provided our data were not attributed to our enterprise
  - iii. We would not share this information under any circumstance
- b. Current funding sources
  - i. We would share this information publicly with attribution to our enterprise
  - ii. We would share this information provided our data were not attributed to our enterprise
  - iii. We would not share this information under any circumstance
- c. Scale of operations
  - i. We would share this information publicly with attribution to our enterprise
  - ii. We would share this information provided our data were not attributed to our enterprise
  - iii. We would not share this information under any circumstance
- d. Coverage of current and projected growth
  - i. We would share this information publicly with attribution to our enterprise
  - ii. We would share this information provided our data were not attributed to our enterprise
  - iii. We would not share this information under any circumstance
- e. Feedback on new potential funding sources
  - i. We would share this information publicly with attribution to our enterprise
  - ii. We would share this information provided our data were not attributed to our enterprise

iii. We would not share this information under any circumstance

## **5. CHALLENGES (10 minutes)**

The Survey requests your views on the challenges you now face anticipate in the near future. Please discuss and rate this section by considering the following two statements:

The challenges listed include the most critical for my organization. Agree / disagree

Some important challenges are missing including . . .

## **6. CONCLUSION (2 minutes)**

We've come to the end of our discussion. The BBRB team has worked hard to develop these questions so we can improve the Survey for Financial Sustainability.

Do you have any additional comments you would like to make on our focus group topics?

On behalf of the BBRB, I want to thank you for your participation. This has been a valuable session. I want to remind you that all of your comments are secure to the extent permitted by law, and will be used only for research purposes. Thank you again for your comments and your time.