

MODERATOR'S GUIDE

Online Focus Groups to Inform the Development of a National Biorepository Advanced Strategy Lab (ASL)

**Research to be Conducted for:
Office of Market Research and Evaluation,
Office of Communications and Education
National Cancer Institute**

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Background on Participants

1. Please indicate your title and area of specialization:
2. Please indicate how long you have been involved in biospecimen research and issues overall as a professional career:

Times Selected	Items
0 (0%)	1. Less than 1 year
0 (0%)	2. Between 1 and 5 years
0 (0%)	3. Between 5 and 10 years
0 (0%)	4. Between 10 and 20 years
0 (0%)	5. More than 20 years

Identification of Needs

Instructions: What could or should a national, standardized human biospecimens resource offer that does not exist in the current infrastructure? What issues could this resource resolve? What unmet existing needs might it fill? (multiple responses)

(1) Categorization of Needs

Instructions: The following is a summary of the needs we identified. In a moment, we'll assess the list...

(1A) Prioritization of Needs

Instructions: Now, please assess each of the following aspects in terms of how much value the development of a national, standardized human biospecimens resource would add to your work. Use a scale of 1-10 where a '1' means no value at all and a '10' means a great deal of value:

Implications of the Most Important Need

Instructions: MOST IMPORTANT NEED was identified by the group as the most important need. Why is this need so important to address and improve on a broad scale? What are some solutions that would address this need and allow you to do what you currently cannot do within the existing infrastructure? (Please be as specific as you can and submit your response as a paragraph style position statement.)

Benefits of a National, Standardized Human Biospecimen Resource

Instructions: What do you feel would be the benefits of a national, standardized human biospecimens resource? What would this resource enable us to do or do differently? (multiple responses)

(2) Categorization of Benefits

Instructions: The following is a summary of our responses. In a moment, we'll prioritize the list...

(2A) Prioritization of Benefits

Instructions: Now, please assess each of the following aspects in terms of how important you feel each would be as a benefit of a national, standardized human biospecimens resource. Use a scale of 1-10 where a '1' means not at all important and a '10' means extremely important:

Most Important Benefit

Instructions: As a group, you selected MOST IMPORTANT BENEFIT as the most important benefit. Why is this benefit so important, so vital? What do you feel it will allow researchers to do or do differently in their research? How will it make things better? (Please be as specific as you can and submit your response as a paragraph style position statement.)

Challenges in Developing a National, Standardized Human Biospecimen Resource

Instructions: What do you see as the most significant challenges or barriers we might face in the development of a national, standardized human biospecimens resource? (multiple responses)

(2) Categorization of Challenges

Instructions: The following is a summary of our responses. In a moment, we'll prioritize the list...

(2A) Prioritization of Challenges

Instructions: Now, please assess each of the following aspects in terms of how significant you feel each would be as a challenge in the development of a national, standardized human biospecimens resource. Use a scale of 1-10 where a '1'

means not at all significant/challenging and a '10' means extremely significant/challenging:

Addressing Biorepository Challenge 1

Instructions: How do you feel we could most effectively address CHALLENGE 1? What might allow us to move forward on this issue? (multiple responses)

Addressing Biorepository Challenge 2

Instructions: How do you feel we could most effectively address CHALLENGE 2? What might allow us to move forward on this issue? (multiple responses)

Motivations to Contribute

Instructions: In order to populate a national biorepository resource with a large, diverse range of specimen types, NCI must rely on organizations with biospecimen resources to contribute specimens and high quality data associated with those specimens. What do you believe would motivate organizations to contribute their biospecimens and data to a national biospecimens resource? (multiple responses)

Barriers to Contribute

Instructions: What do you see as barriers that would prevent an organization from contributing biospecimens and the associated data to a national biospecimens resource? (multiple responses)

(3) Categorization of Barriers to Contribute

Instructions: The following is a summary of the barriers we identified. In a moment we'll assess the list...

(3A) Prioritization of Barriers to Contribute

Instructions: Now, please assess each of the following aspects in terms of how significant you feel each is in potentially preventing organizations from contributing specimens and data to a national biorepository. Use a scale of 1-10 where a '1' means not at all a significant barrier and a '10' means an extremely significant barrier:

Most Significant Barrier

Instructions: As a group, you selected MOST SIGNIFICANT BARRIER as the most significant barrier. Why is this barrier so challenging and so critical to overcome? (Please be as specific as you can and submit your response as a paragraph style position statement.)

Policies to Address Barriers

Instructions: What policies or incentives might be used to overcome this and other barriers and encourage sharing of biospecimens, data and research results? (multiple responses)

Challenges in Getting the Right Specimens

Instructions: What, if any, challenges have you encountered in obtaining the size and quantity of specimens that you have sought? (multiple responses)

(4) Categorization of Challenges in Getting the Right Specimens

Instructions: The following is a summary of the challenges we identified. In a moment, we'll assess the list...

(4A) Prioritization of Challenges in Getting the Right Specimens

Instructions: Now, please assess each of the following aspects in terms of how big it is as a challenge to obtaining the size and quantity of specimen you are seeking. Use a scale of 1-10 where a '1' means not at all an issue/concern and a '10' means it is an extremely significant issue/concern:

Quality Assurance Issues

Instructions: What quality assurance issues are you struggling with currently? What aspects of the current quality assurance infrastructure are you concerned with? (multiple responses)

(5) Categorization of Quality Issues

Instructions: The following is a summary of the issues we identified. In a moment, we'll

assess the list...

(5A) Prioritization of Quality Issues

Instructions: Now, please assess each of the following aspects in terms of how big it is as a quality issue/concern. Use a scale of 1-10 where a '1' means not at all an issue/concern and a '10' means it is an extremely significant issue/concern:

Addressing the Most Significant Quality Issue

Instructions: As a group, you selected MOST SIGNIFICANT QUALITY ISSUE as the greatest quality concern. Why is this issue such a challenge? How do you feel we could most effectively address this concern? What might allow us to move forward on this issue? (Please be as specific as you can and submit your response as a paragraph style position statement.)

Identification of Operating Procedures and Practices

Instructions: What operating procedures or practices must be in place in a national, standardized human biospecimens resource for you to have confidence and trust in it? (multiple responses)

(6) Categorization of Operating Procedures and Practices

Instructions: The following is a summary of the procedures and practices we identified. In a moment we'll assess the list...

(6A) Prioritization of Operating Procedures and Practices

Instructions: Now, please assess each of the following in terms of how important it is for the national, standardized human biospecimens resource to follow. Use a scale of 1-10 where a '1' means not at all important to follow and a '10' means it is extremely important to follow:

Input on Most Important Operating Procedures

Instructions: Please respond to the following survey questions. There will be an instruction at the end of the survey on how to submit your responses.

Operating Procedure 1:

1. Thinking of this specific recommended operating procedure, what do you see as the main barrier for implementing it AND what do you see as the best way to overcome that barrier?

Operating Procedure 2:

2. Thinking of this specific recommended operating procedure, what do you see as the main barrier for implementing it AND what do you see as the best way to overcome that barrier?

Input on Intellectual Property

Instructions: Please respond to the following survey questions. There will be an instruction at the end of the survey on how to submit your responses.

Intellectual Property: Concerns

1. What are your specific concerns around intellectual property in using a national, standardized human biospecimens resource?

Intellectual Property: Policies

2. What specific policies would you like to see to deal with intellectual property concerns?

Identification of Additional Services

Instructions: In addition to providing biospecimens and data, what other services would be of value to you from a national, standardized human biospecimens resource? (multiple responses)

Session Feedback Survey

Instructions: Please respond to the following survey questions. There will be an instruction at the end of the survey on how to submit your responses.

Session Identification and Feedback

1. What did you enjoy most about the session today? What did you find to be most positive?

2. Do you have any additional comments or observations about today's session or any additional advice/input to NCI as they move forward in the development of a national, standardized human biospecimen resource?

