

Supplemental Materials: Online Resources 1-4

**Building Trustworthiness to Increase Diversity in Colorectal Cancer Biospecimen
Research: A Multi-Phase, Multi-Site Qualitative Study**

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Online Resource 1 Key Informant Interview Guide

Welcome and introduction

I'm <insert name>. I'm here today to talk with you about your experiences collecting research biospecimens in diverse communities, with a specific focus on Black, Latino/a/x or Native American populations. Our purpose for this interview is to learn from your experiences so we can design effective strategies to enroll Black, Latino/a/x or Native American populations in a biorepository where we plan to collect blood and stool. Thank you so much for joining us today. Is it okay if I record the audio of today's conversation?

Discussion

- Please describe the context in which you were recruiting participants for biospecimen research. What was the broader project? What biospecimens were you collecting? What was your role?
 - Probe: Ask whether they are involved in multiple studies v. a single study. If multiple, follow-up with differences between studies for remaining questions.
 - Probe: Was biospecimen collection the main focus of the study or was it part of a broader research study and biospecimen collection was just one component of the study.
- Was recruiting Black, Latino/a/x or Native American populations a priority? Did you use any specific recruitment strategies designed to increase participation of Black, Latino/a/x, or Native American populations in biospecimen research? If so, what were they? How effective do you feel they were?
 - Probe: Diverse team members, language, Community outreach; Collaboration with community advocates;
 - Probe: Differentiate between research study recruitment and biospecimen recruitment.
- When working with Black, Latino/a/x or Native American populations do you feel that there were any specific facilitators to participation in biospecimen research? If so, what were they? Were there specific differences that you noted based on the patient community?
 - Probe: Study staff from their community; location and timing of collection; incentives; novel approaches to informed consent; education for research participants; education or training for research staff
- When working with Black, Latino/a/x or Native American populations do you feel that there were any specific barriers for individuals to participate in biospecimen research? If so, what were they? Were there specific differences that you noted based on the patient community?
 - Probe: Documentation status, language, fear, mistrust, concerns about privacy
- Were there specific biospecimen samples that patients were more or less willing to provide? Were there any differences you noticed based on patient race or ethnicity? If so, what were they?
 - Probe: saliva, urine, blood, feces, buccal cells

- Were there any biospecimen sample collection approaches or techniques that potential participants were more or less willing to do? Were there any differences you noticed based on patient race or ethnicity? If so, what were they?
 - Probe: At home visits, lab collection, self-sampling, mobile van

Wrap-up

Our purpose for this interview was to understand your experiences collecting research biospecimens in diverse communities, with a specific focus on Black, Latino/a/x or Native American populations. Have we missed anything? Is there anything you would like to add to today's discussion?

Online Resource 2 Rapid Qualitative Analysis Transcript Summary Template

PREPARED BY: Analyst Name

PARTICIPANT: Name

RESEARCH POPULATION: Black, Latino/a/x, Native American

DATE OF SUMMARY: XX/XX/XXXX

Include line number for where short quote and/or paraphrase can be found in the transcript (line xx-xx)

- SUBJECT MATTER EXPERT (SME) BACKGROUND
- SPECIFIC FOCUS ON BIPOC RECRUITMENT
- RECOMMENDATIONS FOR WORKING WITH BLACK, LATINO/A/X, OR
NATIVE AMERICAN POPULATIONS
- LESSONS LEARNED FROM WORKING WITH BLACK, LATINO/A/X, OR NATIVE
AMERICAN POPULATIONS
- SAMPLE SPECIFIC FEEDBACK
- BIOSPECIMEN COLLECTION APPROACHES
- OTHER

Online Resource 3 Rapid Qualitative Analysis Matrix Template

Participant ID	Subject Matter Expert (SME) background	Specific focus on BIPOC recruitment	Recommendations for working w/ Black, Latino/a/x, or Native American populations	Lessons learned from working with Black, Latino/a/x, or Native American populations	Sample specific feedback	Biospecimen collection approaches	Other

Online Resource 4 Focus Group Discussion Guide

Welcome and Introduction

Moderator: *I'm <insert name>. I'm here today to talk with you about the collection of biospecimens—for example, blood, stool, and urine—and barriers and facilitators to the collection of biospecimens. To be clear, we will not be asking you to provide a specimen.*

Information from biospecimens has led to important advances in our understanding of the causes of disease and can help tailor treatment options, and can ultimately lead to a more personalized approach to health care. Unfortunately, biorepositories often lack racial and ethnic diversity. In an effort to increase diversity in our collection of biospecimens, we are interested in learning from you how we can design effective strategies to enroll Black, Latino/a/x or Native American populations in a biorepository where we plan to collect blood and stool. Thank you so much for joining us today.

We know we've talked with all of you here today about informed consent, but let's quickly review what it means to participate in this focus group and how you are protected as a research participant:

- *Your participation is completely voluntary.*
- *You may choose to not answer a question or stop participating at any time.*
- *You can change your mind to participate in this study (even after you take part), and your decision will not be held against you.*
- *The meeting will be recorded and transcribed for the purposes of analysis; your name and other identifying information will not be included in notes or reports.*
- *We will NOT be asking questions relating to your health or other personal information—we're only asking you for your views and ideas that you are comfortable with sharing.*
- *To be sensitive to all, we encourage everyone here today not to discuss other participants' comments outside of the focus group.*

Any questions before we begin?

Discussion

Moderator: *In this first section of our time together, I'd like to talk a little bit about what you know about biorepositories and biospecimens. There are no right or wrong answers, I'm just trying to gather information about what is unknown and what questions you might have.*

1. Before this study, had you ever heard of the term biospecimen? Whether you have heard it before or not, what comes to mind for you when you hear the word?
 - a. Probe: Where have you heard this term and when did you first hear it? Have you heard the term sample?
 - b. Probe: What types of biospecimen samples have you heard of? (blood, saliva, cheek cells, stool)
 - c. Probe: What do you know about how samples are collected?
 - d. Probe: What do you know about who collects these samples?
 - e. Probe: What do you know about what happens to the samples after they are collected? How are they used?

2. Before this study, had you ever heard of the term biorepository? Whether you have heard it before or not, what comes to mind for you when you hear the word?
 - a. Sometimes people use the term biobank interchangeably with biorepository. Have you heard this term before and what comes to mind for you when you hear it?
 - b. Probe: Where have you heard the term biorepository and when did you first hear it?
3. Probe question if this has not come up in previous responses]: Have you ever been asked to participate in a biorepository or submit a biospecimen?
 - a. If YES: Did you participate? What was the experience like for you?

Moderator: *Ok, thank you for sharing what you know about biorepositories and biospecimens. So that we are all on the same page for the next section, a biospecimen is a sample of biological material, such as urine, blood, tissue, cells, DNA, RNA, or protein. Biospecimens may be used for a laboratory test or stored in a biorepository. A biorepository (AKA biobank) is a facility that collects, catalogs, and stores samples of biological material for laboratory research. If the samples are from people, medical information may also be stored along with a written consent to use the samples in laboratory studies. Any questions?*

Now I'd like to talk about how you would decide whether or not to participate in a biorepository or donate biospecimens for research.

4. If you were invited to participate in a biorepository or to donate a biospecimen for research, what questions or concerns would you have before making a decision?
 - a. Probe: Concerns about:
 - i. Storage
 - ii. Who has access/privacy, linkage to other information in medical record
 - iii. Purpose
 - iv. Type of results generated from the sample
 - v. Consent process
 - vi. Return of results and implications for family members
 - b. Probe: Mistrust
 - c. Probe: Immigration and documentation status worries
 - d. Probe: Language barriers
 - e. Probe: Ethical, cultural, or religious beliefs
 - f. Probe: Transportation barriers
5. Do you have any concerns about donating a biospecimen?
 - a. Probe: Concerns about type (e.g., blood v. stool)
 - b. Probe: Questions about process including pain or discomfort
 - c. Probe: Concerns about time commitment (how long the process takes); Number of visits required
 - d. Probe: Not understanding purpose of collection or how the samples will be used
 - e. Probe: Collection point/access (e.g., at home, lab, self-sampling, mobile van)
 - f. Probe: For anyone who reported that they were approached to participate in biospecimen collection—why they did participate or not participate.
 - g. Probe: Experiences of friends and family

Moderator: *Thank you for sharing some concerns you or people you know might have for participating in biospecimen collection. For the next section, I want to shift gears and talk about what might encourage or motivate you or people you know to participate in biospecimen collection.*

6. What could researchers do to address the concerns you've raised in the previous section?
[Remind the group of the concerns they shared during the discussion before the video]
7. How would you or someone you know respond to being asked to donate a biospecimen:
 - a. if you were approached by someone from your community?
 - b. if you were approached by someone from the hospital or facility where you receive care?
 - c. If you were approached by someone who spoke your primary language?
8. How would you like to be invited to participate in a biorepository or donating a biospecimen to research?
 - a. Probe: At the doctor's office or hospital; Letter sent to your home; Message sent in your patient portal; Phone call.
 - b. Probe: Are there preferred/recommended words or terms to use to describe it?
9. How would an incentive affect your willingness to participate?
 - a. Probe: Types of incentives (e.g., monetary, gas card); Amount
10. How does the purpose of the biorepository affect your motivation to participate?
 - a. Probe: Potential to prevent disease or improve health of future generations; learn about personal disease risk or diagnose disease early
 - b.
11. Are there other things we haven't yet discussed that would encourage you to participate in a biorepository?
12. You've identified some key information that it would be important to provide to potential research participants.
 - a. Who should provide this information?
 - b. How should this information be provided?

Wrap-up

Moderator: *That is the end of the questions that I have for you today. Thank you for sharing your time with us today to help us understand the barriers and facilitators to participating in a biorepository, what you know and don't know about biospecimen collection, and how we can improve outreach to increase participation in biorepositories. Are there any questions you have or anything else that you would like to add before we end today?*

Thank you again for sharing your time with us today. Once we have summarized our learnings, we will share those with you so that you can let us know if we captured the ideas, you shared today accurately.