
SMALL GROUP DISCUSSION GUIDE

(BASE FOR ADAPTATION)

SETTING THE STAGE

Goal: Share information about the what, why, and how of biobanking. The content can be pulled from the PowerPoint shared during the training and the Background document.

WHAT - This section includes definitions such as the ones below:

WHY – This section addresses the opportunities for better prevention and treatment afforded by biobanking.

HOW – This section addresses the details of how one could donate, as well as the importance of informed consent. The key here is to make an informed decision.

CHALLENGES – The facilitator can raise issues of insufficient representation in the biobanks of racial / ethnic minorities, lower-income people, and other groups. This may also be the time to discuss the mistrust of research and medical institutions felt by many underserved communities. The “Count Me In” video (or something similar) can be a nice way to end the introduction portion.

DISCUSSION GUIDE (STARTING POINT FOR YOUR ADAPTATIONS)

1. What do you think of when you hear about biobanks or donating biospecimens?
2. In the video, one of the patients says “who wouldn’t want to be counted” and another mentions wanting to “pay it forward.” What struck a chord with you? (Facilitator can remind the group that there are so many opportunities for new therapies or preventive services coming out of this kind of research and that the research can’t benefit groups that aren’t represented.)
3. What do you think the major barriers to participation in donating biospecimens would be for our community? (This may be the point at which to return to the mistrust conversation.)
4. One of the important things we covered today was the idea of informed consent. In general, that means a document that provides information and a process to ensure people understand what they are agreeing to and have an opportunity to ask further questions. As a reminder, for biobanking, that would include information about the collection of the biospecimen(s), anticipated uses of the biospecimen(s), and what will happen with the findings.
 - If you are offered the opportunity to participate but have questions, how might you get the information you need to make an informed decision either way?
5. What are other local resources you know about for anyone interested in learning more about medical research or other kinds of scientific research?
6. What additional information would you like to have? (There is a list of resources in the background document. The facilitator can pass additional requests back to the U54 team.)