

## Why do we need to educate the public before asking for their opinion?

Public attitudes and opinions have always been important in health research. For example, many research studies use a community-based approach to inform the outcomes and design, while other studies include a member of the public as a citizen scientist. However, as genetics and technology continue to grow within health research so does the difficulty. Making sure research participants are educated about new advancements in health care is important to gather quality attitudes and opinions.

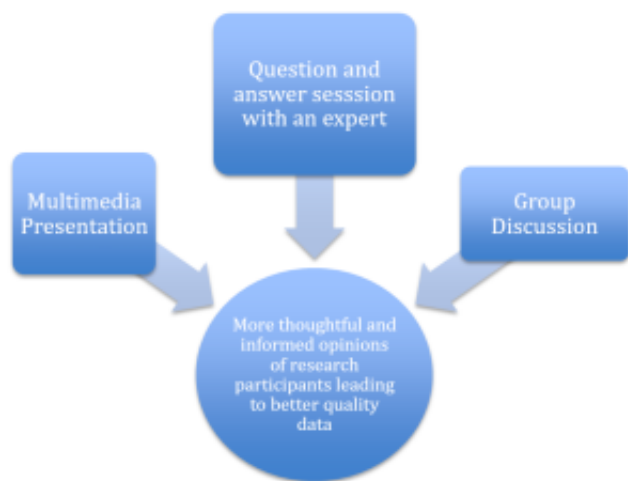


Fig. 1. Deliberative Discussion Focus Group Approach

We developed a way to educate participants prior to asking them questions during a group discussion called a focus group. Research participants watch a multimedia video that explains as well as visually shows the topic we are interested in talking about during the group. An expert attends the group to answer questions from participants about anything they did not understand or would like more information after the multimedia presentation. Then another individual leads the group discussion. Participants are able to ask questions of the expert at any time during the group (see Figure 1). The addition of a multimedia presentation and an expert to the group experience creates a more meaningful experience for data collection because participants can seek more information and also hear what questions other research participant may have about the topic.

We have used this approach to educate participants in several federal funded research studies about genetic testing. For example, we used this approach to educate participants prior to asking their opinions about newborn screening, the largest application of genetic testing in the United States. We also used this approach to gather public opinion on how population-based pilot

research for new tests for newborn screening should be conducted.

Two important outcomes from using this deliberative discussion approach within focus groups have occurred. This approach gives additional insight about what type of questions the public may have about a topic and how their opinions may change after talking about it. This is achieved by:

- 1) The ability to analyze participant questions separately from their opinions; and
- 2) The ability to ask, if at all, how their opinions changed after watching the video, talking with an expert and engaging in a group discussion.

Promoting learning allow participants to hear and discuss issues that may not have arisen without someone else first asking the question. Individuals do not make healthcare decisions alone, but they often discuss them with friends or family prior to the final decision. Deliberative discussion focus groups allow this type of discussion about pros and cons of a decision to be heard. The more educated and informed the research participant, the better quality data for health research.

## **Publication**

[Deliberative Discussion Focus Groups.](#)

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