

Supplemental Material

For Gene-Environment Interactions and Health Inequalities: Views of Underserved Communities
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Focus Group Discussion Guide for Community Voices Project

Introduction

Thank you for participating in this discussion group. We are interested in learning about some of your community's experiences with health issues. When we say community, it can be how you define your ethnic identity and how you feel you belong to a neighborhood. In our discussion, we are also interested in your opinions about the reasons why some groups of people have higher rates of diseases than others. Finally, we want to learn about your opinions on genetics and health and your views about genetic research.

We want to hear what everyone thinks, so please feel free to express your views, even if you disagree with someone else. All of your comments - both positive and negative - are important. The discussion will be tape-recorded so that we don't lose any of your comments. A report will be prepared. The report will not identify anyone by name. The information you provide in our discussion will be kept private.

Health Questions

I want to begin our discussion by talking about health issues in your community.

1. Can you describe some of the health issues that people have in your community?

Probes:

Can you tell me more about what these issues? Can you give some examples?

Can you describe some of the difficulties people in your community have had when they need to see the doctor or go to the hospital? Can you tell me more about what made these experiences difficult?

2. Certain diseases like diabetes or high blood pressure are found in higher rates in some groups than in others. What do you think causes these differences?

Probes:

What about things like the availability of health clinics or hospitals—things like how far the clinic might be from someone's home, or problems traveling to the clinic, or having money to pay for health care?

What about people's diet, or being able to buy nutritious food at a local grocery store—things like vegetables or fruits?

What about exercising?

What about the environment, for example, poor housing, or exposure to things like lead in paint, or living near a factory?

What about diseases that run in families?

What about social support?

Can you think of any other reasons?

Addressing Health Inequalities/Disparities

Some groups in Cleveland and other places face greater inequalities in health care than other groups. In the next few questions, I'd like to talk about doing things to improve health and decrease health inequalities in your community.

3. What do you think are some things that could be done to improve people's health in your community?

Probes:

What kinds of changes do you think are needed to improve people's health in your community?

Can you give me an example of things that could be done to improve people's health in your community? What can people do to improve their health? Can you tell me more about that?

What about other communities? (if person feels the health in their community is fine)

4. In your opinion, what are some things that could be done to decrease health inequalities in your community?

Probes:

What kinds of changes do you think are needed to decrease health inequalities in your community? Can you give me an example? Can you tell me more about that?

What can be done to improve how people get health care in your community?

What about other communities? (if person feels the health in their community is fine)

5. Who do you think is responsible for improving people's health in your community?

Probes:

For example, people in the community? People who provide health care, like doctors or other health professionals? Health clinics or hospitals? What about local government, or national government?

What about other communities? (if person feels the health in their community is fine)

General Genetic Knowledge and Attitude Questions

In the next part of our discussion, we'll be talking about genetics and health issues.

6. I want to begin by asking you what comes to your mind when I say the word "genes" or "genetics"?

Probes:

What do you think of when you hear "genetics"? What about "heredity"? or "genes"?

Can you tell me more about that?

7. Now I'd like to ask what comes to your mind when I say "genetic disease"?

Probes:

What about diseases that run in the family? Inherited diseases?

Can you tell me more about this? What do you mean (*when you say*)?

8. In your opinion, how does genetics or heredity influence your health or your family's health?

Probes:

Can you think of any examples? Can you tell me more about that?

Genetic Research Questions

Now I want to shift the focus of our discussion to genetic research.

9. What comes to your mind when I say “genetic research,” the kind that looks at whether genes put people at risk for disease or illness? *[Example: research that studies how genes affect high blood pressure or diabetes; research that looks at how people might inherit genes that make them more likely to get high blood pressure or diabetes.]*

Probes: Can you tell me what you’ve heard about genetic research? Can you give me an example?

Can you tell me more about that? What do you mean when you say *[repeat...]*?

10. Overall, how positive or negative do you feel about genetic research, the kind that looks at whether genes put people at risk for disease or illness
Can you tell me more about why you feel positive or negative about genetic research?

What are some reasons that you feel (positive or negative)?

What about donating a sample of your blood for a genetic research project—what do you think about this? Can you tell me more about this?

11. Can you tell me, in your opinion, what are some of the **good things that could happen for you or your family** if you took part in genetic research studies?

Probes:

Can you give me an example of something good that could come from taking part in a genetic study—for yourself, or your family?

Can you tell me more about this?

12. Now, I would like to ask you, in your opinion, what are some of the **bad things** that could happen **for you or your family** if you took part in genetic research studies?

Probes: Can you give examples of some of the bad things that might happen for yourself or your families? Can you tell me more about that?

13. Now I want to ask you how you feel about genetic research in your community. Can you tell me, in your opinion, what are some of the **good things that could happen for your community** from participating in genetic research studies?

Probes: Can you give examples of some good things that might happen for your community? Can you tell me more about that?

14. Can you tell me, in your opinion, what are some of the **bad things that could happen for your community** from participating in genetic research?

Probes: Can you give examples of some of the bad things that might happen for your community? Can you tell me more about that?

15. Sometimes genetic researchers want people to join a study that looks at diseases that are experienced at higher rates in some groups of people than other groups.
Can you tell me how you feel about this

Probes: What are some reasons that you might join a study like this?

What are some reasons that you would not join a study like this?

Source of Information about Genetics

16. Now I'd like to ask you, if you were interested in finding information about genetics, where would you go, or who would you talk with to learn more?

Probes: Would you talk with your doctor? Read books? Use the Internet?

Trust and Research Participation

Now I want to shift the focus of our discussion and talk about trust.

17. How much do you think people in your community trust researchers doing studies about health and genetics?

Probes:

Can you give me an example of this? Can you tell me more about this?

18. How do you think someone's trust in doctors, medicine *or health systems* might influence their decision to participate in genetic research?

Probes:

How does trust in doctors influence people's decision about whether or not to join a genetic study? Can you give me an example? Can you tell me more about this?

Social Obligations to Join Research

In this last set of questions I want to talk with you about your opinions on whether or not people have a duty, or obligation, to participate in research.

19. Some people say that there is duty to participate in research that might benefit the general public. Other people say there is no duty to participate in studies that might benefit the general public.

What is your opinion about this? What are some reasons that people might or might not feel they have a duty to participate in research that benefits the public?

Probes: Can you give examples of some of the reasons people might feel they **have a duty** to join a study that might benefit the general public?

Can you give some examples of reasons why people might feel like they are **not obligated** to participate in research that might benefit the public?

20. Do you believe there is a duty to participate in research that may help reduce health inequalities in your community?

Probes:

What are some reasons that you think people might feel obligated to join a study, or not join a study?

What are some reasons that you think people might feel obligated to join a study, or not join a study?

Conclusion

21. Is there anything else you want to say about genetic research?