

Appendix E

Key Informant and Focus Group Moderator Guide

A. Introduction and Purpose

Welcome, and thank you for coming tonight.

My name is _____ and I work for the National Children's Study Orange County Vanguard Center. I will be moderating today's discussion.

The information we will be asking you to provide tonight will be a very important part of our preparation to conduct the National Children's Study in Orange County. We are hoping that you will give us candid, honest responses to what we share with you tonight. Every opinion is equally important. Together the information you give us will help us better understand what we will need to do to engage communities and individuals in the National Children's Study.

I want to give you a brief background on the National Children's Study before we begin. Children and families today are facing serious challenges to health and wellbeing that include asthma, infant mortality, obesity, diabetes, learning disabilities, and injuries. The purpose of the National Children's Study is to help understand how the chemical, physical, social, and family environments affect the health, growth, and development of children. We are also interested in how these environments interact with individual characteristics, such as genes, to prevent disease and promote health.

This study will involve 100,000 children and families followed over the course of 21 years. Those 100,000 families are in communities scattered all across the United States. In Orange County, 1250 children and families will be involved. The study will involve a large, representative sample of the nation's children, which means that it will include children from all socioeconomic, racial and ethnic groups. 15 neighborhoods in Orange County have been selected by chance to be included in the study. We will be asking all women who live in those neighborhoods to participate in the early part of the study, and we will ask the women who end up having a baby during the next 5 years to enroll themselves and their babies in the full study.

In spite of the fact that ALL communities and parents care deeply for the health and wellbeing of their children, when we ask women in the selected neighborhoods to participate, there will be some who will enthusiastically agree to participate and some who will not. We want to better understand the reasons that both motivate people to participate and the concerns that might cause them to hesitate or decide not to participate.

We have prepared a few questions to help guide our discussion. We will ask each of you to respond to the questions and to share your perspective. Our goal is not to reach consensus on issues, but rather to identify a range of opinions and ideas. This 90-minute focus group discussion will be audiorecorded and transcribed, although individuals will not be identified in the transcription.

B. Procedure

Before we begin, let me share some ground rules for our discussion today.

- *Our session will last an hour and a half.*
- *We ask that only one person talk at a time.*
- *I may call on you to ask you to share your perspective.*
- *Please turn off (or place on vibrate) your cell phones and pagers.*

C. Introduction/Transitional Question

Before we begin, I would like each of you to take 2-3 minutes to introduce yourself. Please tell the group:

- *Your name*
- *In about one sentence, briefly tell us what concerns related to child health and the environment are most important to you and your community?*

D. Questions

The moderator will provide more detail on the National Children Study recruitment and data collection requirements:

We will be asking women in selected neighborhoods to participate in this study. If she joins the study, we will schedule visits with her, her child, and the child's father (if she agrees) to collect information for the study.

There will be about 15 visits spread out over the 21 years. The information we collect at visits may vary, but will include interviews, ultrasounds, blood samples, and samples from the environment, such as dust in the home.

The initial visits will be at her home during her first 12 weeks of pregnancy. Two other visits during the course of her pregnancy will be at the clinic. When she gives birth, we will coordinate with her doctor to visit her and her baby in the hospital to get information about the birth and to examine and take pictures of the child.

When the baby is 6 months old and 12 months old, we will make another home visit. When the baby gets older, there will be about 1 visit every 2-3 years. Each visit will probably last about two to three hours and be conducted either at home or at the Vanguard Center. Between scheduled visits, we will contact the mother from time to time.

Now that you understand the basics about what participating in the study will entail, we would like to know how you would initially respond if you were invited to participate.

In a few months, interviewers are going to knock on doors of residents in the selected community.

The first questions address the different methods we might use to raise awareness and inform the community about the study.

1. *What materials would you like to see or receive before making your decision to participate?*
2. *Where do you get trusted information about services, programs, or events?*
(probe for information on distribution methods such as newsletters, church bulletins, flyers in community centers, newspapers, etc.)
3. *Who in the community might you ask for advice when considering whether or not to participate?*
(probe for community leaders, etc.)

The remaining questions address considerations involved in deciding whether or not to participate in the study.

4. *Would you feel more comfortable or more likely to participate if you were approached first in person or through a letter, phone call, or some other form of communication?*
5. *Who would you be more likely to listen to or feel more comfortable with?*
(e.g., probe for level of training, education, ethnic background, etc., of recruiter/enumerator)
6. *Families make decisions in different ways. Some people in families make decisions themselves, sometime one person makes all the decisions, and some families make decisions together. When approached and asked to participate, who in your family needs to be involved in the decision-making?*
7. *What would your initial response be if invited to participate in the study?*
 - a. *Are there certain aspects of involvement that would impact your decision to participate?*
(probe for any opinions about various aspects such as blood samples/genetics, travel to visits, etc.)
 - b. *What do you recommend we do to address those challenges in a way that would make you feel more comfortable participating?*

E. FINAL COMMENTS AND THANK YOU

Now the assistant moderator will summarize briefly the main opinions that were shared tonight. When she is done, I will ask you if this is a complete list, and you will have an opportunity to add to what she says.

[AFTER SUMMARY] *Did she leave off anything important?*

Thank you for taking the time to come here to be a part of this focus group. Your opinions will be an important part of our preparation for this important study. The assistant moderator will now distribute a brief demographic survey, which we ask that you complete before leaving the room. Your responses will help us make sure that we obtain a wide variety of opinions from a diverse group of people in Orange County.