

FOCUS GROUP SCRIPT:

Estimating the Benefits of Reduced Risks to Health

I. Overview

The purpose of the focus groups is to develop a stated preference survey to generate data for nonmarket valuation of selected health improvements. The broad objective of the study is to provide benefit estimates for selected health improvements at the national level. Factors that may affect household benefits include the severity of the health effect, the size of the improvements, and baseline health conditions. Early focus groups will involve discussion on participants' familiarity with the various health outcomes, perceptions of causes and consequences, and potential preventive interventions. The moderator will guide the conversation as needed, by asking questions regarding specific topics of interest. Data from early focus groups will be used to create information treatments and draft questions for later focus groups. In early focus groups, the discussion will largely focus on topics such as:

- Perceptions and familiarity with selected birth and neurodevelopmental outcomes. Which of the health outcomes are of most concern to participants? Do respondents have an emotional response to the endpoints that make it difficult to consider tradeoffs?
- Separability of health outcomes. Can participants distinguish between the outcomes in a meaningful way (preterm birth vs. low birth weight; ADHD vs. conduct disorder)? How are the dimensions of these outcomes (e.g., physical and neurological impacts, severity of impacts) best communicated, and over what time frame?
- Understanding essential scientific information. Do participants understand information regarding exposures to pollutants and the health outcomes? How do respondents react to interventions that can reduce exposure and mitigate risks?

We have provided a draft script for the initial focus groups below.

Several elements of the survey design, including but not limited to visual aids, informational text, and valuation questions will be tested in later focus groups. In addition, we plan to test various response formats (e.g., dichotomous choice, discrete choice experiment, and contingent ranking), selecting that which will provide more reliable responses. The selection of the response format, as with the other design elements of the survey instrument, will be informed and guided by the results of the focus groups.

As we conduct more focus groups we will eventually converge on a complete survey instrument that can be tested in final focus groups and cognitive interviews.

II. Discussion Guide for Initial Focus Groups

This guide provides a general framework to help structure the initial focus group discussions. Actual questions posed may deviate from those listed below depending on the direction of the discussion.

I. Background Information

A. Introductions and purpose

1. Introduce focus group participants

- a. State your first name and town where you live.
 - b. Briefly tell who lives in your household and if you have children, their ages.
 2. Purpose of focus group is to help develop a public opinion survey about the preferences and values for different health outcomes for infants and children.
- B. Ground rules
1. Session is being video-taped.
 2. Discussion is strictly confidential. No names will be used in reporting and no one will contact you regarding anything you say. No one will follow-up with you after the discussion in any way.
 3. Expect the session to last 2 hours.
 4. Want to hear from everyone. Important that everyone contribute; there are no right or wrong answers, we are simply asking your honest opinions about various topics.
 5. Important for people to speak one at a time and that you refrain from interrupting others. We ask that you respect the right of others to be heard and voice opinions that may differ from yours. Try not to let the group sway you in your opinion; say what you think.
 6. The moderator's job is to keep the discussion on task.
- C. We are going to talk about different topics related to birth outcomes and developmental outcomes in children. We recognize that these are sensitive topics and everyone has different experiences and opinions about causes, treatments, and impacts. There are no right or wrong answers and we are just trying to explore your thoughts in each of these areas. We want to hear from everyone so sometimes we will need to move to a new person or topic quickly.
- D. Questions?

II. Low birth weight and pre-term births

- Identify thoughts and experiences concerning these outcomes, including causes, consequences, and possible interventions
- Determine if low birth weight and pre-term birth can be considered separately or if people think about these outcomes together
- Consider the language people use to describe these outcomes; are people able to think about these outcomes in a neutral manner, or is this an emotionally charged area

The first area we want to explore with you is about health challenges that many newborns face. One is low birth weight, which means a baby weighs less than 5 ½ pounds when born. (That's 2500 grams if you prefer metric.) The average newborn in the US weighs 8 lbs. The other topic we want to discuss is pre-term birth, which is when a baby is born before 37 weeks of pregnancy. A full term birth occurs at 39 weeks.

Many times low birth weight and pre-term birth happen together, because a baby that is born early does not have as much time to grow to a normal weight. But low birth weight can happen in full-term babies. And babies who are pre-term may have birthweight that is normal for their age.

Low Birth Weight

Let's discuss these separately, starting with **low birth weight**. The average birthweight in the US is about 8 pounds, but anything greater than 5 lbs 8 ounces is still considered normal birthweight. Babies weighing less than this are considered to be low birth weight.

- Babies weighing less than 5lb 8 ounces (2500 grams) are **low birth weight**. Most low birthweight babies fall into this category.
 - Babies weighing less than 3 pounds 5 ounces (1500 grams) are considered to be **very low birthweight**
1. Have you ever heard or read about low birth weight as a health issue? Or have you known anyone who experienced having a child with low birthweight?
 2. What about low birth weight but that was not preterm?
 3. What are some concerns you might have or be aware of as a result of a baby being born with low birthweight? Areas to explore, if needed:
 - a. Immediate post-natal consequences/treatment, for mother and child
 - b. Concern for infant mortality
 - c. Effects during childhood: Do you think there might be effects or consequences that last into childhood? What kinds of effects?
 - d. Longer term effects
 4. What are some of the causes that you have heard of or are aware of for these effects?

Preterm birth (or prematurity)

Let's now talk about **pre-term or premature births**, which are babies born earlier than 37 weeks. Depending upon how early a baby is born he or she may be:

- Late preterm (34 – 36 weeks of pregnancy)
- Moderately preterm (32 – 34 weeks of pregnancy), or
- Extremely to very preterm (less than 32 weeks of pregnancy)

Late preterm babies who are born between 35 and 37 weeks gestation may not look premature. They may not be admitted to an intensive care unit, but they are still at risk for more problems than full-term babies.

Most premature babies are in the late preterm stage.

1. Have you ever heard or read about pre-term births as a health issue? Or have you known anyone who experienced having a child born preterm?
2. What are some concerns you might have or be aware of as a result of a baby being born preterm or premature? Do these differ by just how premature the baby is? Areas to explore, if needed:
 - a. Beliefs about immediate post-natal consequences/treatment, for mother and child
 - b. Concern for infant mortality
 - c. Effects during childhood: Do you think there might be effects or consequences that last into childhood? What kinds of effects?

- d. Longer term effects
3. What are some of the causes that you have heard of or are aware of for these effects?

III. ADHD

- Assess beliefs, knowledge, experiences concerning ADHD, including beliefs about prevalence, persistence, symptoms, consequences, treatments, causes, and possible preventive interventions.
- Identify thoughts and experiences concerning ADHD, including beliefs about causes, consequences and possible interventions.
- Consider the language people use to describe ADHD; are people able to think about this in a neutral manner, or is this an emotionally charged area

Next, we would like to discuss your thoughts and experiences with attention deficit hyperactivity disorder, or ADHD.

1. Have you ever heard or read about ADHD? Or have you known anyone who was diagnosed with ADHD?
2. Have you ever been told by a health care professional that you or one of your children have ADHD? Or have you had a teacher or school official suggest that one of your children be tested for ADHD or suspected that one of your children might have ADHD?
3. What comes to mind when you hear the term "ADHD"? What are symptoms, consequences, impacts on others, treatment/medication?
4. What do you think happens when a child has ADHD? Probe for beliefs about consequences, including
 - a. Falling behind normal development for age
 - b. Academic performance and conduct (e.g., in school)
 - c. Participation/performance in activities like sports, music, clubs

IV. Conduct disorder in children

- Assess how people think about conduct disorder in children
- Beliefs about causes, consequences and possible interventions
- Identify thoughts and experiences concerning conduct disorder, including beliefs about causes, consequences and possible interventions.
- Consider the language people use to describe conduct disorder; are people able to think about this in a neutral manner, or is this an emotionally charged area

Finally, we would like to turn to other problem behaviors in children, namely conduct disorder.

1. Have you ever heard or read about conduct disorders? Or have you known anyone who was diagnosed with conduct disorders?
2. Have you ever been told by a health care professional that one of your children has conduct disorders? Or have you had a teacher or school official suggest that one of your children be tested for conduct disorders? Or have you suspected that one of your children might have conduct disorders?

3. What comes to mind when you hear the term “conduct disorder”? PROBE for symptoms, consequences, impacts on others, treatment/medication.
4. What do you think happens when a child has conduct disorder? Probe, if needed:
 - d. Falling behind normal development for age.
 - e. Academic performance and conduct (e.g., in school)
 - f. Participation/performance in activities like sports, music, clubs.
 - g. Relationships with other people
 - h. Learning disabilities, anxiety, depression