

Stated Preference HEALTH VALUATION SURVEY

Draft Script for Initial Focus Groups.

- 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 4 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. Initial exploration of beliefs about low birth weight and pre-term births.

Purpose: Assess beliefs and experiences concerning these outcomes, including beliefs about causes, consequences and possible interventions.

The first area we want to explore is low-birth weight and pre-term births. Let's talk about a couple of 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 either low birth weight or pre-term birth can happen without the other.

1. What are some concerns you might have or be aware of as a result of a baby being born:
 - a. Pre-term?
 - b. With low birth weight?
 - c. PROBE for beliefs about immediate post-natal consequences/treatment, for mother and child. Impact on family. How serious are these problems?
 - d. Probe for longer term - Are there longer-lasting consequences? What kinds of consequences?

2. Do you consider this a frequent problem for births in the US? You might think about pre-term and low birth weight in terms of how often it happens for every 100 births.
 - a. For pre-term?
 - b. For low birth weight?
 - c. If necessary, assist. Do you think more than 50 of 100 babies are born pre-term/low birth weight, or fewer than 50 of 100? More than 25 in 100, or fewer? Etc.

3. What are some of the causes that you have heard of or are aware of for these effects? PROBE as necessary:
 - a. Do you think genetic background plays a role?
 - b. Health of the mother before pregnancy? During pregnancy?
 - c. Exposure to substances that we can control, like food, smoking?
 - d. Exposure to substances we have less control over, like things in the environment, water we drink, air we breathe?
 - e. Exposures at home or work or school? Any specific substances?

4. What do you think could be done to improve the health of newborns? PROBE as necessary:
 - a. Are there any actions a pregnant woman can take to improve chances of delivering a baby with normal birth weight at full term? What actions?
 - b. What about doctors or other health care professionals? Are there things they could do so that more newborns are born with normal birth weight at full term? What could they do?
 - c. How about the government? Is there anything the government could do to improve chances for babies to be born with normal birth weight at full term?

III. Initial exploration of beliefs about birth outcomes.

Purpose: Assess how people define healthy/unhealthy birth outcomes; their beliefs about causes, consequences and possible interventions.

Introduction: Next, we'd like to talk about other aspects of the health of an infant at birth. We'll talk about what comes to your mind when we say "health at birth", what it means to you, and what you think might affect a healthy birth versus a birth outcome that is unhealthy. There are no right or wrong answers. We recognize that your personal experiences and those of your family and friends will affect your thoughts. We are trying to learn what people think about when they hear about the health of an infant at birth, potential causes of adverse outcomes, and treatments.

1. Please think about a healthy newborn. What does that mean from your point of view?
2. Now think about what it means if a newborn baby is not perfectly healthy? What comes to mind?
 - a. Immediate concerns?
 - b. Long-term concerns?
3. What do you think are some of the causes of adverse birth outcomes? ? PROBE as necessary:
 - a. Do you think genetic background plays a role?
 - b. Health of the mother before pregnancy? During pregnancy?
 - c. Exposure to substances that we can control, like food, smoking?
 - d. Exposure to substances we have less control over, like things in the environment, water we drink, air we breathe?
 - e. Exposures at home or work or school? Any specific substances?
4. What do you think could be done to improve the health of newborns and birth outcomes? PROBE as necessary:
 - a. Are there any actions a woman can take to improve chances of delivering a healthy newborn? What actions?
 - b. What about doctors or other health care professionals? Are there things they could do so that more newborns are born without health problems or complications? What could they do?
 - c. How about the government? Is there anything the government could do to improve chances for babies to be born without health problems?

IV. Initial exploration of beliefs about some neuro-developmental disorders. Example: ADHD.

Purpose: Assess beliefs and experiences concerning these outcomes, including beliefs about causes, consequences and possible interventions.

Next, we would like to discuss your thoughts and experiences with neuro-developmental disorders in children. These include problems in the brain or nervous system that affect

things like learning ability, emotion, or self-control as a child develops. These disorders usually appear in early childhood, before a child enters grade school and can impair personal, social, and academic function. Examples include ADHD, autism spectrum disorder, language or speech disorders.

1. Please think about a baby that goes through childhood without any neurodevelopmental disorders. What does that mean from your point of view?
2. Now think about what it would mean for a child or baby to go on to have some kind of neurodevelopmental disorders. What does that mean from your point of view?

Let's talk about a specific neurodevelopmental disorder that children may experience during childhood. "ADHD," or attention deficit/hyperactivity disorder, is a brain disorder usually diagnosed during elementary school.

People with ADHD often have trouble paying attention and staying focused, organized and on-task; they may show hyperactivity by moving about a lot, fidgeting or talking excessively even when it is not appropriate; and they may make impulsive decisions without first thinking about possible consequences.

3. Have you ever...
 - a. Heard or read about neurodevelopmental disorders? Which ones in particular? (Prompt with examples if needed)
 - b. Known anyone who was diagnosed with neurodevelopmental disorders?
 - c. Been told by a health care professional that you have a neurodevelopmental disorder?
 - d. Been told by a health care professional that one of your children has a neurodevelopmental disorder?
 - e. Suspected that one of your children might have a neurodevelopmental disorder?
4. How widespread do you think neurodevelopmental disorders are among children in the U.S.? You might think of this as out of 100 12 year-old kids, how many do you think have been diagnosed with a neurodevelopmental disorder?
 - a. If necessary, assist. Do you think it's more or less than 50 of 100? More than 25 in 100, or fewer? Etc.
 - b. Were you thinking of any specific neurodevelopmental disorders?
5. What do you think happens when a child has a neurodevelopmental disorder? [Probe for any beliefs about any consequences, including:]
 - a. Falling behind normal development for age.
 - b. Academic performance
 - c. Conduct, e.g., in school
 - d. Participation/performance in activities like sports, music, clubs.

- e. Relationships with other people.
 - f. Learning disabilities, conduct disorder, anxiety, depression.
6. What about treatment for children with neurodevelopmental disorders?
- a. Is there a cure?
 - b. Do kids outgrow them? Learn to deal with them?
 - c. Are they treated with medications? Are the medications effective? What about side effects?
 - d. Psychotherapy?
5. Why do you think some children have neurodevelopmental disorders? PROBE as necessary:
- a. Do you think genetic background plays a role?
 - b. Health of the mother before pregnancy? During pregnancy?
 - c. Exposure to substances that we can control, like food, smoking?
 - d. Exposure to substances we have less control over, like things in the environment, water we drink, air we breathe?
 - e. Exposures at home or work or school? Any specific substances?
6. What do you think could be done to reduce the chances that children have neurodevelopmental disorders? PROBE as necessary:
- a. Are there any actions a mother/a parent can take to reduce chances that a child gets neurodevelopmental disorders? What actions?
 - b. What about doctors or other health care professionals? Are there things they could do so that fewer children have neurodevelopmental disorders? What could they do?
 - c. How about the government? Is there anything the government could do to reduce neurodevelopmental disorders in children?
 - d. Do you think these actions differ according to the disorder?

- V. Initial exploration of beliefs about mental health/behavioral problems in children.
Purpose: Assess how people think about children's mental health or behavior problems; beliefs about causes, consequences and possible interventions.

Introduction: Finally, we would like to turn to other behavioral effects and mental health concerns in children. We will first talk about very young children – before school age. And then we'll talk about older children – school age. Again, there are no right or wrong answers and we know that everyone will have different thoughts and experiences with this topic. We'd like to hear from everyone.

1. Please think about a baby and young child, under age 5, without any behavioral problems or mental health concerns. What does that mean from your point of view?

2. Now think about what it means to have a baby and young child that has some type of behavioral or mental health concerns? What does this mean in terms of day-to-day life? Medical or other professional intervention? Interactions with friends and family?
3. Why do you think some children have mental health or behavior problems, while others do not? PROBE as necessary:
 - a. Do you think genetic background plays a role?
 - b. Health of the mother before pregnancy? During pregnancy?
 - c. Exposure to substances that we can control, like food, smoking?
 - d. Exposure to substances we have less control over, like things in the environment, water we drink, air we breathe?
 - e. Exposures at home or work or school? Any specific substances?
4. What do you think could be done to reduce the chances that children have mental health or behavior problems? PROBE as necessary:
 - a. Are there any actions a mother/a parent can take to reduce chances that their children have mental health or behavior problems? What actions?
 - b. What about doctors or other health care professionals? Are there things they could do so that fewer children have mental health or behavior problems? What could they do?
 - c. How about the government? Is there anything the government could do to reduce mental health or behavior problems in children?