

Public reporting burden for this collection of information is estimated to average 10 minutes, including completing and reviewing the collection of information. An agency may not conduct or sponsor and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS H21-8, Atlanta, GA 30333: ATTN: PRA (0920-1433).

#### Appendix B CHD FG Screening Tool

## INDIVIDUALS WITH CONGENITAL HEART DEFECTS: Focus Group Participant Screener

**NOTE: TEXT IN BOLD IS PRORAMMING LANGUAGE AND WILL NOT BE VISIBLE TO PARTICIPANTS VIEWING THE SCREENER SURVEY**

You indicated that you are interested in participating in a focus group held online using a tablet, laptop, or desktop computer. The sole sponsor of this activity is the Centers for Disease Control and Prevention (CDC).

To start, we will ask you a few questions about yourself.

**IF TERMINATED:** Thank you for completing this survey. Based on your responses, we have determined that you are not eligible to participate in the focus group. We greatly appreciate the time you took to answer these questions and thank you for your participation in CH STRONG.

### Demographic Information

These first questions ask for some general information about you.

1. What is your age?
  - a. [numeric entry field] **TERMINATE IF < 18**
2. What is your preferred language of communication? (This will not affect your eligibility to participate in the focus group.)
  - a. English
  - b. Spanish
  - c. Other (please specify): [text entry]
3. Are you comfortable participating in a 90-minute focus group where the discussion will take place in English?
  - a. Yes
  - b. No **TERMINATE**

### CHD Care

The following questions will ask about your heart defect and use of healthcare.

4. When was the last time you visited the office of any general health care provider, such as a doctor, nurse, or physician assistant, for any reason pertaining to your health? Do not include dentists.
- a. Less than 6 months ago
  - b. 6 months to 11 months ago
  - c. 1 to 2 years ago
  - d. 3 to 5 years ago
  - e. More than 5 years ago
  - f. Never
  - g. Don't know or can't remember
5. When was the last time you saw a cardiac specialist or healthcare provider who specializes in cardiac care or care of your heart? For example, this could be a visit to a cardiology clinic to see a doctor known as a cardiologist, or might also be a nurse, or physician assistant that specializes in cardiac care.
- a. Less than 6 months ago
  - b. 6 months to 11 months ago
  - c. 1 to 2 years ago
  - d. 3 to 5 years ago
  - e. More than 5 years ago
  - f. Never **TERMINATE**
  - g. Don't know or can't remember **TERMINATE**

**IF Q5 = a, b, OR c, CODE RESPONDENTS AS "RECENTLY IN CARE"**

**IF Q5 = d OR e, CODE RESPONDENTS AS "NOT RECENTLY IN CARE"**

6. **IF Q5 = a, b, c** What is the longest stretch of time you have gone without seeing a cardiac specialist or healthcare provider who specializes in cardiac care or care of your heart?
- a. Less than 6 months **TERMINATE**
  - b. 6 months to 11 months **TERMINATE**
  - c. 1 to 2 years **TERMINATE**
  - d. 3 to 5 years
  - e. More than 5 years
  - f. Don't know or can't remember **TERMINATE**
7. What type of heart defect(s) were you born with? (Select all that apply.)
- a. Aortic valve stenosis
  - b. Atrial Septal Defect (ASD)
  - c. Atrioventricular Septal Defect (AVSD) or Atrioventricular canal (AV canal)
  - d. Bicuspid aortic valve
  - e. Coarctation of the Aorta
  - f. Double-outlet Right Ventricle
  - g. Ebstein Anomaly
  - h. Hypoplastic Left Heart Syndrome (HLHS)
  - i. Interrupted Aortic Arch
  - j. Pulmonary Atresia
  - k. Pulmonary valve stenosis

- l. Single Ventricle (double inlet left ventricle)
- m. Tetralogy of Fallot
- n. Transposition of the Great Arteries (DTGA or TGA)
- o. Total Anomalous Pulmonary Venous Return
- p. Tricuspid Atresia
- q. Truncus Arteriosus
- r. Ventricular Septal Defect
- s. Other (please specify):
- t. Don't know
- u. Prefer not to say

Additional Demographic Information

- 8. What is your sex? **RECRUIT A MIX**
  - a. Female
  - b. Male
- 9. What is your ethnicity?
  - a. Hispanic or Latino
  - b. Not Hispanic or Latino
- 10. What is your race? (Select all that apply) **RECRUIT A MIX**
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian or other Pacific Islander
  - e. White
- 11. Do you have health insurance or some other kind of healthcare plan?
  - a. Yes
  - b. No
  - c. Don't know
- 12. **IF YES TO Q10** If yes, which type of health insurance do you have? (Select all that apply.)
  - a. Medicaid
  - b. Medicare
  - c. Private (employer, marketplace, individual)
  - d. Military/TRICARE/VA
  - e. Other (please specify): [text entry field]
  - f. Don't know
  - g. Prefer not to answer
- 13. What state do you live in? [dropdown menu of states] **RECODE INTO FOUR US REGIONS**
- 14. What type of area do you live in? **RECRUIT A MIX**
  - a. Rural
  - b. Suburban
  - c. Urban

- d. Prefer not to answer

15. Which of the following categories best describes your current employment status? **RECRUIT A MIX**

- a. Employed, working full-time
- b. Employed, working part-time
- c. Not employed, looking for work
- d. Not employed, NOT looking for work
- e. Disabled, not able to work
- f. Student
- g. Retired
- h. Other (please specify): [text entry field]
- i. Prefer not to answer

16. Including yourself, how many people living in your household are the following ages?

- a. There are [numeric text box] people living in my household that are under the age of 18.
- b. There are [numeric text box] people living in my household that are 18 years of age or older.
- c. Prefer not to answer

17. Which of the following best describes your annual household income?

- a. Under \$15,000
- b. \$15,000 - \$24,999
- c. \$25,000 - \$49,999
- d. \$50,000 - \$74,999
- e. \$75,000 - \$99,999
- f. \$100,000 - \$149,999
- g. \$150,000 or greater
- h. Don't know
- i. Prefer not to answer

18. What is the highest level of school you have completed? **RECRUIT A MIX**

- a. Less than high school diploma
- b. High school diploma or equivalent (e.g., GED)
- c. Some college but no degree
- d. Associate or 2-year degree
- e. Bachelor's or 4-year degree
- f. Graduate degree (e.g., MS, PhD, JD, MD, etc.)
- g. Prefer not to answer

#### Focus Group Discussion Participation

19. Would you be interested in participating in a 90-minute online focus group? You will receive \$75 as a token of appreciation for your participation, which will be provided to you after the completion of the focus group.

- a. Yes
- b. No **TERMINATE**

20. Thank you for completing the survey. Based on your responses, we have determined that you may be eligible to participate in the focus groups. If you are selected to participate, we will reach out via email to provide more information and determine your availability.
- a. Please enter your name [text entry field]
  - b. Please provide the best email address to reach you if you are selected to participate in the focus group. [text entry field]
  - c. What is the best phone number to reach you? [numeric entry field]

Thank you for completing the survey. We greatly appreciate the time you took to answer these questions and for your participation.