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Appendix B MD FG Screening Tool

INDIVIDUALS/CAREGIVERS OF INDIVIDUALS WITH MUSCULAR DYSTROPHY: Focus Group Participant Screener

NOTE: TEXT IN BOLD IS PROGRAMMING LANGUAGE 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. This information will not be associated with your name or other identifying information and will not be shared with CDC.

IF TERMINATED: Thank you for completing the screener. Based on your responses, we have determined that you are not eligible to participate in the focus groups. We greatly appreciate the time you took to complete these questions.

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? (Note that 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**

4. Have you been diagnosed with any of the following conditions? **RANDOMIZE**
 - a. Muscular dystrophy **CODE AS INDIVIDUAL**
 - b. Spina bifida
 - c. Down syndrome
 - d. Hemophilia
 - e. Cleft lip/palate
 - f. Tay-Sachs disease
 - g. Congenital heart defects
 - h. None of the above

5. **IF Q4 ≠ A** Are you the primary caregiver for another person or child?
 - a. Yes
 - b. No **TERMINATE**

6. **IF Q5 = A** Has the person or child you care for been diagnosed with any of the following conditions? **RANDOMIZE, TERMINATE IF MD NOT SELECTED**
 - a. Muscular dystrophy **CODE AS CAREGIVER**
 - b. Spina bifida
 - c. Down syndrome
 - d. Hemophilia
 - e. Cleft lip/palate
 - f. Tay-Sachs disease
 - g. Congenital heart defects
 - h. None of the above
 - i. Not a caregiver

7. **IF CAREGIVER** What is your household member's age?
 - a. 0-17 years
 - b. 18 or older **TERMINATE**

Healthcare (IF INDIVIDUAL)

The following questions will ask about muscular dystrophy and use of healthcare.

8. What type of muscular dystrophy do you have? (Select all that apply.)
 - a. Becker muscular dystrophy **CODE AS DBMD**
 - b. Duchenne muscular dystrophy **CODE AS DBMD**

- c. Facioscapulohumeral dystrophy **CODE AS FSHD**
 - d. Limb-girdle muscular dystrophy **CODE AS LGMD**
 - e. Myotonic dystrophy **CODE AS DM**
 - f. Congenital or juvenile onset myotonic dystrophy **CODE AS DM**
 - g. Congenital muscular dystrophy **CODE AS CMD**
 - h. Other type (please specify): [text entry]
 - i. Don't know
9. How old were you when a healthcare provider told you that you have muscular dystrophy?
- a. [numeric entry field]
 - b. Don't know
10. When was the last time you visited the office of any health care provider such as a doctor, nurse, or physician assistant, for any reason related to your health? Do not include dentists.
- a. Less than 6 months ago
 - b. 6 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
11. When did you last receive health care for muscular dystrophy?
- a. Less than 6 months ago
 - b. 6 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
12. On a scale of 1 to 5 (with 5 being excellent and 1 being poor) how would you rate your overall health over the last week? **INCLUDE SCALE 1-5 (1=POOR, 5=EXCELLENT)**

Healthcare (IF CAREGIVER)

The following questions will ask about muscular dystrophy and use of healthcare. These questions refer to the person you care for, sometimes referred to as "care recipient" or "they."

13. What type of muscular dystrophy does the person you care for have? (Select all that apply.)
- a. Becker muscular dystrophy **CODE AS DBMD**
 - b. Duchenne muscular dystrophy **CODE AS DBMD**
 - c. Facioscapulohumeral dystrophy **CODE AS FSHD**

- d. Limb-girdle muscular dystrophy **CODE AS LGMD**
 - e. Myotonic dystrophy **CODE AS DM**
 - f. Congenital or juvenile onset myotonic dystrophy **CODE AS DM**
 - g. Congenital muscular dystrophy **CODE AS CMD**
 - h. Other type (please specify): [text entry]
 - i. Don't know
14. How old was the person you care for when a healthcare provider told them that they have muscular dystrophy?
- a. [numeric entry field]
 - b. Don't know
15. When was the last time your care recipient visited the office of any health care provider such as a doctor, nurse, or physician assistant, for any reason related to their health? Do not include dentists.
- a. Less than 6 months ago
 - b. 6 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
16. When did the person you care for last receive health care for muscular dystrophy?
- a. Less than 6 months ago
 - b. 6 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
17. On a scale of 1 to 5 (with 5 being excellent and 1 being poor) how would you rate the overall health of the person you care for over the last week? **INCLUDE SCALE 1-5 (1=POOR, 5=EXCELLENT)**

Additional Demographic Information

The following questions will ask for some more information about you.

18. What is your sex? **RECRUIT A MIX**
- a. Female
 - b. Male

19. What is your ethnicity?

- a. Hispanic or Latino
- b. Not Hispanic or Latino

20. 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

21A. **IF INDIVIDUAL:** Are you covered by health insurance or some other kind of healthcare plan?

- a. Yes
- b. No
- c. Don't know

21B. **IF CAREGIVER:** Is the person you care for covered by health insurance or some other kind of healthcare plan?

- a. Yes
- b. No
- c. Don't know

22A. **IF Q21A = A** Which type of health insurance are you covered by? Select all that apply.

- a. Medicaid
- b. Medicare
- c. Private (employer, marketplace, individual)
- d. Military/TRICARE/VA
- e. Other, please describe [TEXT FIELD]
- f. Don't know
- g. Prefer not to answer

22B. **IF Q21B = A** What type of health insurance is the person you care for covered by?

- a. Medicaid
- b. Medicare
- c. Private (employer, marketplace, individual)
- d. Military/TRICARE/VA
- e. Other, please describe [TEXT FIELD]
- f. Don't know
- g. Prefer not to answer

22. What state do you reside in?

- a. [Dropdown list of states] **RECODE INTO FOUR US REGIONS**
23. What type of area do you live in? **RECRUIT A MIX**
- a. Rural
 - b. Suburban
 - c. Urban
 - d. Prefer not to answer
24. Which of the following categories best describes your 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]
 - i. Prefer not to answer
25. Including yourself, how many people living in your household are the following ages? **IF CAREGIVER:** If you do not live in the same household as the person you care for, say so.
- a. There are [Numeric text field] people living in my household that are under the age of 18.
 - b. There are [Numeric text field] people living in my household that are 18 years of age or older.
 - c. I do not live in the same household as the person I care for.
 - d. Prefer not to answer
26. 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
27. What is the highest level of education 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 participation

28. 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**

29. Thank you for completing this 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 and phone number 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 this survey. We greatly appreciate the time you took to answer these questions.