**INDIVIDUALS/CAREGIVERS OF INDIVIDUALS WITH SPINA BIFIDA: 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

This section is for basic demographic information about yourself.

1. What is your age?
2. [numeric entry field] **TERMINATE IF < 18**
3. What is your preferred language of communication? (Note that this will not affect your eligibility to participate in the focus group)
   1. English
   2. Spanish
   3. Other (please specify): [text entry]
   4. Prefer not to answer
4. Are you comfortable participating in a 90-minute focus group where the discussion will take place in English?
   1. Yes
   2. NoTERMINATE
5. Have you been diagnosed with any of the following conditions? **RANDOMIZE**
   1. Spina bifida **CODE AS INDIVIDUAL**
   2. Muscular dystrophy
   3. Down syndrome
   4. Hemophilia
   5. Cleft lip/palate
   6. Tay-Sachs disease
   7. Congenital heart defects
   8. None of the above
6. **ASK IF NOT AN INDIVIDUAL WITH SB** Are you the primary caregiver for another person or child?
7. Yes
8. No **TERMINATE**
9. Has the person or child you care for been diagnosed with any of the following conditions? **RANDOMIZE, TERMINATE IF SB NOT SELECTED**
   1. Spina bifida **CONTINUE,** **CODE AS CAREGIVER**
   2. Muscular dystrophy
   3. Down syndrome
   4. Hemophilia
   5. Cleft lip/palate
   6. Tay-Sachs disease
   7. Congenital heart defects
   8. None of the above
   9. Not a caregiver

# Healthcare (IF INDIVIDUAL)

The following questions will ask about spina bifida.

1. What type of spina bifida do you have?
2. Spina bifida occulta **TERMINATE**
3. Non-myelomeningocele (such as lipomyelomeningocele, meningocele, fatty filum, terminal myelocystocele, or split cord malformation)
4. Myelomeningocele
5. Don’t know **TERMINATE**
6. Do you have a shunt?
7. Yes
8. No
9. Don't know
10. Other (please specify): [text entry]
11. What is your lesion level? The greatest level of voluntary movement is described in parentheses.
12. Thoracic (I can control the trunk of my body but not my legs)
13. High lumbar (I can control the trunk of my body and can move my thigh towards the trunk of my body)
14. Mid lumbar (I can control the trunk of my body and can straighten my leg)
15. Low lumbar (I can control the trunk of my body, can straighten my leg, and can flex my foot)
16. Sacral (I can control the trunk of my body, can straighten my leg, can flex my foot, and can point my toes)
17. Don’t know
18. Not applicable
19. Other (please specify): [text entry]
20. Do you need a device to help you get around when you leave the house, for example to go to the grocery store? (Select all that apply.)
    1. Crutches
    2. Wheelchair
    3. Braces
    4. Walkers
    5. Other (please specify): [text entry]
    6. No aid(s) needed
21. At what age did you become fully independent in your bladder care?
    1. [numeric entry] years
    2. I am not fully independent in bladder care.
    3. I was fully independent, but things have changed, and I am no longer fully independent with bladder care.
    4. I have had surgery that excludes my need for bladder care (for example, a urostomy or suprapubic tube).
    5. Don’t know
22. When was the last time you received healthcare for spina bifida?
23. Less than 6 months ago
24. 6 to 11 months ago
25. 1 to 2 years ago
26. 3 to 5 years ago
27. More than 5 years ago
28. Never
29. Don’t know or can’t remember

# Healthcare (IF CAREGIVER)

The following questions will ask about spina bifida. These questions refer to the person you care for, sometimes referred to as “your care recipient” or “they.”

1. What type of spina bifida does the person you care for have?
2. Spina bifida occulta **TERMINATE**
3. Non-myelomeningocele (such as lipomyelomeningocele, meningocele, fatty filum, terminal myelocystocele, or split cord malformation)
4. Myelomeningocele
5. Don’t know **TERMINATE**
6. How old is the person you care for?
7. 0-17 years
8. Eighteen or older
9. Does the person you care for have a shunt?
10. Yes
11. No
12. Don't know
13. Other (please specify): [text entry]
14. What is your care recipient's] lesion level? The greatest level of voluntary movement is described in parentheses.
15. Thoracic (I can control the trunk of my body but not my legs)
16. High lumbar (I can control the trunk of my body and can move my thigh towards the trunk of my body)
17. Mid lumbar (I can control the trunk of my body and can straighten my leg)
18. Low lumbar (I can control the trunk of my body, can straighten my leg, and can flex my foot)
19. Sacral (I can control the trunk of my body, can straighten my leg, can flex my foot, and can point my toes)
20. Don’t know
21. Not applicable
22. Other (please specify): [text entry]
23. Does your care recipient need a device to help them get around when they leave the house, for example to go to the grocery store? (Select all that apply.)
24. Crutches
25. Wheelchair
26. Braces
27. Walkers
28. Other (please specify): [text entry]
29. No aid(s) needed
30. At what age did your care recipient become fully independent in their bladder care?
    1. [numeric entry] years
    2. They are not fully independent in bladder care.
    3. They were fully independent, but things have changed, and they are no longer fully independent with bladder care.
    4. They have had surgery that excludes their need for bladder care (for example, a urostomy or suprapubic tube)
    5. Don’t know
31. When did the person you care for last receive healthcare for spina bifida?
32. Less than 6 months ago
33. 6 months to 11 months ago
34. 1 to 2 years ago
35. 3 to 5 years ago
36. More than 5 years ago
37. Never
38. Don’t know or can’t remember

# Additional Demographic information

1. How do you currently describe yourself? (Select all that apply) **RECRUIT A MIX**
2. Female
3. Male
4. Transgender
5. I use a different term [text entry field]
6. What is your ethnicity?
7. Hispanic or Latino
8. Not Hispanic or Latino
9. What is your race? (Select all that apply.) **RECRUIT A MIX**
10. American Indian or Alaska Native
11. Asian
12. Black or African American
13. Native Hawaiian or other Paciﬁc Islander
14. White

23A. **IF INDIVIDUAL**: Are you covered by health insurance or some other kind of health care plan?

1. Yes
2. No
3. Don’t know
4. Prefer not to answer

23B. **IF CAREGIVER**: Is the person you care for covered by health insurance or some other kind of health care plan?

1. Yes
2. No
3. Don’t know
4. Prefer not to answer

24A**. IF 23A = A** Which type of health insurance are you covered by? (Select all that apply.)

* 1. Medicaid
  2. Medicare
  3. Private (employer, marketplace, individual)
  4. Military/TRICARE/VA
  5. Other (please specify): [text entry]
  6. Don’t know
  7. Prefer not to answer

24B. **IF 23B = A** Which type of health insurance is your care recipient covered by? (Select all that apply.)

1. Medicaid
2. Medicare
3. Private (employer, marketplace, individual)
4. Military/TRICARE/VA
5. Other (please specify): [text entry]
6. Don’t know
7. Prefer not to answer
8. What state do you reside in?
   1. [Dropdown list of states] **RECODE INTO FOUR US REGIONS**
9. Which type of area do you live in? **RECRUIT A MIX**
10. Rural
11. Suburban
12. Urban
13. Prefer not to answer
14. Which of the following categories best describes your employment status? **RECRUIT A MIX**
15. Employed, working full-time
16. Employed, working part-time
17. Not employed, looking for work
18. Not employed, NOT looking for work
19. Disabled, not able to work
20. Student
21. Retired
22. Other (please specify): [text entry]
23. Prefer not to answer
24. 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.
    1. There are [Numeric text field] people living in my household that are under the age of 18.
    2. There are [Numeric text field] people living in my household that are 18 years of age or older.
    3. I do not live in the same household as the person I care for.
    4. Prefer not to answer
25. Which of the following best describes your annual household income?
26. Under $15,000
27. $15,000 – $24,999
28. $25,000 - $34,999
29. $35,000 - $49,999
30. $50,000 - $74,999
31. $75,000 - $99,999
32. $100,000 - $149,000
33. $150,000 or greater
34. Don’t know
35. Prefer not to answer
36. What is the highest level of education you have completed? **RECRUIT A MIX**
37. Less than high school diploma
38. High school diploma or equivalent (e.g., GED)
39. Some college but no degree
40. Associate or 2-year degree
41. Bachelor or 4-year degree
42. Graduate degree (e.g., MS, PhD, JD, MD, etc.)
43. Prefer not to answer

# Focus group participation

1. Would you be interested in participating in a 90-minute virtual focus group discussion? 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.
   1. Yes
   2. No **TERMINATE**
2. Thanks for completing the screener. 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.
   1. Please enter your name. [text entry field]
   2. Please provide the best email address and phone number to reach you at if you are selected to participate in the focus group. [text entry field]
   3. 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.