



Women Living with Muscular Dystrophy Survey

Instructions for Telephone Interviews

Overview

This telephone interview script is provided to assist interviewers when a respondent requests to do the interview by phone. The script asks the questions so that the interview flows smoothly. Please read and complete preparation steps before calling the participant. Make sure you have a good understanding of how to use this document. You should complete at least one mock phone interview prior to calling any participants. Because this phone survey does not have automated skip patterns, it requires careful attention to detail, and that interviewers are familiar with the survey.

Who can respond on the phone to the survey?

Do not conduct the survey with a proxy. *An individual may assist the participant by repeating questions or with translation of the survey -- but only the participant may provide answers to the survey.*

General Interviewing Conventions and Instructions

- There are two versions of the survey: one for males and one for females. At the bottom of the pages you will a M for males and an F for females next to the page number. Make sure you have the correct version before you call the participant.
- Before you do anything else, write the participant's ID number at the bottom of every page.
- The survey introduction script and questions must be read verbatim
- Always read the text in the survey. Reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts.
- Practice pronouncing the participant's name before initiating the call
- All questions and all answer categories must be read exactly as they are worded
 - o During the course of the survey, the use of **neutral** acknowledgment words such as the following is permitted:
 - Thank you
 - Alright
 - Okay
 - I understand, or I see
 - Yes, Ma'am
 - Yes, Sir

Public reporting burden of this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and 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 D-74, Atlanta, Georgia 30333; Attn: OMB-PRA (0920-New)

- Adjust the pace of the survey interview to be conducive to the needs of the respondent
- No changes are permitted to the order of the survey
- No changes are permitted to the order of the answer categories for the questions
- All transitional phrases must be read
- Instructions to go to the next question must NOT be read. For example, do not read “→ **Go to question 52**”. Simply go to that question and continue survey.
- MISSING/DON'T KNOW (DK) response options are not read. If a participant is unable to provide a response for a given question (or refuses to provide a response), you mark the appropriate response and proceed to the next question
- Be prepared to probe if the participant answers outside of the answer categories provided. Probe by repeating the answer categories only; do not interpret for the participant.
- Pay attention to skip patterns.
- There are some open text responses. Do your best to capture the respondent's answer in the available space. If the person states more than you can fit, you can take notes on an additional piece of paper or the back of the survey packet. In these cases, please clearly indicate the question number. You can also tell the participant you only have limited space to record the answer, if necessary.
 - o Example: If person speaking more than 2-3 minutes, you can say “Thank you, I have recorded what you have provided. I have a limited amount of space for this answer. Can we move on to the next question?”

Recording

If the participant agrees, the survey will be recorded for quality control purposes. Make sure you are familiar with the recording function from your zoom phone, such as knowing how to start and stop a recording and where the audio file will be saved. Do not start recording until or if the participant agrees. Follow all relevant privacy, data security, and IRB requirements with the storage, transmission, and deletion of survey data on audio files.

Scripts

Before starting, identify which script you will need:

- **Initiating Contact**
- **Call back to complete a previously started survey**

Make sure to have the necessary information to fill in the content of these scripts (participant gender, name, and age).

If the person asks to finish the survey later, you will need to use the script for:

- **Setting call back time when completing survey**

For all scripts, please note:

- All text that appears in lowercase letters must be read out loud
- Text in UPPERCASE letters must not be read out loud

- o However, YES and NO response options are to be read if necessary

INITIATING CONTACT

START Hello, may I please speak to [PARTICIPANT NAME]?

OPTIONAL START:

Hello, my name is [INTERVIEWER NAME], may I please speak to [PARTICIPANT NAME]?

<1> YES → Go to INTRODUCTION

This is [INTERVIEWER NAME] calling from the <Site> MD STARnet program at <grantee organization>. The MD STARnet program is funded by the Centers for Disease Control and Prevention. You have asked for assistance with completion of our survey. May we complete the survey together now?

<2> NO [REFUSAL]

<3> NO, NOT AVAILABLE RIGHT NOW → Go to SETTING CALLBACK TIME WHILE COMPLETING A SURVEY

IF ASKED WHO IS CALLING:

This is [INTERVIEWER NAME] calling from the <Site> MD STARnet program at <grantee organization>. The MD STARnet program is funded by the Centers for Disease Control and Prevention. We are conducting a survey about people's experiences living with muscular dystrophy. Is [PARTICIPANT NAME] available?

IF ASKED WHETHER PERSON CAN SERVE AS PROXY FOR SAMPLED PARTICIPANT:

For this survey, we need to speak directly to [PARTICIPANT NAME]. Is [PARTICIPANT NAME] available?

IF THE SAMPLED PARTICIPANT IS NOT AVAILABLE:

Can you tell me a convenient time to call back to speak with (him/her)?

IF THE SAMPLED PARTICIPANT SAYS THIS IS NOT A GOOD TIME:

If you don't have the time now, when is a more convenient time to call you back?

IF ASKED IF YOU WOULD LIKE TO SPEAK TO "SR." OR "JR.":

I would like to speak with [PARTICIPANT NAME] who is approximately [AGE RANGE]. Is that person available?

IF SOMEONE OTHER THAN THE SAMPLED PARTICIPANT ANSWERS THE PHONE RECONFIRM THAT YOU ARE SPEAKING WITH THE SAMPLED PARTICIPANT WHEN HE OR SHE PICKS UP.

CALL BACK TO COMPLETE A PREVIOUSLY STARTED SURVEY

START Hello, may I please speak to [PARTICIPANT NAME]?

OPTIONAL START:

Hello, my name is [INTERVIEWER NAME], may I please speak to [PARTICIPANT NAME]?

<1> YES → **Go to INTRODUCTION**

<2> NO [REFUSAL]

<3> NO, NOT AVAILABLE RIGHT NOW → **Go to SETTING CALLBACK TIME WHILE COMPLETING A SURVEY**

IF ASKED WHO IS CALLING:

This is [INTERVIEWER NAME] calling from the <Site> MD STARnet program at <grantee organization>. The MD STARnet program is funded by the Centers for Disease Control and Prevention. Is [PARTICIPANT NAME] available to complete a survey that [HE/SHE] started at an earlier date?

CONFIRM PARTICIPANT FOR A PREVIOUSLY STARTED SURVEY:

This is [INTERVIEWER NAME] calling from <grantee organization>, on behalf of <Site> MD STARnet program. I would like to confirm that I am speaking with [PARTICIPANT NAME]. I am calling to continue the survey started on an earlier date. CONTINUE SURVEY WHERE PREVIOUSLY LEFT OFF.

CONFIRM PARTICIPANT FOR A CALL BACK:

This is [INTERVIEWER NAME] calling from <grantee organization>, on behalf of <Site> MD STARnet program. I would like to confirm that I am speaking with [SAMPLED PARTICIPANT NAME]. I am calling back at the time you requested to take the survey.

SETTING CALLBACK TIME WHILE COMPLETING A SURVEY

Occasionally, a participant may need to leave the telephone call after starting the survey with you. When this occurs, you will secure a day and time to call the participant back and record that information here.

START I would like to schedule a day and time when I can call you back to complete the survey.
What day and time is best for you?

[SET CALLBACK]

Day of the week: _____

Date: _____

Time: _____

Any additional Notes about Callback:



Women Living with Muscular Dystrophy Survey

START HERE

INTRODUCTION

This survey asks about you and your experiences as a person diagnosed with muscular dystrophy. We will ask you about you and your household, your experience with COVID-19 and vaccination, chronic pain and fatigue related to your muscular dystrophy, and your experiences with family planning and family building.

The survey should take no more than 20 minutes to complete. You may skip any questions you do not wish to answer. We will not publish any information that can be linked to you or your household.

This survey is conducted by <Site> Muscular Dystrophy Surveillance, Research and Tracking Network (MD STARnet) with funding from the Centers for Disease Control and Prevention.

If you have any questions about this survey, you can call our study coordinator at <1 (XXX) XXX-XXXX>.

If you have questions about your rights as a research participant, please contact the <grantee institution office of research> at <1 (XXX)XXX-XXXX>.

Thank you for helping improve care for people like you living with muscular dystrophy!

We would like to record this call for quality assurance. Is it ok for me to record this call?

- Yes **Start Recording** "Thank you. I have started the call recording"
- No **Do Not Record** "Thank you. I will not record the call."

If the person asks for more information about the call recording: The recording will be kept on a secure server only accessible to the research team. It will only be used to ensure your answers are accurately recorded in the research dataset.

The first set of questions are about you and your household.

1. What is your ethnicity? Are you Hispanic or Latino?

- Yes, Hispanic or Latino
- No, Not Hispanic or Latino

2. Now, I am going to read a list of categories. Please choose one or more of the following categories to describe your race. What race do you identify with?

- American Indian/Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Pacific Islander
- White
- Other

3. Are you currently attending a school or college?

- Yes
- No

Do not read:

- I don't know
- I prefer not to answer

4. What is the highest level of education you completed? Is it...

- Elementary school (grades 1 through 8)
- Some high school (grades 9 through 11)
- Graduated high school (grade 12)
- Some college or technical school
- Graduated college or technical school
- Graduate school

Do not read:

- I don't know
- I prefer not to answer

5. Do you own or rent your home?

- Own
- Rent
- Other arrangement

Do not read:

- I don't know
- I prefer not to answer

6. What is your current employment status?

- Employed for wages (**Go to next question, otherwise → Go to question 8**)
- Self-employed (**Go to next question, otherwise → Go to question 8**)
- Out of work for a year or more
- Out of work for less than a year
- Homemaker
- Student
- Retired
- Unable to work
- Other, please specify: _____

Do not read:

- I don't know
- I prefer not to answer

7. If employed, how many hours per week are you working?

- Less than 20 hours per week
- 20-40 hours per week
- More than 40 hours per week

Do not read:

- I don't know
- I prefer not to answer

8. During the last 12 months, what was your yearly total household income before taxes? Was it...

- \$40 to \$9,999
- \$10,000 to \$24,999
- \$25,000 to 49,999
- \$50,000 to 74,999
- \$75,000 to 99,999
- \$100,000 to 149,999
- \$150,000 and greater

Do not read:

- I don't know
- I prefer not to answer
-

The following questions are about COVID-19 and influenza.

9. To your knowledge, have you had COVID-19?

- Yes
- No → **Go to question 13**

Do not read:

- I don't know → **Go to 13**
- I prefer not to answer → **Go to 13**

10. Was your infection confirmed by a test?

- Yes, confirmed by test
- No, not confirmed by test

Do not read:

- I don't know
- I prefer not to answer

11. Describe the level of care you received. Would you say you...

- Did not seek medical care
- Received medical care but was not hospitalized
- Were hospitalized

Do not read:

- I don't know
- I prefer not to answer

12. How would you characterize your symptoms? Would you say you had...

- No symptoms
- Mild symptoms (Such as low-grade fever, cough, shortness of breath)
- Moderate symptoms (Such as moderate difficulty breathing, body aches, fatigue)
- Severe symptoms (Such as severe difficulty breathing, persistent pain, inability to stay awake)

Do not read:

- I don't know
- I prefer not to answer

13. Have you received a COVID-19 vaccine?

- Yes → **Go to question 15**
- No

Do not read:

- I don't know → **Go to 15**
- I prefer not to answer → **Go to 15**

14. What are the reasons you have not received a COVID-19 vaccine? I will read a list of potential reasons. Please tell me whether

each one is a reason you have not had the COVID vaccine.

- I would like to get it but have not been able to
- I am worried about the side effects of the vaccine
- I do not like vaccines or needles
- I am not worried about getting COVID-19
- I already had COVID-19
- I have a medical condition that prevents me from getting the vaccine
- I do not think the vaccine is effective
- I just don't want the vaccine
- Other

[If "other selected"] Please specify the reason:

Do not read:

- I don't know
- I prefer not to answer

15. Have you ever received a flu vaccine?

- Yes
- No → **Go to question 17**

Do not read:

- I don't know → **Go to question 18**
- I prefer not to answer → **Go to 18**

16. Did you receive the flu vaccine any time in the last 12 months?

- Yes → **Go to question 18**
- No

Do not read:

- I don't know → **Go to 18**
- I prefer not to answer → **Go to 18**

17. What are the reasons you have not received the flu vaccine during the past 12 months? I will read a list of potential reasons. Please tell me whether each one is a reason you have not had the flu vaccine in last 12 months.

- I would like to get it but have not been able to

- I am worried about the side effects of the vaccine
- I do not like vaccines or needles
- I am not worried about getting the flu
- I already had the flu
- I have a medical condition that prevents me from getting the vaccine
- I do not think the vaccine is effective
- I just don't want the vaccine
- Other
 - [If "other selected]** Please briefly specify the reason:

Do not read:

- I don't know
- I prefer not to answer

The next set of questions ask about your experience with chronic pain and fatigue related to your muscular dystrophy.

18. In the past **30 days**, how many days have you experienced pain related to your muscular dystrophy in any part of your body?

Do not read response options:

- _____ number of days
- I cannot recall having muscular dystrophy-related pain in the last 30 days → **Go to question 52**
- I prefer not to answer → **Go to 52**

19. Is your pain managed by medication or other methods?

- Yes
- No

Do not read:

- I don't know
- I prefer not to answer

20. What time of day is your pain the worst?
Please tell me all that apply.

- Morning
- Afternoon
- Evening and night

Do not read:

- I don't know
- I prefer not to answer

21. Where in your body do you typically have pain? I will read a list of potential responses. Please tell me whether this is a part of your body where you typically have pain.

Check all that apply.

- Head
- Neck
- Shoulders
- Arms
- Back
- Chest
- Stomach
- Hips
- Legs
- Feet
- Other
 - [If "other selected]** Please specify the other area where you have pain:

Do not read:

- I don't know
- I prefer not to answer

The next questions are about how you have managed your pain in the past 30 days.

22. Do you use over-the-counter/non-prescription pain medications such as aspirin, ibuprofen, or acetaminophen to manage the pain related to your muscular dystrophy?

- Yes
- No → **Go to question 25**

Do not read:

- I don't know → **Go to 25**
- I prefer not to answer → **Go to 25**

23. How often do you use any combination of this type of medication to manage your pain?

- Every day
- 2-6 days per week
- Once a week
- Once a month
- Not in the last month

Do not read:

- I don't know
- I prefer not to answer

24. How helpful are any combination of these medications in managing your pain? Do they...

- Completely relieve the pain
- Reduce pain so you can manage your normal activities
- Provide some relief but not enough that you can resume normal activities
- Provide little or no pain relief

Do not read:

- I don't know
- I prefer not to answer

25. Do you use prescription opioid pain medications – such as Percocet (oxycodone), Vicodin (hydrocodone), or Ultram (tramadol) – to manage the pain related to your muscular dystrophy?

- Yes
- No → **Go to question 28**

Do not read:

- I don't know → **Go to 28**
- I prefer not to answer → **Go to 28**

26. How often do you use any combination of this type of medication to manage your pain?

- Every day
- 2-6 days per week
- Once a week
- Once a month
- Not in the last month

Do not read:

- I don't know
- I prefer not to answer

27. How helpful are any combination of these medications in managing your pain? Do they...

- Completely relieve the pain

Reduce pain so you can manage my normal activities

Provide some relief but not enough that you can resume normal activities

Provide little or no pain relief

Do not read:

- I don't know
- I prefer not to answer

28. Do you use cannabidiol (CBD) or any other marijuana-based treatment products to manage the pain related to your muscular dystrophy?

- Yes
- No → **Go to question 31**

Do not read:

- I don't know → **Go to 31**
- I prefer not to answer → **Go to 31**

29. How frequently do you use any combination of CBD or marijuana-based treatment products to manage your pain?

- Every day
- 2-6 days per week
- Once a week
- Once a month
- Not in the last month

Do not read:

- I don't know
- I prefer not to answer

30. How helpful are any combination of CBD or marijuana-based treatment products in managing your pain?

- Completely relieve the pain
- Reduce pain so I can manage my normal activities
- Provide some relief but not enough that I can resume normal activities
- Provide little or no pain relief

Do not read:

- I don't know
- I prefer not to answer

31. Do you use alternative medications – such as herbal supplements – to manage the pain related to your muscular dystrophy?

- Yes
- No → **Go to question 34**

Do not read:

- I don't know → **Go to 34**
- I prefer not to answer → **Go to 34**

32. How frequently do you use any combination of this type of medication to manage your pain?

- Every day
- 2-6 days per week
- Once a week
- Once a month
- Not in the last month

Do not read:

- I don't know
- I prefer not to answer

33. How helpful are any combination of these medications in managing your pain?

- Completely relieve the pain
- Reduce pain so you can manage my normal activities
- Provide some relief but not enough that you can resume normal activities
- Provide little or no pain relief

Do not read:

- I don't know
- I prefer not to answer

34. Do you use nonpharmacological methods such as biofeedback, physical therapy, behavioral modifications, better sleep practices, better hygiene practices, or diet to manage the pain related to your muscular dystrophy?

- Yes
- No → **Go to question 37**

Do not read:

- I don't know → **Go to 37**
- I prefer not to answer → **Go to 37**

35. How frequently do you use any combination of these methods to manage your pain?

- Every day
- 2-6 days per week
- Once a week
- Once a month
- Not in the last month

Do not read:

- I don't know
- I prefer not to answer

36. How helpful are any combinations of these methods in managing your pain?

- Completely relieve the pain

- Reduce pain so you can manage your normal activities
- Provide some relief but not enough that you can resume normal activities
- Provide little or no pain relief

Do not read:

- I don't know
- I prefer not to answer

37. Do you use any other method or therapy to manage your pain?

- Yes
- No → **Go to question 41**

Do not read:

- I don't know → **Go to 41**
- I prefer not to answer → **Go to 41**

38. What other methods or therapies do you use?

39.
39.
39.
39.
39.
39.
39.

How frequently do you use any combination of these other methods to manage your pain?

- Every day
- 2-6 days per week
- Once a week
- Once a month
- Not in the last month

Do not read:

- I don't know
- I prefer not to answer

40. How helpful are any combination of these other methods in managing your pain?

- Completely relieve the pain
- Reduce pain so I can manage my normal activities
- Provide some relief but not enough that I can resume normal activities
- Provide little or no pain relief

Do not read:

- I don't know
- I prefer not to answer

The next questions ask about the intensity of your pain. For each item, please tell me the option that *best* describes the intensity of your pain during the indicated time-period.

41. In the past 7 days, how intense was your pain at its worst? Was it...

- No pain
- Mild
- Moderate
- Severe
- Very severe

Do not read:

- I don't know
- I prefer not to answer

42. In the past 7 days, how intense was your average pain? Was it...

- No pain
- Mild
- Moderate
- Severe
- Very severe

Do not read:

- I don't know
- I prefer not to answer

43. What is your level of pain right now? Is it...

- No pain
- Mild
- Moderate
- Severe
- Very severe

Do not read:

- I don't know
- I prefer not to answer

The next questions are about the impact of pain on your activities. For each item, please select the option that best describes how often the impact of pain occurred in the past 7 days.

44. In the past 7 days, how much did pain interfere with your day to day activities?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

45. In the past 7 days, how much did pain

interfere with work around the home? Was it...

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

46. In the past 7 days, how much did pain interfere with your ability to participate in social activities? Was it...

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

47. In the past 7 days, how much did pain interfere with your household chores? Was it...

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

48. In the past 7 days, how much did pain interfere with the things you usually do for fun? Was it...

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

49. In the past 7 days, how much did pain interfere with your enjoyment of social activities?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

50. In the past 7 days, how much did pain interfere with your enjoyment of life?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

51. In the past 7 days, how much did pain interfere with your family life?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Do not read:

- I don't know
- I prefer not to answer

The next questions are about how tired you felt during the past week and how feeling tired impacted your daily activities.

52. In the past 7 days, how often was the statement "I felt exhausted." true?

- Never
- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

53. In the past 7 days, how often was the statement "I felt like I had no energy" true?

- Never

- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

54. In the past 7 days, how often was the statement "I felt fatigued" true?

- Never
- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

55. In the past 7 days, how often was the following statement true? "I was too tired to do my household chores."

- Never
- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

56. In the past 7 days, how often was the following statement true? "I was too tired to leave the house."

- Never
- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

57. In the past 7 days, how often was the following statement true? "I was frustrated by being too tired to do the things I wanted to do."

- Never
- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

58.
58.
58.
58.
58.
58.
58.
58.
58.
58.

In the past 7 days, how often was the statement "I felt tired" true?

- Never
- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

59. In the past 7 days, how often was the statement following statement true? "I had to limit my social activity because I was tired."

- Never
- Rarely
- Sometimes
- Often
- Always

Do not read:

- I don't know
- I prefer not to answer

If the respondent's response to all of the statements 52-59 was 'Never' or 'Rarely', please go to question 61.

60. How have you managed your fatigue in the past 7 days? Please tell me all that apply.

- Stimulants
- Exercise

- Coffee and/or other caffeine containing beverages
- Prescription medications
- Non-prescription medications
- Dietary Supplements
- Sleep
- Herbal remedies
- Other, specify _____

Do not read:

- I don't know
- I prefer not to answer

61. Please tell us anything else about your experience with pain or fatigue:

The next questions are about your experience with muscular dystrophy and family planning.

62. At what age were you diagnosed with muscular dystrophy?

Do not read:

- I don't know
- I prefer not to answer

63. Have you ever talked with a genetic counselor or other medical provider about the chance for your children or other family members to have muscular dystrophy?

- Yes
- No → **Go to question 66**

Do not read:

- I don't know → **Go to 66**
- I prefer not to answer → **Go to 66**

64. When did you talk with the genetic counselor or medical provider?

- Before considering or having children
- During a pregnancy
- Between pregnancies
- After I was done having children → **Go to question 66**

Do not read:

- I don't remember/I don't know → **Go to 66**
- I prefer not to answer → **Go to 66**

65. How did speaking with this person affect your decision to have (more) children?

- It did not/will not affect your decision to have children
- You decided not to have your own children
- You decided to adopt

- You decided to see a medical provider who could help me have children without muscular dystrophy
- Other

[If "other selected"] Please specify the effect on your decision to have children

Do

not read:

- I don't know
- I prefer not to answer

66. Have you ever been pregnant?

Do not read:

- Yes
- No
- I don't know
- I prefer not to answer

67. Did you ever have trouble getting pregnant or were unable to get pregnant?

Do not read:

- Yes
- No
- I have not tried to get pregnant
- I don't know
- I prefer not to answer

68. Were you ever told by a medical provider that you would not be able to get pregnant or might have a hard time getting pregnant due to your muscular dystrophy?

Do not read:

- Yes
- No
- I don't know
- I prefer not to answer

69. Did you ever decide not to become pregnant because it would be a risk to your own health?

Do not read:

- Yes

- No
- I don't know
- I prefer not to answer

If the respondent has never been pregnant (Q66), skip to Q119.

Next, we are going to ask some questions about your pregnancies

70. How many times have you been pregnant, including pregnancies that may have ended in miscarriages, stillbirths, abortion, or a tubal or molar pregnancy?

Do not read:

_____ times

- I don't know
- I prefer not to answer

71. In your **first** pregnancy, how many babies were you carrying?

Do not read (If the person is confused, say "Would you say..." and read response options).

- 1
- 2 (twins)
- 3 or more (triplets or more)
- I don't know
- I prefer not to answer

72. What was the outcome(s) of the pregnancy?

Read if multiple babies indicated in previous question: If applicable, you can select more than one option.

Was the outcome that...

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)

Do not read:

- I don't know

I prefer not to answer

73. When did this pregnancy end? Please tell me the month and year.

__ / ____ (mm/yyyy)

Do not read:

- I don't know
- I prefer not to answer

If the respondent only had one pregnancy (See Q70), please go to question 86.

74. In your **second** pregnancy, how many babies were you carrying?

- 1
- 2 (twins)
- 3 or more (triplets or more)

Do not read:

- I don't know
- I prefer not to answer

75. What was the outcome(s) of the pregnancy?

Read if multiple babies indicated in previous question: If applicable, you can select more than one option.

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)

Do not read:

- I don't know
- I prefer not to answer

76. When did this pregnancy end?

__ / ____ (mm/yyyy)

Do not read:

- I don't know

I prefer not to answer

If respondent had only two pregnancies, please go to question 86.

77. In your **third** pregnancy, how many babies were you carrying?

Do not read:

- 1
- 2 (twins)
- 3 or more (triplets or more)
- I don't know
- I prefer not to answer

78. What was the outcome(s) of the pregnancy? **If you carried more than one baby, please check all that apply.**

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)

Do not read:

- I don't know
- I prefer not to answer

79. When did this pregnancy end?

__ / ____ (mm/yyyy)

Do not read:

- I don't know
- I prefer not to answer

If the respondent only had three pregnancies, please go to question 86.

80. In your **fourth** pregnancy, how many babies were you carrying?

Do not read:

- 1
- 2 (twins)
- 3 or more (triplets or more)

- I don't know
- I prefer not to answer

81. What was the outcome(s) of the pregnancy?
If you carried more than one baby, please check all that apply.

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)
- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)

Do not read:

- I don't know
- I prefer not to answer

82. When did this pregnancy end?
 __ / ____ (mm/yyyy)

Do not read:

- I don't know
- I prefer not to answer

If you only had **four** pregnancies, **please go to question 86.**

83. In your **fifth** pregnancy, how many babies were you carrying?

- 1
- 2 (twins)
- 3 or more (triplets or more)

Do not read:

- I don't know
- I prefer not to answer

84. What was the outcome(s) of the pregnancy?
If you carried more than one baby, please check all that apply.

- Baby was born alive at less than 37 weeks of pregnancy (early or preterm)

- Baby was born alive at 37 weeks or later (term)
- Miscarriage (fetal loss) before 20 weeks of pregnancy
- Stillbirth (fetal loss) at 20 weeks of pregnancy or later
- Abortion (pregnancy medically ended for any reason)

Do not read:

- I don't know
- I prefer not to answer

85. When did this pregnancy end?
 __ / ____ (mm/yyyy)

Do not read:

- I don't know
- I prefer not to answer

The following questions are about the first time you were pregnant.

86. How old were you when you became pregnant with your **first** pregnancy?
 ____ years

Do not read:

- I don't know
- I prefer not to answer

87. Did you or your partner use any of the following assisted technologies to get pregnant with your **first** pregnancy? **Please indicate all that apply**

- No assistance needed
- Hormone therapy or medications
- In-vitro fertilization (IVF)
- Pre-implantation diagnosis. (Genetic testing of the embryo before implantation following IVF)
- Artificial insemination with your partner's sperm
- Artificial insemination with donor sperm
- Drugs to improve ovulation
- Surgery to correct blocked tubes
- Treatment for varicocele
- Other types of medical help

Do not read:

- I don't know
- I prefer not to answer

88. Did you have any of the following problems with your **first** pregnancy? **Please indicate all that apply.**

- No problems
- Gestational Hypertension (high blood pressure that started during this pregnancy)
- Pre-eclampsia or eclampsia
- Significant bleeding with delivery
- Significant bleeding while pregnant
- Infection
- Gestational diabetes (diabetes that started during this pregnancy)
- Too much amniotic fluid
- Too little amniotic fluid
- Labor pains more than 3 weeks before my baby was due (preterm or early labor)
- Water broke more than 3 weeks before your baby was due (preterm premature rupture of membranes or PPROM)
- Bad reaction to the anesthetic used during delivery

Do not read:

- I don't know
- I prefer not to answer

If respondent's first pregnancy did not end in a live birth (Q78), please go to question 91.

89. How was your **first** baby delivered?

- Unassisted vaginal delivery
- Assisted vaginal delivery (forceps or vacuum extraction)
- Planned cesarean section
- Unplanned cesarean section, including emergency C-section

Do not read:

- I don't know
- I prefer not to answer

90. Did your **first** baby have any of the following problems?

- Born too small (Low birth weight)
- Died before she/he was 1 month old
- Neither of these problems

Do not read:

- I don't know
- I prefer not to answer

The next questions are about how your muscular dystrophy symptoms changed during your first pregnancy.

For each of the following symptoms of muscular dystrophy, please tell me how the symptom changed **during** your **first** pregnancy.

91. During your pregnancy, was your muscle weakness

- Worse
- Better
- About the same
- Did not have muscle weakness before or during pregnancy

Do not read:

- I don't know
- I prefer not to answer

92. During your pregnancy, was your muscle pain

- Worse
- Better
- About the same
- Did not have pain before or during pregnancy

Do not read:

- I don't know
- I prefer not to answer

93. During your pregnancy, were your muscle cramps

- Worse
- Better
- About the same, or
- Did not have muscle cramps before or during pregnancy

Do not read:

- I don't know

I prefer not to answer

94. During your pregnancy, was any difficulty you had walking

- Worse
- Better
- About the same, or
- Did not have difficulty walking before or during pregnancy

Do not read:

- I don't know
- I prefer not to answer

95. During your pregnancy, did you need more help with daily activities?

Do not read:

- Yes
- No
- About the same
- Did not need help with daily activities before or during my pregnancy
- I don't know
- I prefer not to answer

Now, please tell me how each of the following symptoms of muscular dystrophy changed after your first pregnancy ended compared to your symptoms during the pregnancy.

96. After your pregnancy ended, was your muscle weakness

- Worse
- Better
- About the same, or
- Did not have muscle weakness before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

97. After your pregnancy ended, was your muscle pain

- Worse
- Better
- About the same

Did not have pain before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

98. After your pregnancy ended, were your muscle cramps

- Worse
- Better
- About the same. or
- Did not have muscle cramps before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

99. After your pregnancy ended, was any difficulty you had walking

- Worse
- Better
- About the same. or
- Did not have difficulty walking before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

100. After your pregnancy ended, did you need more help with daily activities than you did during your pregnancy?

- Yes
- No
- About the same
- Did not need help with daily activities before, during or after my pregnancy

Do not read:

- I don't know
- I prefer not to answer

101. Did any symptoms related to muscular dystrophy in your **first** pregnancy affect your decision to have future pregnancies?

- Yes
- No

Do not read:

- I don't know
- I prefer not to answer

102. After your **first** pregnancy, did a doctor, nurse, or other health care worker tell you that you had depression?

- Yes
- No

Do not read:

- I don't know
- I prefer not to answer

If the respondent only had one pregnancy, please go to question 119

The following questions are about the most recent or last time you were pregnant.

103. How old were you when you became pregnant with your most recent pregnancy?

Do not read:

_____ years

- I don't know
- I prefer not to answer

104. Did you or your partner use any of the following assistive technologies to get pregnant with your most recent pregnancy?

Please check ALL that apply.

- No assistance needed
- Hormone therapy or medications
- In-vitro fertilization (IVF)
- Pre-implantation diagnosis. (Genetic testing of the embryo before implantation following IVF)
- Artificial insemination with your partner's sperm
- Artificial insemination with donor sperm
- Drugs to improve ovulation
- Surgery to correct blocked tubes
- Treatment for varicocele

- Other types of medical help

Do not read:

- I don't know
- I prefer not to answer

105. Did you have any of the following problems with your most recent pregnancy? **Please check all that apply.**

- No problems
- Gestational Hypertension (high blood pressure that started during this pregnancy)
- Pre-eclampsia or eclampsia
- Significant bleeding with delivery
- Significant bleeding while pregnant
- Infection
- Gestational diabetes (diabetes that started during this pregnancy)
- Too much amniotic fluid
- Too little amniotic fluid
- Labor pains more than 3 weeks before my baby was due (preterm or early labor)
- Water broke more than 3 weeks before your baby was due (preterm premature rupture of membranes or PPROM)
- Bad reaction to the anesthetic used during delivery

Do not read:

- I don't know
- I prefer not to answer

If the participant's last pregnancy did not end in a live birth, go to question 119.

106. Did your most recent baby have any of the following problems?

- Born too small (Low birth weight)
- Died before she/he was 1 month old
- Neither of these problems

Do not read:

- I don't know
- I prefer not to answer

107. How was your most recent baby delivered?

- Unassisted vaginal delivery
- Assisted vaginal delivery (forceps or vacuum extraction)
- Planned cesarean section
- Unplanned cesarean section, including emergency C-section

Do not read:

- I don't know
- I prefer not to answer

The next questions are about if and how your muscular dystrophy symptoms changed during your last pregnancy.

For each of the following symptoms, please tell me how the symptom changed during your **most recent** pregnancy compared to right **before your most recent** pregnancy.

108. During your pregnancy, was your muscle weakness

- Worse
- Better
- About the same, or
- Did not have muscle weakness before or during pregnancy

Do not read:

- I don't know
- I prefer not to answer

109. During your pregnancy, was your muscle pain

- Worse
- Better
- About the same, or
- Did not have pain before or during pregnancy

Do not read:

- I don't know
- I prefer not to answer

110. During your pregnancy, were your muscle cramps

- Worse
- Better
- About the same, or

- Did not have muscle cramps before or during pregnancy

Do not read:

- I don't know
- I prefer not to answer

111. During your pregnancy, was any difficulty you had walking

- Worse
- Better
- About the same, or
- Did not have difficulty walking before or during pregnancy

Do not read:

- I don't know
- I prefer not to answer

112. During your pregnancy, did you need more help with daily activities?

- Yes
- No
- About the same, or
- Did not need help with daily activities before or during my pregnancy

Do not read:

- I don't know
- I prefer not to answer

Now, please tell me how each of the following symptoms changed after your **most recent pregnancy** ended compared to your symptoms during your **most recent pregnancy**.

113. After your most recent pregnancy ended, was your muscle weakness

- Worse
- Better
- About the same, or
- Did not have muscle weakness before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

114. After your most recent pregnancy ended, was your muscle pain

- Worse

- Better
- About the same, or
- Did not have pain before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

115. After your most recent pregnancy ended, were your muscle cramps

- Worse
- Better
- About the same, or
- Did not have muscle cramps before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

116. After your most recent pregnancy ended, was any difficulty you had walking

- Worse
- Better
- About the same, or
- Did not have difficulty walking before, during or after pregnancy

Do not read:

- I don't know
- I prefer not to answer

117. After your most recent pregnancy, did you need more help with daily activities than you did during your pregnancy?

- Yes
- No
- About the same, or
- Did not need help with daily activities before, during or after my pregnancy
- I don't know
- I prefer not to answer

118. After your **most recent** baby was born or your **most recent** pregnancy ended, did a doctor, nurse, or other health care worker tell you that you had depression?

Do not read:

- Yes
- No
- I don't know
- I prefer not to answer

119. Please tell us anything else about your experience with pregnancy or family planning.

This is the end of the survey. Additional information on MD STARnet can be found at the following links:

<https://www.cdc.gov>

AND

XXXX>.

If you have questions about your rights as a research participant, please contact the **<grantee institution office of research>** at **<1 (XXX)XXX-XXXX>**.

Thank you for taking the time to answer our questions. Your answers will help us to better understand the lives of people with muscular dystrophy and can inform decision makers who plan services to support people with muscular dystrophy and their families.

Space For Additional Notes:

INTERVIEWER: You can use this space to record additional notes for open-text responses. Please indicate the question number for all additional notes.

